Promoting Successful Transition to Community through Increased Caregiver Training

BY

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THESIS

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**LIST OF ABBREVIATIONS**

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<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
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<tr>
<td>ASI</td>
<td>American Spinal Injury Association Impairment Scale</td>
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<tr>
<td>CNA</td>
<td>Certified Nursing Assistant</td>
</tr>
<tr>
<td>FOCUS</td>
<td>Facts, Optimism, Creativity, Understanding and Solve</td>
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<td>MVA</td>
<td>Motor Vehicle Accident</td>
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<td>NSCISC</td>
<td>National Spinal Cord Injury Statistical Center</td>
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<td>OMSA</td>
<td>Outcomes Management Systems and Analysis</td>
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<td>RIC</td>
<td>Rehabilitation Institute of Chicago</td>
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<tr>
<td>SCI</td>
<td>Spinal Cord Injury</td>
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<tr>
<td>UAB</td>
<td>University of Alabama-Birmingham</td>
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<td>WHO</td>
<td>World Health Organization</td>
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SUMMARY

The purposes of this study were to identify the needs and benefits of caregiver education to enhance an existing post-rehabilitation education program through development of supplemental caregiver education and training. This supplemental program was designed to increase caregiver interaction with rehabilitation professionals, and to improve the transition of individuals from inpatient rehabilitation to their community. This supplemental education and training included weekend based sessions that were not currently a part of the traditional rehabilitation process. These educational sessions included increased training with equipment not typically available outside scheduled caregiver training sessions. Four individuals with acute spinal cord injury and one of their family members participated in the training intervention. The training intervention included four, one hour educational sessions in topical areas including medical information related to spinal cord injury, use of adaptive equipment to perform daily activities, performance of transfers, and peer education related to the transition from acute rehabilitation to the community. Individuals who participated in the caregiver intervention reported it to be a positive experience and reported success with the transition to their home environment. Further research in the areas of caregiver training and preparation for transition to the community in the acute rehabilitation spinal cord injury population would be beneficial to rehabilitation professionals to promote evidence based practice.
I. INTRODUCTION

A. Background

The incidence of spinal cord injury (SCI) is estimated to be 12,000 new occurrences each year. This equates to approximately 262,000 individuals within the United States who have had a SCI. Despite the increase in average age of injury acquired, this age remains at 40 (DeVivo & Chen, 2011). At this stage of life, an individual has been engaged in many important life roles and expectations that may be disrupted due to the likely hospitalization and further challenges associated with acquiring a disability (Boschen, Tonack, & Gargaro, 2003). When individuals discharge from inpatient rehabilitation programs to return to their pre-injury homes, the responsibility of assisting the individual with activities of daily living (ADL), mobility skills, and re-facilitating role participation frequently becomes that of family members, friends, or other types of acquaintances who have little or no experience with disability or SCI. Without external support to limit barriers which can include complex medical complications and susceptibility to acquire secondary conditions, isolation due to decreased transportation options, inaccessible home environment, and lack of available financial sources to hire qualified assistance; the transition from rehabilitation to community living can be extremely challenging.

From 2005 to 2008, the average days spent on a rehabilitation unit for individuals with spinal cord injury have decreased from 98 to 37 days (Whiteneck, Gassaway, & Marcel, 2011). With the amount of time decreasing that individuals are in inpatient rehabilitation, the importance of caregiver and family training is taking on a larger role
for successful transition to home. The majority of this training in traditional rehabilitation is currently completed in individual therapy sessions. Due to a decrease in availability of resources and time or scheduling constraints, training is frequently more limited within this medical model of service provision. Access to lecture based education has been increased in order to meet learning needs, but has been associated with limited success and impact on the satisfaction of rehabilitation patients and their families and caregivers.

Traditional rehabilitation is being defined as the typical services that one may expect to receive during the inpatient rehabilitation process and how that process is completed. This process is systematically suggested through the use of SCI careways designed to provide increased structure and consistency across the continuum of care dependent upon the patient’s medical diagnosis related to his or her neurological level of SCI level (Appendix B). The SCI careways are a timeline, by week, including generalized outlines of key factors and interventions determined necessary and vital by the rehabilitation team at the Rehabilitation Institute of Chicago (RIC) for individuals with paraplegia, paralysis in lower extremities, and tetraplegia, paralysis in four extremities. In traditional rehabilitation, family and caregiver education and training is being completed during specific scheduled sessions with primary therapists. To further enhance learning, two lecture based educational sessions are available for everyone to attend during the week. The topics of these sessions include topics deemed most critical to learn before leaving inpatient rehabilitation by the rehabilitation staff. Some of these lectures are available for viewing in a continuous cycle on a closed channel network on the hospital television station.
II. LITERATURE REVIEW

A. Spinal Cord Injury Demographics

The recent demographics of individuals who acquire a spinal cord injury (SCI) have been compiled by the University of Alabama-Birmingham (UAB) through the nationally funded program of the National Spinal Cord Injury Statistical Center (NSCISC). This information was published in February of 2010. Additional evaluation of the demographic profile of SCI was further explored and updated by DeVivo and Chen in 2011.

The most common etiology for SCI is motor vehicle accidents (MVA). This is followed by falls, acts of violence, and sporting accidents. The overall incidence of SCI resulting from sporting has been decreasing since 2005, while SCI resulting from a fall has increased. This may correlate to the overall increase in average age for acquiring an injury since 2005. SCI has historically been a unique disability in that this has traditionally been observed as an acquired disability of young men. Although SCI is seen as primarily affecting young adults, the average age to acquire a SCI is increasing. The average age of injury has increased over the past 26 years from 28.7 years in 1979 to 40.2 years of age in 2005 (DeVivo & Chen, 2011). The NSCISC reports, in statistics obtained in 2005, that 80.8% of individuals in the United States are male; but initial, more recent data demonstrates a decreasing gap between men and women with SCI.

Because there is a diverse nature to SCI, the American Spinal Cord Injury Association designed a methodology for classification of SCI to improve communication between health care professionals and to develop a way to standardize medical care and measurement of outcomes related to SCI. This classification, which is still prevalent in
the rehabilitation community, is the American Spinal Cord Injury Association Scale (ASI) classification. These five main classification levels are based upon motor and sensory function determined by examination of an individual post spinal injury. This examination assists with determining a general understanding of motor and sensory innervations throughout an individual’s body. This Standard Neurological Classification of Spinal Cord Injury divides the classifications of severity of neurological injury from A, complete injury, to E, normal muscle and sensory presentation upon exam (Appendix C).

In addition to the ASI classifications of spinal injury, SCI is also classified by muscle and sensory preservation in individuals’ extremities. This is a division of spinal injuries resulting in tetraplegia, a limitation in all four extremities, or paraplegia, a limitation in two extremities. Paraplegia results typically in decreased sensory and/or motor abilities and neurological innervations in an individual’s bilateral lower extremity.

The most frequent neurologic category at discharge of persons with SCI reported to the NSCISC database is incomplete tetraplegia (38.3%), followed by complete paraplegia (22.9%), incomplete paraplegia (21.5%), and complete tetraplegia (16.9%). Over the last 15 years, the percentage of persons with incomplete tetraplegia has increased while complete paraplegia and complete tetraplegia have decreased slightly (National Spinal Cord Injury Statistical Center, 2010).

In addition to physical limitations associated with decreased sensation and muscle activation following an acquired SCI, there are several other medical complications and associated conditions with a spinal injury. These are body changes that one acquires as part of the SCI. These can include neurogenic bladder and bowel, an inability to control one’s ability to void, and spasticity, which is an increase in muscle tone or involuntary
muscle contraction in the body. These can be complicated and functionally limiting conditions in addition to the SCI. If they are not managed, they may decrease an individual’s ability to engage in daily activities.

In addition to associated medical conditions, there are many serious secondary conditions of SCI which must be noted. Secondary conditions are medical complications that an individual with SCI has a significantly higher percentage of experiencing. These are additional medical complications which are a direct result of having an SCI. Secondary conditions are preventable with appropriate care and education. Secondary conditions which are frequently seen in the SCI population include pressure ulcers, joint contractures, and urinary tract infections (National Spinal Cord Injury Statistical Center, 2010).

Despite increased risk of medical complications with SCI, the longevity of life expectancy following SCI now approaches that of the general population (Lucke, Coccia, Goode, & Lucke, 2004). Exposure to high quality education regarding SCI and related topics are ways to maximize health and wellness throughout the aging process. For many individuals who acquire an SCI, entering a rehabilitation program is an important key to maintaining their health and wellness and ability to take on new roles as an individual with SCI.

B. Rehabilitation Medicine

In an era of increasing health care costs and managed health care, there are many significant ways these factors impact traditional rehabilitation. The most significant influence of the current health care system can be seen when examining the average number of days individuals with SCI traditionally are receiving for both medically acute
care and rehabilitation participation. Overall, the median number of days hospitalized in
the acute care unit for those who enter a SCI Model System immediately following injury
has declined from 24 days between 1973 and 1979 to 12 days since 2005. Similar
downward trends are noted for days in the rehabilitation unit. When individuals once
remained in rehabilitation for 98 days, they may now only be receiving 38 days of
rehabilitation programming (National Spinal Cord Injury Statistical Center, 2010).

With the decreasing length of hospitalization, establishing the discharge
destination and initiating caregiver education are occurring very soon after first initiating
the rehabilitation process. Due to this decrease in time, dramatic life planning decisions
need to be made shortly after arriving to a rehabilitation facility. Furthermore, they need
to be made with very little knowledge base of what is possible and what choices are
available. “With changes in health care allocation, more individuals will be compelled to
assume the role of primary caregiver for a family member” (Elliott, Shewchuk, &
Richards, 2001, p. 223). These choices frequently include where the individual will live
and who will be able to assist with the return to previous and new life occupations and
role. As choices are made within a decreased time frame, limited exposure to options may
occur. Many times, in order to return back to their homes, family members are asked to
occupy the roles that medical professionals had been assuming up to the point of
discharge with high expectations from all individuals.

Individuals are now spending less time in rehabilitation, so it is important to
maximize the experience to best meet each individual’s needs. This has been historically
a safe discharge as determined by the medical team. Typically, this is a discharge to a
community setting. It has been noted that 87.7% of individuals with SCI discharged from
a Model Systems SCI center return to their previous homes (National Spinal Cord Injury Statistical Center, 2010).

When defining a safe discharge, medical professionals may evaluate on specific criteria. These criteria may include the accessibility of the home, if an individual deemed responsible to be a caregiver can be present as needed, if the individual has achieved an appropriate level of personal care independence and mobility, and the amount of access one may have to continued rehabilitation and medical care services if needed. From the first week in inpatient rehabilitation, goals for achieving the criteria of a safe discharge are established.

It is becoming even more important to fully integrate not only the individual with SCI receiving direct, traditional rehabilitation services, but also family members, friends, and other caregivers into the process as well from the first week of rehabilitation and initial discharge planning. This can be accomplished in several ways, and traditional rehabilitation has begun to increase the ability to document and track the integration of family and caregivers involved in the rehabilitation process. Success in this process is still uncertain.

As time in traditional rehabilitation decreases, the use of effective teaching and learning techniques becomes even more critical. “SCI individuals depend on their learning the necessary techniques during and after rehabilitation to manage their physically changed body as well as developing strategies to reenter the world as a person with a disability” (Lucke, Coccia, Goode, & Lucke, 2004, p. 97). Research is just beginning to investigate what types of programming are best preparing individuals with SCI and their caregivers to leave rehabilitation and find success in the community. “It
appears that caregiver problem solving abilities predict the emotional and physical health of the caregiver and the care recipient” (Post, Bloemen, & de Witte, 2005, p. 315). Due to this, studies are now emphasizing the importance of problem solving skills for improved functional outcomes. One study, by Kurylo, Elliott, and Shewchuk (2001) investigated the effectiveness of the FOCUS program. FOCUS is described by Facts, Optimism, Creativity, Understanding, and Solve (FOCUS) and can be used as problem solving techniques for caregivers. It was determined by the related results that three things are necessary traits for a caregiver to be successful. These included the ability to initiate problem orientation, have a positive problem orientation, and develop a sense of competency and self efficacy promoted through successful experiences (Kurylo, Elliott, & Shewchuk, 2001). Kurylo, Elliott, and Shewchuk (2001), also explored factors that related to levels of optimism. These were determined to be an increased insight to problems which are a common part of everyone’s life, an understanding that many other caregivers have similar problems, and the realization that problems can be predicted and prevented. By acknowledging these things, the caregivers were able to have positive experiences in successful problem solving (Kurylo, Elliott, & Shewchuk, 2001).

Being able to incorporate this type of training into interdisciplinary inpatient rehabilitation may be helpful for both caregivers and individuals with SCI. “Care recipients who are with caregivers who possess many impulsive and careless problem-solving tendencies have more difficulty accepting their condition and are at risk for developing preventable health complications over time” (Kurylo, Elliot, & Shewchuk, 2001, p. 277). Incorporating the ideas of the FOCUS program with traditional SCI
education and training may lead to improved functional SCI outcomes and increase in community roles.

It is important for caregivers to establish a positive outlook for their own mental health as well. A study by Lucke, Coccia, Goode, and Lucke (2004) noted similar problem solving difficulties and levels of poor optimism were also correlated with behaviors of increased depression in caregivers. It is difficult, though, to determine if caregiver depressive behavior can be a result of caregiving or can lead to decreased success with filling the role of caregiver.

C. Rehabilitation and Education

Family Education is a thoughtfully conducted therapeutic exchange that imparts critical information and leaves both parties with a better understanding of what is needed and how prepared the caregiver and patient are to be on their. This family education is traditionally conducted with an identified caregiver. The definition of family caregiver is a family member or other significant individual who provides unpaid personal care assistance and/or emotional support to an individual with a physical or mental disability (Ellenbogen, Meade, Jackson, & Barrett, 2006). Prior to the life experiences of the individual with an acquired SCI and their family, many have had no prior exposure to disability, SCI, or the role of caregiver or support provider. This is one factor in the traditional rehabilitation model involving inclusion of the family in the process early on because they can be such a critical part of the rehabilitation team. The family role in therapy demonstrated by participation and attendance is significant in decreasing the misconceptions they may have regarding disability.
Acquiring a disability can challenge previous life roles and dynamics of the family which are difficult to initially manage. An example of this is the family seeing physical dependency as a weakness and limitation for fulfillment of other roles such as parent, child, and friend and not knowing how to proceed with these new challenges. “We [rehabilitation professionals] need to listen carefully to the clients themselves regarding how they see success in rehabilitation outcomes” (Boschen, Tonack, & Gargaro, 2003, p. 158). The client must include not only the family member who has had the injury, but also the family unit, as these rehabilitation outcomes can be global. “Allied health professionals in spinal injury care should be aware of the psychological morbidity and quality of life states of the caregivers and spouses of SCI patients” (Unalan, Gencosmanoglu, Akgun, & Karamehmetoglu, 2001, p. 319). It is critical as allied health professionals to provide client based care, but traditional rehabilitation standards may need to be expanded as rehabilitation is advanced in the future. “With the increasing incidence of chronic health problems in American society and corresponding increases in the number of family caregivers, greater emphasis is being placed on the needs of caregivers across the life span” (Elliott, Shewchuk, & Richards, 2001, p. 223).

As we focus on the healthy aging across there lifespan following an acquired SCI, we must also educate and prepare caregivers on ways for themselves to maintain health. “The support providers’ own health and adjustment are vital not only to the individual requiring care, but also to the whole SCI service provision system to avoid the secondary conditions of health erosion that are both expensive and preventable” (Boschen, Tonack, & Gargaro, 2005, p. 397). Studies, such as those by Boshen, Tonack, and Gargaro (2005) and Kurylo, Elliott, and Shewchuk (2001), report that current rehabilitation programs do
not provide support providers positive reinforcement for what they do or foster emotional health and wellness. It is never too early for a family member or caregiver to become an active participant in the rehabilitation process to gain those much needed positive experiences which will improve both the fostering of their optimism and positive problem solving skills. “Although inpatient rehabilitation focuses primarily on the physical aspects of recovery because of the reimbursement structure, the emotional aspects of recovery and their impact on role function deserve attention in the research community” (Lucke, Coccia, Goode, & Lucke, 2004, p. 107) and in clinical rehabilitation, including that of the support provider.

With increased satisfaction with daily task performance post rehabilitation, a key person was identified who facilitated the rehabilitation and community reintegration process (Boschen, Tonack, & Gargaro, 2003). It is the responsibility of the modern rehabilitation centers to adapt to best meet the needs of those that are receiving their services. These services should include physical and emotional supports provided to that individual’s family caregivers as an integral component of the health care delivery system. “It is critical to remember that these family caregivers will be responsible for a wide range of care assistance that, in the past, were provided formally by traditional health care providers and that usually have to be carried out for an indefinite period” (Post, Bloemen, & de Witte, 2005, p. 311). It is a necessary process for the health care providers to educate how they perform those responsibilities in order to best provide a transitional period for all involved. Transitional planning can be a complicated and multi-step process due to many factors. One factor is financial.
D. **Caregiving**

Financial cutbacks in public funding in many states have limited the availability of vocational rehabilitation and independent living programs for individuals with severe physical disability. Thus, these individuals are compelled to reside with family members who then provide assistance and personal care (Kurylo, Elliot, & Shewchuk, 2001). This can be the first transition in a complex transitional plan due to decreased choice and exposure to other resources not available to someone just leaving rehabilitation. Needing assistance with daily activities can be a concern for many for both short and long terms. “40% of all individuals with SCI have at least some assistance with personal care. 50% of these individuals receive assistance from family members” (Ellenbogen, Meade, Jackson, & Barrett, 2006, p. 35). An associated study determined that those who provided assistance with personal care, on average, spent “11.3 hours per day caring for the person with SCI” (Blanes, Carmagnani, & Ferreira, 2007, p. 402). This is a significant portion of one’s day in addition to other familial and community roles the caregiver may have as well. Despite the focus of research on the negative aspect and strain of having a family member assume the role of caregiver, research has reported a positive aspect of family members as caregivers. These results seemed related to the importance of social support, not necessarily medical knowledge or skill. “Respondents who lived with at least one other family member had greater satisfaction with their own performance of daily tasks” (Boschen, Tonack, & Gargaro, 2003, p. 162). It appears that having the availability of a positive family member led to increased positive outcomes. This same concept was evident even if the caregiver was not necessarily an immediate family member. Mitchell and Kemp (1999) reported increased success and satisfaction with paid personal
attendants that the individual already knows. The results of this study have reported increased success and satisfaction with paid and unpaid attendants when clear boundaries and expectations were present. If in a rehabilitation plan, an individual has the availability to hire caregivers as part of his or her discharge plan, rehabilitation professionals can assist more with the process of selection of a caregiver and provide support and assistance by preparing individuals to hire and manage their personal attendants for increased satisfaction (Mitchell & Kemp, 1999). The more research is completed on this topic, the more effective rehabilitation professionals can be to facilitate successful caregiver relationships. This can involve determining the best family member or a more professional relationship with a paid caregiver to provide assistance.

Significant correlations between caregiver and individual with disability and health and wellness have been well established in the literature. There is a documented relationship between the wellness of these relationships and individual health status. “Research consistently reports elevated levels of physical stress, emotional stress, burnout, fatigue, anger and resentment, and depression among caregivers of persons with SCI” (Schultz, Czaja, Lustig, Zdaniuk, Martire, & Perdomo, 2009, p. 1). An example of this is poor health and reported quality of life by the caregiver which has been correlated to decreased health related quality of life of persons with paraplegia (Blanes, Carmagnani, & Ferreira, 2007). Research professionals may assume that these poor health and quality of life reports by the caregiver have a relationship correlated to the type of injury or severity of SCI and SCI related deficits. The research shows that this is not the case. The difference in the amount of stress felt by the caregiver is regardless of injury level (Unalan, Gencosmanoglu, Akgun, & Karamehmetoglu, 2001; Boschen,
Tonack, & Gargaro, 2005). “Bladder and/or bowel incontinence, lesion level, duration of spinal cord injury, presence and degree of spasticity, presence and degree of pressure sores, and ASIA grades had no significant effect” (Unalan, Gencosmanoglu, Akgun, & Karamehmetoglu, 2001, p. 319) on quality of life scaling of caregivers.

Because there is no evidence of physical limitations of the individual with SCI correlating to the health and wellness of caregivers, alternative explanations are being reviewed. Emerging research is beginning to demonstrate the close association between wellness of individuals with disability and the health and wellness of their caregivers. “Wellness is a proactive lifestyle in which a person is responsible for choices of self care, self sufficiency, and empowerment” (Kurylo, Elliot, & Shewchuk, 2001, p. 276). Further research is required to determine how cultural, ethical, and social factors affect caregiver response and wellness following a catastrophic event in the family, such as a spinal injury. This may include further research regarding changing and shifting of familial roles leading to increased distress and lower quality of life reporting (Unalan, Gencosmanoglu, Akgun, & Karamehmetoglu, 2001). Initial exploration regarding the influence of previous experiences and behavior patterns of new caregivers may impact their ability to take on new tasks related to the roles of caregiver. “Persons who have a history of mutually communal behaviors would likely perceive caregiving as a continuation of a caring and reciprocally rewarding relationship with a family member who may now require assistance in tasks of daily living” (Hui, Elliot, Shewchuk, & Rivera, 2007, p. 113). Personality traits may have a greater impact in one’s perception. “Providing care may induce resentment because it qualities as a highly communal but “out of role” activity for people unaccustomed to placing their partner’s needs ahead of
their own” (Hui, Elliot, Shewchuk, & Rivera, 2007, p. 114). Hui, Elliot, Shewchuk, and Rivera’s research demonstrates the importance of the link between the culture of the relationship an individual may have had previously with his or her caregiver and the personality of that caregiver in dealing with interactions with others in general. Another example of how the caregiver’s perceptions closely correlate to his or her fulfillment as a caregiver was explored by Post was regarding problem solving skills and task provision. Having a negative self-appraisal of skills will lead to future difficulties with novel problems and “caregiver coping strategies may be a better predictor of caregiver adjustment than social support” (Post, Bloemen, & de Witte, 2005, p. 318). Without early training in problem solving skills to address the process of role re-organization, these concerns will not only increase, but will further decrease the quality of care and quality of the relationship in terms of growth and coping. It is critical that these psychosocial aspects of rehabilitation care are addressed as related to the physical and medical treatments for both the individual with SCI and their caregiver to ensure health.

E. **Caregiving and Burnout**

It has been demonstrated both in general literature and literature more specific to SCI, that there are significant barriers and difficulties of family being a caregiver and the role of providing care overall. “[The] adjustment period may take longer to play out for support providers than it does for the person with the SCI” (Boschen, Tonack, & Gargaro, 2005, p. 403). Commonly associated within this adjustment period are stress, depression, and poor health reported by the caregiver. It has been reported that “96% said their health was important to them, but only 65% said that their needs were well met in this area” (Boschen, Tonack, & Gargaro, 2005, p. 399). Poor health related to stress in
caregivers of individuals with SCI are even more critical for the following reason as well. “Caregivers of persons with physical disability have higher levels of distress than non-caregivers” (Elliott, Shewchuk, & Richards, 2001, p. 223).

When enduring a high level of stress and other similar negative health effects and lacking active strategies to address these areas of health, the further development of caregiver burnout is a serious concern for anyone. Burnout is defined as an emotional condition marked by tiredness, loss of interest, or frustration that affects occupational performance. Prolonged stress is primarily the root cause of burnout. Because of the documented increased stress associated with caregiving, individuals who fulfill this role are highly susceptible. “I feel the carer has more stress than the patient” (Chen & Boore, 2008, p. 174). In addition to the role of stress and caregiver burnout, increased depression in caregivers is correlated to the number of hours providing care with daily activities (Unalan, Gencosmanoglu, Akgun, & Karamehmetoglu, 2001). It is important for everyone on the professional rehabilitation team to be educated in caregiver burnout and share this information with clients and caregivers to be aware of how to decrease its effects on them and their relationship with each other and their communities.

In their book, Spinal Cord Injury and the Family, Alpert and Wisnia (2008) discuss ways to decrease caregiver burnout. A study published by Post, Bloemen, and de Witte (2005) concluded that caregivers who learn how to identify early signs of caregiver fatigue and burnout and ways to maintain emotional and social support to best serve themselves in their continued role as caregivers reported decreased overall stress and depression. Much of Alpert and Wisnia’s advice centered on these concepts recorded by Post, Bloemen, and de Witte through the management of relationships and respecting
everyone’s contributions to the family unit. It is important to establish boundaries between spouse and caregiver. Both partners should be involved in decision making and activities to the best of their abilities (Alpert & Wisnia, 2008).

Many of the recommendations of Alpert and Wisnia (2008) can be initiated and further developed during the inpatient rehabilitation process. In traditional rehabilitation, individuals are encouraged to be open to vocalizing their needs and how to direct help, most often with items regarding physical assistance. This significant goal area in inpatient rehabilitation needs to be continued and further developed to include meeting emotional and social needs and to confidently direct others when in their own environment and community as well. In Boschen et al.’s study, published in 2005, family caregivers reported they were “scared to death and everything is trial and error regarding community reintegration” (p. 403). A portion of this trial and error process should be explored and included in preparation for leaving institutional care. There is a need to help people explore what is actually possible and not let anyone be limited by themselves or resources.

F. Caregiving and the Community

“The ability of family caregivers to meet the demands of routine family life while providing informed, skilled, and emotional support to a family member with a severe disability can have a direct impact on the health and well being of both individuals” (Hui, Elliott, Shewchuk, & Rivera, 2007, p. 114). Family life and family member roles exceed those required just inside the home. “It is not surprising that better health was correlated with higher ranked productivity status, greater satisfaction with community reintegration, and greater quality of life” (Boschen, Tonack, & Gargaro, 2005, p. 400). Alpert and
Wisnia (2008) highly agree with Boshen and his research team on this point as well. Regardless of the strong development of a routine and teamwork in the family and at home, it is important to establish social contact and to spend time apart from one’s spouse and/or caregiver. One way to increase time apart to meet personal needs and improve satisfaction is through employment. Vocational rehabilitation research has established positive outcomes related to individuals with disability and employment. The same positive correlations have been shown to be true for those who are also caregivers for a family member. “Employment can enable the caregiver to get respite from the routine of caregiving and be a source for social contacts” (Ellenbogen et al., 2006, p. 36).

In a review of multiple case studies by Ellenbogen et al. (2006), four themes regarding the effects of caregiving were the main themes in the conducted interviews of nine caregivers. These included: 1) Caregivers had to create flexibility in their employment situation in order to successfully maintain employment, especially initially following their family member’s injury; 2) While many caregivers felt that they needed to work for financial reasons, there were times when the two responsibilities of work and caregiving conflicted; 3) Employment allowed them to take time to care for their own personal needs; and 4) Caregivers’ employment was affected by the lack of available Certified Nursing Assistants (CNAs).

This transition back to the workplace is difficult and can have significant barriers as previously stated. Research is still demonstrating support when possible for outside employment. One individual was quoted as saying, “Going back to work was the best thing that they had done” (Boschen, Tonack, & Gargaro, 2005, p. 404). There are concerns regarding timing and long term planning to support outside employment.
“Caregivers who find it necessary to leave work in order to fulfill their caregiver responsibilities are often unable to return to work later because of these responsibilities” (Ellenbogen, Meade, Jackson, & Barrett, 2006, p. 37). It seems important to establish a goal of desired work re-integration and have a plan to achieve that goal in order to truly become successful in increasing occupational roles in this manner. “Caregivers are often forced to neglect their own needs, leisure pursuits, and personal interests” (Kurylo, Elliot, & Shewchuk, 2001, p. 275). Employment can be one example of a means to maintain this self identify and should be supported as such when possible.

It is time for a cultural shift in the area of rehabilitation medicine which the literature is also addressing. “There is a pressing need for interventions which help family caregivers address the routines and tasks essential to maintaining family functioning” (Post, Bloemen, & de Witte, 2005, p. 318). This includes not only the process for how rehabilitation professionals interact and incorporate family and caregivers into the educational and training process following an acquired physical disability, but how the caregiving role is valued and viewed. One way for this process to begin is with the language being utilized. Boschen and her research team believe that caregivers of individuals with SCI should be referred to as support providers. “This emphasizes that the nature of the supporting role to an adult with a traumatic SCI is likely to be quite different from that of a caregiver for an older adult with a chronic condition, and also to a cognitively impaired person with a brain injury” (Boschen, Tonack, & Gargaro, 2005, p. 397). So, regardless of the individual providing support, and if they are a family member, the importance and diversity of this role is to be fully appreciated. “Individuals often report that partners and family members are more helpful to them than professional staff
as they cope with their disabilities” (Hui et al., 2007, p. 114). In addition, “rehabilitation services were not listed [by individuals with SCI] among the top environmental facilitators [for locus of control]” (Boschen, Tonack, & Gargaro, 2005, p. 399).

Rehabilitation professionals need to keep these important statements in mind and be sure that they are providing the support provider with the tools that they need to be successful in the community as well.

Support providers in the community need to be supported themselves and empowered to successfully fulfill a critical role in the disability community. “A one size fits all approach to caregiver intervention is likely to be ineffective” (Schultz, Czaja, Lustig, Martire, & Perdomo, 2009, p. 2). Schulz et al. (2009) reported that the most effective interventions were those offering care provider instructions including the individual receiving care. This data only further stresses the need for a comprehensively structured, yet flexible plan of care so all individuals involved can effectively participate as a critical aspect of rehabilitation.

G. **Health Promotion Programming**

In order to determine the effectiveness of support provider education efforts and overall effectiveness of rehabilitation interventions, it is important to determine the guidelines and criteria necessary for successful outcomes. It has been previously stated that improved health outcomes and support provider satisfaction are related to interactive education programming involving both the individual providing support and receiving the assistance (Schultz et al., 2009). “It has been shown that patients with the correct knowledge and information about their condition can result in improved health outcomes” (Verkaaik, Sinnott, Cassidy, Freeman, & Kunowski, 2010, p. 980). With
increased education regarding disability and newly acquired health roles, a shared model of healthcare can become successful. A shared model of healthcare is interactional between healthcare providers and those receiving health care throughout all stages of decision making to form a therapeutic alliance to promote positive health outcomes (Verkaaik, Sinnott, Cassidy, Freeman, & Kunowski, 2010). Many aspects of community based health promotion programs for individuals with disabilities may also be utilized as guidelines for improvement in rehabilitation programming. These criteria for analysis involve the areas of operation, participation, and accessibility of the program (Drum, Peterson, Culley, Krahn, Heller, Kimpton, & White, 2009). Health promotion for support providers can only be successful at all levels of rehabilitation through careful planning founded upon evidence based principles.
III. METHODOLOGY

A. Study Design

This study utilized a case study methodology through a small selection of cases to maximize a comprehensive understanding of the processes involved with caregiver education and the transition to community living. The outcome measures that were utilized to explore the success of this study include both qualitative and quantitative measures. Standardized measures based on the World Heath Organization (WHO) recommendations on disability and data collection were utilized when formatting these collection strategies. This information was collected through the use of interview and survey data collection to gain an increased understanding of life and routine following the initial transition from rehabilitation one month post intervention. The importance of each participant’s input was seen as an integral component in the data collection process and exploration of this topic.

This study explored the idea that increased specialized, hands-on, didactic instruction and training beyond traditional therapy based education, will result in improvement in success and satisfaction from patients and their caregivers regarding transition from inpatient rehabilitation to community living. Data collection was compared to a control group of data collected by the Outcomes Management Systems and Analysis (OMSA) department at the Rehabilitation Institute of Chicago (RIC) from past individuals with tetraplegia who have completed traditional rehabilitation only with a discharge between September and October 2010. This control information was synthesized from survey information collected one and three months post discharge from RIC through phone interview. There were two concurrent collections of data completed
to maximize depth of information. One involved RIC patients through data collected through a needs assessment survey. This needs survey was completed prior to the initiation of the intervention (Appendix D). The results of this survey were utilized to determine the educational components included within the intervention process. Topics for the educational series were selected directly in response to expressed areas of concern or educational interest areas of previous patients and further enhanced by other areas of recognized need in the rehabilitation program. The second collection of data involved caregivers and/or family members through the use of pre and post surveys. A pretest, posttest, and a one to two month post intervention survey were utilized as methods for caregiver data collection (Appendices E, F, and G). This study focused on exploration regarding areas of patient and caregiver satisfaction, patient discharge environment from inpatient rehabilitation, and effective methods to provide caregiver education.
<table>
<thead>
<tr>
<th>Data Collection Method</th>
<th>How Data Was Collected</th>
<th>Population</th>
<th>Purpose of Survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs Assessment</td>
<td>Verbal or written report through survey</td>
<td>Current Inpatient Population within RIC SCI Program</td>
<td>Determine areas of further education needs, barriers to participation in educational programming</td>
</tr>
<tr>
<td>Consent Forms</td>
<td>Verbal and handout education provided. Signed forms returned</td>
<td>Current patient and their family member</td>
<td>Determine sample size for study and educate participants in study</td>
</tr>
<tr>
<td>Pre-Intervention</td>
<td>Completed survey form returned 1 week prior to intervention</td>
<td>Identified family member</td>
<td>Determine baseline comfort and experience with SCI and current participation level</td>
</tr>
<tr>
<td>Post Intervention</td>
<td>Completed survey form returned at discharge from RIC</td>
<td>Identified family member</td>
<td>Determine current comfort and experience with SCI and acquired participation level, and satisfaction with training</td>
</tr>
<tr>
<td>Comparison Group Data</td>
<td>Retrospective data collection from RIC OSMA database</td>
<td>Previous inpatients with Tetraplegia; 1 month and 3 month RIC surveys post discharge</td>
<td>Determine averaged satisfaction and discharge information of a comparison group</td>
</tr>
<tr>
<td>Program Analysis</td>
<td>Retrospective analysis of caregiver education series programming</td>
<td>Educational program</td>
<td>Systematic evaluation of intervention provided</td>
</tr>
<tr>
<td>Follow up functional status survey</td>
<td>Phone Interview or complete survey form returned 2 months following discharge from RIC</td>
<td>Identified family member and past recipient of inpatient rehabilitation</td>
<td>Determine current functional independence of individual with SCI and satisfaction with education at RIC</td>
</tr>
</tbody>
</table>
The intervention involved the development of a four week series of training sessions (Appendix H). The chosen four topics included Basics of Spinal Cord Injury Diagnoses and Medical Information, Introduction to Adaptive Equipment utilized to promote functional independence, Mobility and Transfer Technique Training, and an interactive, Panel with caregivers and individuals with SCI. This newly developed educational program implemented as the intervention of this study was evaluated utilizing the Community Based Health Promotion Program for People with Disabilities-Operational Guidelines Involving Seven Criteria (Drum et al., 2009) to determine effectiveness of programming.

B. **Setting**

All intervention and data collection occurred at the Rehabilitation Institute of Chicago, Spinal Cord Injury Program.

C. **Sample**

Control data was taken from the RIC OMSA database from the Spinal Cord Injury Program from the past year for patients with tetraplegia who discharged between September and October 2010. Current patients of the Spinal Cord Injury Program at RIC were recruited utilizing established inclusion and exclusion criteria for participation in the intervention of the study.

Inclusion criteria:
1. Each caregiver/family member/friend, needed to attend a minimum of 50% of education sessions.
2. This individual must be a family member/friend/caregiver of an individual with SCI currently in rehabilitation.
3. Patient and caregiver must agree to participate in the study and sign consent forms.

4. Both the patient and their caregiver needed to be able to understand both written and spoken English.

There were no additional exclusion criteria.

All current individuals receiving inpatient rehabilitation at the Rehabilitation attend any of the four scheduled Saturday training sessions and participant recruitment strategies were utilized for all of the above stated individuals.

1. **Participant recruitment**

Participants included individuals with SCI and their designated family members and/or caregivers who had been identified by the individual as a primary caregiver. All current inpatients of the Spinal Cord Injury Program at the RIC were encouraged and recruited to participate in the study and/or attend the educational series.

Recruitment strategies were coordinated through the study’s student researcher and recruitment was completed by the rehabilitation professionals who are employed by the RIC Spinal Cord Injury Program. Strategies for recruitment included assistance from the rehabilitation therapy team through encouragement and verbal recruitment of individuals to attend recommended topics of education. At the initiation of the recruitment phase, marketing flyers describing the research study were provided to each individual who was currently receiving inpatient rehabilitation following a spinal cord injury (Appendix I). Additional visual reminders of the time and location of the training session were provided on each current individual’s daily therapy schedule and recruitment flyers were posted in highly visible areas through the program’s unit.
All individuals who were interested, and met the inclusion criteria, were welcome to participate. Their rehabilitation programs were not affected by their decision to participate or not participate in study activity.

There was no charge for participation and continued participation within the study was determined by the participants’ interest in the program activities and seminar.

2. **Sample size**

A convenience sample of six participant pairs was the recruitment goal for this study. There were several limitations which affected achieving this goal.

Of an initial total of four pairs of participants who consented to participate in this study, a total of three pairs of participants were part of the experimental group and completed all levels of data collection. One participant passed away shortly after returning home due to medical complications prior to completion of post discharge and follow up data collection.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Sex</th>
<th>Marital and Living Status</th>
<th>SCI ASI Level at Admit</th>
<th>Identified Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>65</td>
<td>Male</td>
<td>engaged, Missouri</td>
<td>Tetra- Complete</td>
<td>fiancée</td>
</tr>
<tr>
<td>2</td>
<td>67</td>
<td>Male</td>
<td>engaged, adult children, Chicago</td>
<td>Tetra- Complete</td>
<td>fiancée</td>
</tr>
<tr>
<td>3</td>
<td>40</td>
<td>Male</td>
<td>married, 2 4yo daughters, Chicago</td>
<td>Tetra- Incomplete</td>
<td>wife and hired caregiver</td>
</tr>
<tr>
<td>4</td>
<td>67</td>
<td>Male</td>
<td>Missouri</td>
<td>Tetra- Complete</td>
<td>wife</td>
</tr>
</tbody>
</table>
IV. RESULTS

A total of ten patient needs assessment surveys were returned during the collection period of two weeks. This ten was from a possible 26 of recruited individuals for an approximate return rate of 38%. Of the total of ten, five individuals who completed the survey stated that their family had attended the established education sessions available as part of the SCI Program at RIC. Of this five, only one respondent stated they always attended. Seven respondents stated that their family had attended therapy sessions, with the most stated frequency of six noting sometimes. There were several reported limitations of friends and/or family to attending already established education and therapy. The most frequently reported themes for not attending were not knowing about the classes or schedule, conflicts with work, and limitations related to distance from the rehabilitation center or lack of transportation to travel to the rehabilitation center.

Nine of ten respondents reported that they felt comfortable having their family assist them with personal care and transfers. They just felt like their family was not yet prepared to do so and were concerned about the performance of these activities once discharged from RIC. A total of six caregivers had completed training at the time of this survey for the needs assessment survey population.

The same themes were reported when the question was asked regarding what activities they wished their caregivers knew how to assist them with when asked what they were most concerned about regarding daily activities. The topics included as most concerning to complete were bowel and bladder care, completing transfers, independence
in taking care of self during everyday living, and being able to get out into the community.
<table>
<thead>
<tr>
<th>Question Topics</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of Spinal Cord Injury</td>
<td>Tetraplegia- 7 Paraplegia- 3</td>
</tr>
<tr>
<td>Home Accessible</td>
<td>Yes- 4 No- 4</td>
</tr>
<tr>
<td>Patient Education Series Attendance by</td>
<td>Always- 1 Sometimes- 2 Rarely- 0 Never- 5</td>
</tr>
<tr>
<td>Family and Friends</td>
<td></td>
</tr>
<tr>
<td>Barriers to Family and Friends Attendance</td>
<td>Did not know about classes Work and transportation Women were strictly forbidden form male sexuality class Travel and getting time off of work Not told about them Ability to come to location/increased distance, physical limitations</td>
</tr>
<tr>
<td>Therapy Attendance of Family/Friends</td>
<td>Yes- 7 No- 3</td>
</tr>
<tr>
<td>Frequency of Family/Friends Therapy</td>
<td>Always-1 Sometimes- 6 Rarely- 0 Never- 3</td>
</tr>
<tr>
<td>Attendance</td>
<td></td>
</tr>
<tr>
<td>Caregiver for Home Identified</td>
<td>Yes- 8 No- 1 Unsure- 1</td>
</tr>
<tr>
<td>Caregiver Training Completed</td>
<td>Yes- 6 No- 4</td>
</tr>
<tr>
<td>Comfortable with Family and Friends</td>
<td>Yes- 8 No- 1</td>
</tr>
<tr>
<td>Assisting with Transfers/Personal Care</td>
<td></td>
</tr>
<tr>
<td>Areas of Desired Further Training</td>
<td>Transfers Bowel and bladder Dressing and transfers Shower transfers No, I want to be as independent as possible Getting into chair better Shaving, general hygiene</td>
</tr>
<tr>
<td>Areas of Most Concern Regarding Discharge</td>
<td>Everyday living- being able to get around in my chair Bowel program Taking care of myself Bladder and bowel Being independent Clean up bowel accidents during transfers or while in bed or chair Getting out into community Bathroom, washing, want to live independent, getting out of bed</td>
</tr>
</tbody>
</table>
Prior to the initiation of participation in the intervention, all four original
caregiver participants completed an initial survey. All of the identified caregivers were
female and spouses or significant others of the individual receiving rehabilitation services
following a SCI. The time since initial evaluation at RIC ranged between two weeks to
one month at the time of this initial survey. All four had attended previously established
education sessions, with two women reporting that they always attended. Three of the
dr
four caregivers had participated in therapy training for transfers and all four had stated
participated in therapy training regarding some ADLs. All four had therapeutic education
experience in ADL areas of dressing and feeding, three in bathing and education
regarding SCI medical precautions and emergent situations, and two had initiated bladder
and bowel care management with rehabilitation professionals. These identified caregivers
reported two significant concerns in preparation to going home. These included using a
slideboard for transfers and completing car transfers.

Three caregivers completed and returned the caregiver post survey within the
week of discharge from inpatient rehabilitation. Average attendance for the intervention
was three of four sessions. An increase in reported attendance to all available education
sessions during the inpatient rehabilitation stay by the caregivers was present when
compared to data collected from the patient based needs assessment at the initiation of
this study. The overall frequency of attendance to therapy and educational sessions
slightly increased within the caregivers participating in the study from frequencies
reported within the pre-survey. The greatest attendance increase reported was to caregiver
support groups. An increase in comfort and feelings of preparedness was reported by all
three caregivers to assist their family member with personal care activities and transfers.
Increased areas of concern regarding activity performance outside of RIC were reported. Responses from the caregiver pre-survey regarding concerns were transfer based. Concern regarding bathing, bowel care, sleep, and adequate performance of pressure reliefs were included in post survey reports.

Three individuals and their caregivers completed and returned the functional status update survey within one to two months following discharge from inpatient rehabilitation. One hundred percent of participants of this study returned to their pre-injury homes in the community. This is a significant improvement over the average percentage of 71% at RIC for community based discharge destinations for individuals with tetraplegia. At this follow up functional status survey, two individuals’ significant others were still providing all care and one individual identified a paid attendant now as a primary caregiver. At the time of this post survey, two patient participants required total assistance for all basic ADLs while one participant demonstrated improved independence with all ADLs and progressed to stand-pivot transfers. Two individuals reported increased volitional movement since discharge. All three individuals with SCI were still receiving ongoing therapy. There were no medical concerns reported by two individuals since leaving inpatient rehabilitation. The third participant stated he had developed a small heel sore that was currently being treated when asked about ongoing medical complications. RIC based survey data reported an excellent rating of 66.7% for satisfaction for preparation for discharge. For this study, one participant rated his satisfaction in terms of preparedness for discharge as excellent and two rated their satisfaction as good. Two surveys reported that there wasn’t anything else that could have been done during their inpatient stay to better prepare for transition to home, and one
requested increased practice in the home setting and an increased opportunity to trial equipment options that could be sent to his home to improve his satisfaction with preparedness for discharge.

Participant One is a 65 year old man. Prior to obtaining a traumatic SCI, he was currently engaged and was independently running a small business. It was reported that his grandson has taken over the primary responsibility of running the business at the time of the follow up survey at four months post injury, so Participant One could focus on his neurological recovery, and due to decreased environmental barriers, to successfully oversee his business. Participant One’s caregiver, his significant other, was very present during inpatient rehabilitation. Her participation in personal care and transfers increased as his independence and tolerance to perform activities improved. She also attended more groups independently once the intervention was initiated and she gained increased education regarding additional opportunities. Participant One and his now wife reported that their preparation for the transition to their home was excellent and did not have suggestions for what else could have been provided.
TABLE IV
SURVEY RESULTS OF PARTICIPANT ONE

<table>
<thead>
<tr>
<th>Topic Grouping</th>
<th>Pre-Survey</th>
<th>Post Survey</th>
<th>Follow-Up Survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time since RIC Admission</td>
<td>1 month</td>
<td>2 months, 3 days</td>
<td>4 months</td>
</tr>
<tr>
<td>SCI ASI Level</td>
<td>Incomplete Tetraplegia, ASI B</td>
<td>Incomplete Tetraplegia, ASI B</td>
<td>Incomplete Tetraplegia, ASI C</td>
</tr>
<tr>
<td>Primary Caregiver</td>
<td>Significant Other</td>
<td>Significant Other</td>
<td>Spouse</td>
</tr>
<tr>
<td>Patient Independence Level</td>
<td>Total A</td>
<td>Total A</td>
<td>Total A, Max A for eating</td>
</tr>
<tr>
<td>Therapy Attendance Frequency</td>
<td>Always</td>
<td>Always</td>
<td>Outpatient 3 x /week</td>
</tr>
<tr>
<td>Education Series Attendance Frequency</td>
<td>Always, Wednesday and Sunday</td>
<td>Always, Wednesday, Saturday, Sunday</td>
<td></td>
</tr>
<tr>
<td>Completed Training</td>
<td>dressing, feeding, bathing, bowel and bladder care</td>
<td>dressing, feeding, bathing, bowel and bladder care, transfers</td>
<td>Advanced education on skin care</td>
</tr>
<tr>
<td>Comfortable with ADLs</td>
<td>Yes</td>
<td>Yes</td>
<td>Performing all ADLs</td>
</tr>
<tr>
<td>Comfort with Transfers</td>
<td>Yes, hoyer lift</td>
<td>Yes, hoyer lift, car transfer, use of slideboard</td>
<td>Performing all transfers</td>
</tr>
<tr>
<td>Concerns</td>
<td>Car transfer</td>
<td>Sleep and pressure sores</td>
<td>Healing foot sore</td>
</tr>
<tr>
<td>Rated Experience/Prepared</td>
<td>Yes</td>
<td>Excellent</td>
<td></td>
</tr>
</tbody>
</table>
Participant Two is a 67 year old man. Prior to obtaining a SCI, he was enjoying retirement and was residing with his long-time significant other. He was active in his children and grandchildren’s lives. The participants’ partner was identified as the primary caregiver early on in his rehabilitation and was present daily. She was active in learning personal care tasks, and assisted with transfers as able. Her participation varied due to physical limitations and the increased physical support Participant Two required throughout the day. Training with his caregiver was individualized as possible to decrease the emphasis on hands on activities that she was already participating in and focused on education and discussion regarding caregiver health and energy conservation and the processes for successfully increasing outside assistance for in the home. Participant Two and his caregiver rated their preparation to return to their home as good, but suggested increased home based training for further preparation.
<table>
<thead>
<tr>
<th>Topic Groupings</th>
<th>Pre-Survey</th>
<th>Post Survey</th>
<th>Follow-Up Survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time since RIC admission</td>
<td>1 month</td>
<td>13 weeks</td>
<td>5 months</td>
</tr>
<tr>
<td>SCI ASI Level</td>
<td>Incomplete Tetraplegia, ASI B</td>
<td>Incomplete Tetraplegia, ASI B</td>
<td>Incomplete Tetraplegia, ASI B</td>
</tr>
<tr>
<td>Primary Caregiver</td>
<td>Significant Other</td>
<td>Significant Other</td>
<td>Significant Other</td>
</tr>
<tr>
<td>Patient Independence Level</td>
<td>Total A</td>
<td>Total A</td>
<td>Total A, no bathroom transfers</td>
</tr>
<tr>
<td>Therapy Attendance Frequency</td>
<td>Often</td>
<td>Often</td>
<td>Day Rehabilitation 3 x /week</td>
</tr>
<tr>
<td>Education Series Attendance Frequency</td>
<td>Sometimes</td>
<td>Always, bowel, bladder, skin care</td>
<td></td>
</tr>
<tr>
<td>Completed Training</td>
<td>dressing, feeding, bathing, bowel and bladder care, SCI information</td>
<td>dressing, feeding, bathing, bowel and bladder care, SCI information, transfers</td>
<td></td>
</tr>
<tr>
<td>Comfortable with ADLs</td>
<td>Yes</td>
<td>Yes</td>
<td>Performing all ADLs</td>
</tr>
<tr>
<td>Comfort with Transfers</td>
<td>Yes, hoyer lift and bath chair</td>
<td>Yes, hoyer lift,</td>
<td>Performing all transfers</td>
</tr>
<tr>
<td>Concerns</td>
<td>Concerned overall</td>
<td>N/A reported</td>
<td>Home equipment coverage</td>
</tr>
<tr>
<td>Rated Experience/Prepared</td>
<td>Yes</td>
<td>Good</td>
<td></td>
</tr>
</tbody>
</table>
Participant Three is a 40 year old man living in downtown Chicago with his wife and two young daughters. Prior to obtaining a traumatic SCI from a sporting injury, he independently ran an information systems business. He continued to manage the primary responsibilities of the business approximately one month after injury. Participant’s wife was identified initially as the primary caregiver. She was present at all therapy sessions, but active participation was limited initially. Following participation in caregiver education, she increased her active learning in therapy sessions, especially in areas of mobility and transfers. She was an active trainer of hired caregivers for her husband prior to discharge home. Areas of concern shared for the purposes of this study were addressed further in collaboration with the therapy team of Participant Three, and these activities were emphasized in hired attendant training. Participant Three and his wife reported at the conclusion of data collection for this study that the training they received for discharge preparation was good and nothing needed to be added to their educational experience.
<table>
<thead>
<tr>
<th>Topic Groupings</th>
<th>Pre-Survey</th>
<th>Post Survey</th>
<th>Follow-Up Survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time since RIC admission</td>
<td>3 weeks</td>
<td>2 months, 3 days</td>
<td>4 months</td>
</tr>
<tr>
<td>SCI ASI Level</td>
<td>Incomplete Tetraplegia, ASI B</td>
<td>Incomplete Tetraplegia, ASI C</td>
<td>Incomplete Tetraplegia, ASI D</td>
</tr>
<tr>
<td>Primary Caregiver</td>
<td>Spouse</td>
<td>Spouse</td>
<td>Paid Attendant</td>
</tr>
<tr>
<td>Patient Independence Level</td>
<td>Total A</td>
<td>Total A</td>
<td>Independent to eat, Moderate assist to dress, Minimal assist-stand-pivot transfers</td>
</tr>
<tr>
<td>Therapy Attendance Frequency</td>
<td>Always</td>
<td>Always</td>
<td>Outpatient 3 x /week</td>
</tr>
<tr>
<td>Education Series Attendance Frequency</td>
<td>Sometimes, Wednesday and Sunday</td>
<td>Some on Saturday, Sometimes Wednesday and Sunday</td>
<td></td>
</tr>
<tr>
<td>Completed Training</td>
<td>dressing, feeding, SCI information</td>
<td>dressing, feeding, bladder care, SCI information, transfers</td>
<td></td>
</tr>
<tr>
<td>Comfortable with ADLs</td>
<td>No</td>
<td>Yes</td>
<td>Attendant performing assistance</td>
</tr>
<tr>
<td>Comfort with Transfers</td>
<td>Assisting only, not performing</td>
<td>Yes, use of slideboard</td>
<td>Attendant performing assistance</td>
</tr>
<tr>
<td>Concerns</td>
<td>slideboard</td>
<td>Bathing, bowel care</td>
<td></td>
</tr>
<tr>
<td>Rated Experience/Prepared</td>
<td>Yes</td>
<td>Good</td>
<td></td>
</tr>
</tbody>
</table>
Due to the fact that this was a novel program developed as an intervention for this study, the effectiveness of the program was explored in addition to data collection related to the study participants. This review was completed through analysis and comparison of the “7 Criteria Framework” (p. 95-98) outlined in Drum et al.’s Guidelines and Criteria for the Implementation of Community Based Health Promotion Programs for Individuals with Disabilities (2009). This analysis was completed retrospectively to further evaluate the effectiveness of the utilized training methods and program development. It was determined to be a critical factor that the intervention education program was further studied to ensure that best practice and current theory was utilized in its development and implementation.

Health promotion programs for people with disabilities should have an underlying conceptual or theoretical framework. Content for the program topical areas were taken from multi-disciplinary sources and effort was made to extend these topics beyond traditional rehabilitation standards in current practice. A client centered approach was utilized to determine educational topics and basic theoretical framework. It incorporated other disability study principles by also utilizing peer mentors to provide education and discuss their experiences with the related educational topics. Because education was being provided in an adult learning environment, multiple learning styles were incorporated, and increased use of media was utilized to best match each adult’s learning preferences. Basics of the Transtheoretical Model were referenced to develop a tailored program to meet the needs and readiness for change of the participants throughout this process.
Health promotion programs should implement process evaluation. This study is currently being utilized as a way to initiate the evaluation of caregiver based programming. If this program is to continue, it is recommended to further develop and implement a specific evaluation process for further logistical preferences in relation to learning efficiency and customer satisfaction in relation to attendance and interest regarding topics.

Health promotion programs should collect outcomes data using disability appropriate outcomes measures. Because this program was completed in a rehabilitation hospital setting, evaluating measures referenced and utilized were developed from current rehabilitation standards. An example of this is the reference to the Functional Independence Measure scoring scale to determine success in functional outcomes achievement. Evaluating individual readiness, satisfaction, and quality of life both pre and post intervention will be important to develop further appropriate outcome measure for a more accurate set of data collection tools. Benefits from an increased interdisciplinary collaboration in programming to address all of the above needs would further enhance this program.

People with disabilities and their families and/or caregivers should be involved in the development and implementation of health promotion programs for people with disabilities. The importance of people with disabilities and their caregivers as central role players in this program was highly emphasized in all aspects of the education program. A needs assessment, completed through a survey process, was collected to best determine times for sessions to be held and topics of interest within a similar population of individuals. Caregiver and peer mentors with SCI were also incorporated into the
educational series to further enhance topics and relevance to participants through a more real life, practical component.

Increased participatory action models of research should be expanded in future development of this programming to continue to best meet needs of participants as determined more by individuals themselves and by peer groups, than traditional rehabilitation professionals.

Health promotion programs for people with disabilities should consider the beliefs, practices, and values of its target groups, including support for personal choice. All opinions of each participant during the program and opinions shared during the needs assessment phase of programming development were fully supported and encouraged during discussions. An interactive and collaborative process for problem solving and learning was also highly encouraged within the structure of each training session. A hands on experience was highly encouraged, but participation was optional in order to best allow for personal choice.

Health promotion programs should be socially, behaviorally, programmatically, and environmentally accessible. The day and time of the training sessions was chosen to best match the preferred time and day as determined by the needs assessment. No additional cost was required to participate in this program. It was offered in addition to traditional SCI rehabilitation programming at the RIC. Handouts and other resources were provided related to the topics being discussed for future reference. Video and multimedia were also utilized in presentations to best address multiple learning styles and to enhance interactive learning. Alternatives to high technology and expensive medical equipment were explored to increase universal access, but financial limitations and
logistical concerns decreased their availability at this time. This program was limited to only current patients in the spinal cord injury program at RIC which limited who may have otherwise benefited from attendance from the community. The program was held where participants with SCI were currently residing to increase physical accessibility. It was difficult for some caregivers or family members to attend due to transportation and vocational barriers.

Health promotion programs should be affordable to people with disabilities and their families or caregivers. There was no cost above those required by insurance for the concurrent inpatient rehabilitation services being received. No coverage for transportation for caregiver/family was provided.

Overall, the caregiver program closely followed the recommended guidelines outlined in order to optimize benefit to participants. To continue successful development in future implementation, it would be recommended to continue to increase the direct voice of the participants into topical and logistical planning and to be incorporated for all populations in the community and inpatient rehabilitation who would benefit from caregiver education programming.
V. DISCUSSION

Despite the data collected from a limited number of individuals, the results and programming developed for this intervention are encouraging for future research. The increased awareness of services and educational opportunities following the study intervention demonstrates an area of improvement within the SCI program. Positive formal and informal feedback of participants throughout all aspects of data collection for this study regarding education practices demonstrate an increased need to continue to explore effective ways to facilitate learning and problem solving to provide satisfaction with transition to the community.

The increased concerns reported by the caregivers at discharge were a reflection of increased knowledge of the caregivers of all aspects of personal care that was acquired throughout the inpatient stay. The increase in concerns was unexpected, as with increased education it would be believed to decrease concerns. However, due to the complexity of SCI, increased time may be required to fully appreciate all areas of care.

A. Limitations

There were several limitations to this study. One was the convenience sample of caregivers and individuals with SCI who participated in the study. Due to the decreased sample size, this study’s results cannot be generalized to other SCI programs and populations at this time. Another limitation of the study was related to the study being conducted at a SCI Model Systems center in an urban environment. Because of this, current inpatients have increased exposure to additional opportunities of education and resources which may influence the ability to determine the full extent of the intervention provided for this study. There were a limited number of opportunities to participate in
scheduled sessions for this pilot study of caregiver training education. Each topic was present only one time within the one month long intervention phase of the study. Some difficulty was present for completing timely follow up data due to distance for patients in coming to the center to complete surveys and limitations with access to communication technology to complete phone interviews with participants secondary to physical and environmental barriers related to phone and computer access. Two participants underwent a medical status change during the intervention phase of the study and were unable to attend all training sessions due to receiving medical attention at another facility. This limited their ability to engage in increased educational opportunities. The final limitation for this study involved possible researcher bias. The primary researcher completed all recruitment, intervention, and data collection and was also a staff member that provided therapeutic intervention outside of the study activities.

B. **Implications for Clinical Practice**

This study provides an example of how to increase opportunity and active incorporation of family members and caregivers into the rehabilitation process. Feedback has included a need for education early on in the inpatient rehabilitation process of SCI rehabilitation for patients and their caregivers to best become familiar with the process and how they can best participate in order to maximize success, satisfaction, and functional outcomes. Increased follow up communication after inpatient rehabilitation completed by this study demonstrated a need and opportunity for future interaction between professionals and past patients and their family and caregivers to better enhance education and training programming in the future. Established procedures for communication following discharge would allow for an increased opportunity for
collaboration with caregivers for advanced problem solving training to further incorporate the principles of the successful FOCUS program developed by Kurylo, Elliott, and Shewchuk in 2001 for increased positive outcomes in caregiving.

C. **Implications for Research**

This study provides additional support on the importance of additional research to be completed involving caregivers, successful transition of individuals with SCI returning to the community, and SCI rehabilitation programming. Former individuals who have undergone inpatient rehabilitation following a SCI and those individuals who fulfill a caregiver/support provider role are critical resources and should be included in all aspects of training and education. Future studies need to continue to ask “what else would have been helpful?” The incorporation of focus groups of involved parties may be an effective way to gain an increased insight into the caregiver training and learning methodology. Implications for peer mentoring and increased research options for participation should be emphasized in order to maximize success and efficiency of training, satisfaction, and functional outcomes. This could include researching topics such as the success of peer lead education and if there are benefits to an increased format standardization of education sessions. It is critical for research to provide clinical guidelines to rehabilitation professionals for optimal participation for all individuals involved in the integrated rehabilitation team to achieve the positive outcomes desired.
D.  **Conclusion**

Further research is needed in regard to caregiver training in inpatient rehabilitation. As the length of inpatient rehabilitation stays continued to decrease, the efficiency in which education and training is done for individuals with SCI and their caregivers will become more important to determine and integrate into clinical practice. Initial data from this investigation suggests that with increased commitment early on in the rehabilitation process, the result can be increased feelings of success, comfort, and satisfaction for caregivers and former recipients of inpatient rehabilitation services with transition to home and community. It is important for there to be improved access to education and training within rehabilitation. For many individuals, having themselves or someone important in their lives residing in an inpatient rehabilitation environment is one of their first personal exposures to disability. It is important that their rehabilitation experience is an empowering one. It is not only important to provide access to education regarding medical information, but to promote confidence and the attainment of past and new community roles and opportunities. It is vital for rehabilitation professionals to maximize the incorporation of dynamic and individualized training processes in preparation for transition home from inpatient rehabilitation. The caregiver is the extension of the rehabilitation professional into the home and needs to be incorporated as a critical member of the rehabilitation team for optimal community re-integration and return to desired occupational roles.
APPENDICES
APPENDIX A

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Initial Review (Response To Modifications)

July 12, 2011

Piper Hansen
Disability and Human Development
40 E. Oak Street #1408
Chicago, IL 60611
Phone: (242) 498-4898 / Fax: (312) 238-1035

RE: Protocol # 2011-0483
“Promoting Successful Transition to Community through Increased Caregiver Training”

Dear Ms. Hansen:

Your Initial Review application (Response To Modifications) was reviewed and approved by the Expedited review process on July 11, 2011. You may now begin your research.

Please note the following information about your approved research protocol:

Protocol Approval Period: July 11, 2011 - July 9, 2012
Approved Subject Enrollment #: 8 (limited to secondary data analysis for 8 previously enrolled subjects)

Additional Determinations for Research Involving Minors: These determinations have not been made for this study since it has not been approved for enrollment of minors.

Performance Sites: UIC, Northwestern University-Rehabilitation Institute

Sponsor: None

Research Protocol:

a) Promoting Successful Transition to Community through Increased Caregiver Training; Version 2; 06/28/2011
APPENDIX A (continued)

Recruitment Material:
  a) Analysis of secondary data - no recruitment materials will be used (data collected at Rehabilitation Institute of Chicago/Northwestern University using RIC/NWU-approved recruitment and consent documents; minimal risk)

Informed Consent:
  a) A waiver of informed consent has been granted at UIC under 45 CFR 46.116(d) for the analysis of secondary data collected at the Rehabilitation Institute of Chicago/Northwestern University (subjects were consented using RIC/NWU-approved consent documents; minimal risk)

HIPAA Authorization:
  a) This research meets the regulatory requirements for waiver of authorization as permitted at 45CFR164.512(i)(1)(i)(A). Specifically, that the use or disclosure of protected health information (PHI) meets the waiver criteria under 45CFR164.512(i)(2)(ii); the research involves no more than a minimal risk to the privacy of the individuals; the research could not practicably be conducted without the waiver; and the research could not practicably be conducted without access to and use of the PHI (analysis of secondary data collected at the Rehabilitation Institute of Chicago/Northwestern University; subjects were consented using RIC/NWU-approved consent documents)

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific category:

(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis).

Please note the Review History of this submission:

<table>
<thead>
<tr>
<th>Receipt Date</th>
<th>Submission Type</th>
<th>Review Process</th>
<th>Review Date</th>
<th>Review Action</th>
</tr>
</thead>
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<tr>
<td>06/14/2011</td>
<td>Initial Review</td>
<td>Expedited</td>
<td>06/15/2011</td>
<td>Modifications Required</td>
</tr>
<tr>
<td>06/29/2011</td>
<td>Response To Modifications</td>
<td>Expedited</td>
<td>07/11/2011</td>
<td>Approved</td>
</tr>
</tbody>
</table>

Please remember to:

⇒ Use your research protocol number (2011-0483) on any documents or correspondence with the IRB concerning your research protocol.

⇒ Review and comply with all requirements on the enclosure, "UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB has the prerogative and authority to ask further
APPENDIX A (continued)

questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-2014. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sandra Costello
Assistant Director, IRB # 2
Office for the Protection of Research Subjects

Enclosures:

1. UIC Investigator Responsibilities, Protection of Human Research Subjects
2. Data Security Enclosure

cc: Tamar Heller, Disability and Human Development, M/C 626
    Jennifer Rowland, Disability and Human Development, M/C 626
## APPENDIX B

<table>
<thead>
<tr>
<th>Week 1-2 Date</th>
<th>Week 2-3 Date</th>
<th>Week 3-4 Date</th>
<th>Week 4-6 Date</th>
<th>Week 6-8 Dates</th>
</tr>
</thead>
</table>
| **TX/EDUCATION:**
*Orthoses Intervention (short opponens splint)  *UBD: Bed/WC
*Direct Skin inspection
*Direct Cough Assist
*Direct UE
PROM/AAROM (including tenodesis)

**EQUIPMENT:**
*Wheelchair
*Backpack
*Dycem gloves
*Mirror (nursing)
*Speakerphone
*Mini Relax-TV
*Feeding equip |
| **TX/EDUCATION:**
*Shoulder Assessment including taping and positioning education
*Assess for Mobile Arm Support (as applicable)
*NMES trials (as applicable)
*Home Accessibility
*Tub/Shower Chair Transfers
*Toilet Transfers
--Bed
--Bedside
--At Toilet
*Home Management
*Meal Prep
*LBD/UBD
--Bed
--W/C
*W/C Propulsion
*Tenodesis
*Computer/Desk Skills
*Direct Skin inspection
*Direct Cough Assist
*Direct UE
PROM/AAROM (including tenodesis) |
| **TX/EDUCATION:**
*Tub/Shower Chair Transfers
*Toilet Transfers
--Bedside
--At Toilet
*Bathing: Sponge, Shower Chair, Tub Bench
*Bowel/Bladder Education with Nursing and assess
Adaptive Equipment needs
*Home Management/Meal Prep
*SS/ULS/Ring sit
--Apartment bed
--Mat
--Hosp Bed
*Community Skills
*W/C Propulsion
*UE P/AAROM-Direct and Perform
*Shoulder Positioning and Intervention
*UBD/LBD
--W/C
--Hosp/Std Bed
*NMES trials
*UE HEP PRN |
| **TX/EDUCATION:**
*Perform Skin Inspection
*Adaptive Driving Resources
*UE Prone Scapular Program (as applicable)
*Bowel Care
--Bed
--Commode
--Shower Chair
*Bladder Care
--Bed
--W/C
*Community Skills
*Tub/Shower Chair Transfers
*Toilet Transfers
*Bathing
*Shoulder Assessment including taping as applicable
*NMES trials as applicable
*Bathing:
*Home Management/Meal Prep
*SS/ULS activities
*UE HEP

**PT/PCG TRAINING::**
*PRN
APPENDIX C

Five Classifications of Neurological Injury from ASI

Complete
A no motor or sensory function is preserved in the sacral segments S4-S5

B-E incomplete injury
B sensory but not motor function is preserved below the neurological level and includes sacral segments S4-S5
C Motor function is preserved below the neurological level and more than half of key muscles below the neurological level have a muscle grade less than 3
D motor function is preserved below the neurological level and at least half of muscles below the neurological level have a muscle grade of 3 or more
E normal motor and sensor functions are normal
APPENDIX D

Family and Caregiver Training Feedback Form- Patient Perspective

Please take a moment to complete this survey. Information provided in this survey will be utilized by the Spinal Cord Injury Program at the Rehabilitation Institute of Chicago for caregiver education programming and research regarding the education and training of caregivers of individuals with spinal cord injury. Our goal is to identify the needs and benefits of patient and caregiver education. Participation in this survey is voluntary, and your feedback is greatly appreciated.

1. Level of Spinal Cord Injury
   [ ] Tetraplegia/Quadruplegia (limitations in arms and legs)
   [ ] Paraplegia (limitations in legs)

2. Changes to my home will be needed before I return to my residence because it is not accessible for me now (eg. there are stairs, a ramp, chair lift, new shower)
   YES  NO  UNSURE

Parts of the residence that are not accessible include ____________________________

3. My family/friends have attended the Wednesday and/or Sunday Spinal Cord Injury Patient Education Series with me.
   YES  NO  UNSURE

   Frequency: Always  Sometimes  Rarely  Never

   Who has attended?
   [ ] Spouse
   [ ] Significant Other
   [ ] Friend
   [ ] Sibling
   [ ] Parent
   [ ] Children
   [ ] Other

4. What do you believe are the limitations for your friends/family from attending the Education Series?

   ____________________________________________________________

5. My family/friends have attended and participated in my therapy sessions
   YES  NO  UNSURE

   Frequency: Always  Sometimes  Rarely  Never
APPENDIX D (continued)

Who has attended?
[ ] Spouse
[ ] Significant Other
[ ] Friend
[ ] Sibling
[ ] Parent
[ ] Children
[ ] Other

7. I have identified who will help me with my self care and/or transfers when leaving RIC
YES  NO  UNSURE

[ ] Spouse
[ ] Significant Other
[ ] Friend
[ ] Sibling
[ ] Parent
[ ] Other

8. My family/friends that will help me with my transfers and personal care after leaving RIC have completed training during my therapy sessions for discharge and/or day pass
YES  NO  UNSURE

9. I feel comfortable with my family/friends assisting me with all of my personal care and transfers as is needed
YES  NO  UNSURE

10. I wish my family/friends knew how to assist me better when I am doing the follow task(s)

   ____________________________________________________________________________

11. I am most concerned about having to do this/these activities/tasks when I leave RIC

   ____________________________________________________________________________
APPENDIX E

Family and Caregiver Training Feedback Form

Please take a moment to complete this survey. Information provided in this survey will be utilized by the Spinal Cord Injury Program at the Rehabilitation Institute of Chicago for caregiver education programming and research regarding the education and training of caregivers of individuals with spinal cord injury. Our goal is to identify the needs and benefits of patient and caregiver education. Participation in this survey is voluntary, and your feedback is greatly appreciated.

1. What is your relationship to the person receiving RIC rehabilitation?

[] Spouse  
[] Significant Other  
[] Friend  
[] Sibling  
[] Parent  
[] Other

2. Level of Spinal Cord Injury of family member/friend

[] Tetraplegia/Quadraplegia (limitations in arms and legs)  
[] Paraplegia (limitations in legs)

3. Amount of time since initial admission to RIC_______________________________

4. I have attended the Wednesday and/or Sunday Spinal Cord Injury Patient Education Series to learn about topics related to Spinal Cord Injury

YES  NO  UNSURE  
Frequency: Always  Sometimes  Rarely  Never

5. I have attended and participated in therapy sessions

YES  NO  UNSURE  
Frequency_______________________________

6. I have attended caregiver support groups at RIC

YES  NO  UNSURE  
Frequency: Always  Sometimes  Rarely  Never

7. I have participated in transfer training, getting in/out of the wheelchair, during therapy sessions in preparation to leaving RIC and/or day pass

YES  NO  UNSURE
APPENDIX E (continued)

8. I have participated in training involving assisting with personal care during therapy sessions in preparation for leaving RIC and/or day pass
YES  NO  UNSURE

This includes:
[] Dressing
[] Feeding
[] Bathing
[] Bladder Care
[] Bowel care
[] Information about precautions and/or emergencies with spinal cord injury

9. I feel comfortable assisting with all of the above personal care activities
YES  NO  UNSURE

10. I feel comfortable assisting with transfers to assist getting in/out of wheelchair
YES  NO  UNSURE

Type of transfer(s) you can assist to complete independently and safely without RIC staff

[] Use of slideboard/lateral transfer
[] Hoyer lift and sling
[] Car transfer
[] Bath or toilet chair/seat transfer
[] Other______________

11. I am most concerned/I would like to learn more about assisting with the following task(s) before leaving
RIC___________________________________________________________
APPENDIX F
Family and Caregiver Training Feedback Form
Post Survey

Please take a moment to complete this survey. Information provided in this survey will be utilized by the Spinal Cord Injury Program at the Rehabilitation Institute of Chicago for caregiver education programming and research regarding the education and training of caregivers of individuals with spinal cord injury. Our goal is to identify the needs and benefits of patient and caregiver education. Participation in this survey is voluntary, and your feedback is greatly appreciated.

1. What is your relationship to the person receiving RIC rehabilitation?

[ ] Spouse
[ ] Significant Other
[ ] Friend
[ ] Sibling
[ ] Parent
[ ] Other

2. Level of Spinal Cord Injury of family member/friend

[ ] Tetraplegia/Quadraplegia (limitations in arms and legs)
[ ] Paraplegia (limitations in legs)

3. Amount of time since initial admission to RIC______________________________

4. I have attended the Wednesday and/or Sunday Spinal Cord Injury Patient Education Series to learn about topics related to Spinal Cord Injury
YES  NO  UNSURE
Frequency: Always  Sometimes  Rarely  Never

5. I have attended the Saturday Caregiver Training and Education Sessions for hands on practice on topics related to Spinal Cord Injury
YES  NO  UNSURE
Frequency______________________________
Topics I participated in______________________________

6. I have attended and participated in therapy sessions
YES  NO  UNSURE
Frequency______________________________

7. I have attended caregiver support groups at RIC
YES  NO  UNSURE
Frequency: Always  Sometimes  Rarely  Never
APPENDIX F (continued)

8. I have participated in transfer training, getting in/out of the wheelchair, during therapy sessions in preparation to leaving RIC and/or day pass
YES  NO  UNSURE

9. I have participated in training involving assisting with personal care during therapy sessions in preparation for leaving RIC and/or day pass
YES  NO  UNSURE

This includes:
[] Dressing
[] Feeding
[] Bathing
[] Bladder Care
[] Bowel care
[] Information about precautions and/or emergencies with spinal cord injury

10. I feel comfortable assisting with all of the above personal care activities
YES  NO  UNSURE

11. I feel comfortable assisting with transfers to assist getting in/out of wheelchair
YES  NO  UNSURE

Type of transfer(s) you can assist to complete independently and safely without RIC staff

[ ] Use of slideboard/lateral transfer
[ ] Hoyer lift and sling
[ ] Car transfer
[ ] Bath or toilet chair/seat transfer
[ ] Other______________

12. I feel prepared to assist my family member/friend after leaving RIC
YES  NO  UNSURE

13. I am most concerned about assisting with the following task(s) after leaving RIC
____________________________________________________________________
## Caregiver Training Follow-Up Survey - SCI Program

<table>
<thead>
<tr>
<th>A3 ADULT</th>
<th>A24 NURG HOME</th>
<th>DAY ADULT</th>
<th>FEDS ACUTE DAY</th>
<th>QUESTIONS</th>
<th>ANSWERS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1. What is your current living setting?</td>
<td>1 Home&lt;br&gt;2 Board/ Care (Includes Retirement)&lt;br&gt;3 Transitional Living&lt;br&gt;4 Intermediate Care Nursing Home&lt;br&gt;5 Skilled Care Nursing&lt;br&gt;6 Acute Medical Hospital&lt;br&gt;7 Chronic Hospital&lt;br&gt;8 Rehabilitation Facility&lt;br&gt;9 Other</td>
</tr>
<tr>
<td></td>
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<td>2. What are your current living arrangements?</td>
<td>1 Alone&lt;br&gt;2 Family/ Relatives&lt;br&gt;3 Friends&lt;br&gt;4 Attendant&lt;br&gt;5 Other (Nursing Home, Trans. Living, Hosp)</td>
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<tr>
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<td>3. Do you need any medical assistance or nursing assistance, for anything?</td>
<td>1 No Medical Problems&lt;br&gt;2 No Problem(s) Resolved&lt;br&gt;3 No Problem(s) Currently Being Treated&lt;br&gt;4 Yes; Untreated Medical Problems</td>
</tr>
<tr>
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<td>4. Have you received any type of therapy since your discharge?</td>
<td>1 Yes&lt;br&gt;2 No&lt;br&gt;3 Don't Know</td>
</tr>
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<td></td>
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<td>5. What type of therapy did you receive?</td>
<td>1 Yes&lt;br&gt;Blank No&lt;br&gt;Occupational Therapy&lt;br&gt;Physical Therapy&lt;br&gt;Speech Therapy&lt;br&gt;Pool Therapy&lt;br&gt;Vocational Rehabilitation&lt;br&gt;Other</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6. How much help do you need to get in and out of bed?</td>
<td>7 Complete Independence (timely, safely)&lt;br&gt;6 Modified Independence (device, reasonable time)&lt;br&gt;5 Supervision (hands-on guarding)&lt;br&gt;4 Minimal Assistance (patient more than 75%)&lt;br&gt;3 Moderate Assistance (patient 50% to 75%)&lt;br&gt;2 Maximal Assistance (patient 25% to 49%)&lt;br&gt;1 Total Assistance (patient 0% to 24%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7. What type of transfer do you do to get in and out of bed?</td>
<td>Stand up&lt;br&gt;Scoot over&lt;br&gt;Use of lift and sling&lt;br&gt;Stand pivot</td>
</tr>
<tr>
<td>APPENDIX G (continued)</td>
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<td>------------------------</td>
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<tr>
<td>8. How much help do you need to get on/off a shower or toilet commode chair?</td>
<td></td>
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<td></td>
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<tr>
<td>7 Complete Independence (timely, safely)</td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>6 Modified Independence (device, reasonable time)</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>5 Supervision (hands-off guarding)</td>
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<td></td>
<td></td>
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<tr>
<td>4 Minimal Assistance (patient more than 75%)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>3 Moderate Assistance (patient 50% - 75%)</td>
<td></td>
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<td>2 Maximal Assistance (patient 20% to 49%)</td>
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<td>1 Total Assistance (patient 0% to 24%)</td>
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<td>9. How much help do you need to perform eating?</td>
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<td>7 Complete Independence (timely, safely)</td>
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<td>6 Modified Independence (device, reasonable time)</td>
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<td>5 Supervision (hands-off guarding)</td>
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<td>4 Minimal Assistance (patient more than 75%)</td>
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<td>3 Moderate Assistance (patient 50% - 75%)</td>
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<td>2 Maximal Assistance (patient 20% to 49%)</td>
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<td>1 Total Assistance (patient 0% to 24%)</td>
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<td>10. How much help do you need to perform dressing?</td>
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<td>7 Complete Independence (timely, safely)</td>
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<td>6 Modified Independence (device, reasonable time)</td>
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<td>5 Supervision (hands-off guarding)</td>
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<td>4 Minimal Assistance (patient more than 75%)</td>
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<td>3 Moderate Assistance (patient 50% - 75%)</td>
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<td>2 Maximal Assistance (patient 20% to 49%)</td>
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<td>1 Total Assistance (patient 0% to 24%)</td>
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<td>11. Who typically helps you with some of your self-care or mobility activities?</td>
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<td>1 Patient</td>
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<td>2 Unpaid (family/friend)</td>
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<td>3 Paid Attendant or Aide</td>
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<td>4 Paid Professional (registered nurse)</td>
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<td>12. Are you involved in employment, volunteer work, or schooling on a full-time or part-time basis? Has your workload or tasks been adjusted? How?</td>
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<td>1 Adult: Full-time</td>
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<td>2 Adult: Part-time</td>
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<td>3 Adult: Adjusted</td>
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<td>4 Child: Regular Class</td>
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<td>5 Child: Special Class</td>
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<td>6 Child: Home Based</td>
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<td>7 Child: Day Care</td>
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<td>8 Child: Not a student</td>
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<td>9 Child: Adjusted Full-time or Part-time</td>
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<td>13. In light of your experience at RIC, how well do you feel we prepared you for living back home?</td>
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<td>4 Excellent</td>
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<td>3 Good</td>
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<td>2 Fair</td>
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<td>1 Poor</td>
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<td>14. What could we have done to better prepare you?</td>
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<td>1 Yes</td>
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<td>2 Blank no</td>
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Outcomes Management: Systems & Analysis

Follow-Up Survey Version XII
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APPENDIX H

Caregiver Training/Education Topical Outline

SCI condition information and secondary conditions

I. Spinal Levels
   II. Spinal Cord Injury
       a. Complete
       b. Incomplete
   III. Medical Complications
        a. Autonomic Dysreflexia
        b. Orthostasis

Adaptive Equipment and Orthotics

I. Upper Extremity Splints/Orthoses
    a. Hand
    b. Wrist
    c. Shoulder
   II. Mobile Arm Supports
   III. Eating equipment
   IV. Grooming equipment
   V. Writing equipment

Transfers and Mobility Skills

I. Ergonomics 101
   II. Rolling
   III. Sitting up
   IV. Transfers
       a. Use of lifts/slings
       b. Slideboard Use
       c. Stand/squat-pivot

Caregiver Panel

I. Introduction
   II. Facilitate Question and Answers
Research Studies

Spinal Cord Injury Program Caregiver Training Series

The Rehabilitation Institute of Chicago (RIC) is seeking volunteers who are currently receiving inpatient rehabilitation after a spinal cord injury and their caregivers and/or family. This study is investigating educational training techniques to best prepare people to transition out of rehabilitation.

- Oct. 16: SCI and Health
- Oct. 23: What is all this Equipment in the Backpack?
- Oct. 30: Transfers, Mobility Skills
- Nov. 13: Caregiver Panel

If you are interested in participating, please contact Piper Hansen at 312-238-6157.

IRB Project # STU00003485
Principal Investigator: David Chen, MD
The Rehabilitation Institute of Chicago is an academic affiliate of Northwestern University Feinberg School of Medicine
Date Posted 9.17.10

APPENDIX I
CITED LITERATURE


VITA

NAME: Piper Hansen

EDUCATION: B.S., Occupational Therapy, University of Wisconsin-Madison, Madison, WI, 2004

M.S., Disability and Human Development and Certificate of Management and Leadership in Non-Profit Organizations, University of Illinois-Chicago, Chicago, IL, 2011

TEACHING: Rehabilitation Institute of Chicago Academy, Chicago, IL, 2006-present

Department of Occupational Therapy, Rush University, Chicago, IL, 2011

PROFESSIONAL MEMBERSHIPS:

American Occupational Therapy Association
American Spinal Cord Association
Academy of Spinal Cord Injury Professionals
Illinois Occupational Therapy Association