Identifying issues in acquired brain injury recovery that lead to a productive and fulfilling life

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IDENTIFYING ISSUES IN ACQUIRED BRAIN INJURY RECOVER THAT
LEAD TO A PRODUCTIVE AND FULFILLING LIFE

By

Margaret Calvert
B.S., University of New Hampshire, 2006

Submitted to the University of New Hampshire
in Partial Fulfillment of
the Requirements for the Degree of

Masters of Science
in
Communication Sciences and Disorders

September, 2008
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ABSTRACT

IDENTIFYING ISSUES IN ACQUIRED BRAIN INJURY RECOVER THAT LEAD TO A PRODUCTIVE AND FULFILLING LIFE

By

Margaret Calvert

University of New Hampshire, September, 2008

Primary Objective: To establish and report the shared characteristics of survivors who have demonstrated successful recovery from ABI and who indicate that they live productive lives.

Methods and Procedures: Qualitative case study investigation examined semi-structured interviews of survivors of acquired brain injury (ABI). Interviews of 31 participants were examined to determine the characteristics associated with successful recovery and productive living.

Main Outcomes and Results: Four major themes emerged from the interviews: a) development of support networks, b) learning strategies to cope with emotional issues, c) acceptance of injury and redefinition of self, and d) empowerment.

Conclusions: The issues raised in these interviews may serve to inspire other survivors and provide them with hope and motivation as they progress through the recovery process. Suggestions on how clinicians can help to facilitate this process are discussed.
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INTRODUCTION

Acquired brain injury (ABI) from trauma or stroke impacts the lives of millions of individuals and their families. In the United States, stroke is the leading cause of serious, long-term disability with a prevalence of 5.7 million survivors. An additional 5.4 million individuals live with long-term disability from traumatic brain injury (TBI). These two populations continue to grow because of medical advancements that have decreased the mortality rate for survivors. In addition, people are living longer with their injuries, with life expectancies closing in on those of the uninjured population.

The long-term needs of survivors of ABI are numerous and diverse. Despite active involvement in rehabilitation, these needs tend to persist following the first year of recovery. For many survivors, the struggle to integrate back into their communities is insurmountable. They are no longer able to return to their previous work roles, they have difficulties developing and maintaining relationships, and they report an overall depressed quality of life (QOL).

Much of the short term recovery from brain injury is done in inpatient facilities, where survivors, family members and clinicians are unable to see the external impact of the injury on the individual’s life. In this environment, the focus of short term recovery is on the physical injuries of the survivor; while emotional, cognitive and psycho-social issues, which are key to long term recovery and successful community integration, are often inadequately met.
Long term needs can be slow to develop; emerging after an individual has seen the full impact of how ABI affects different factors in their life. Changes in behavior and personality often impact the survivors’ ability to develop and maintain social networks. Meanwhile increased physical and cognitive demands place limits on vocational pursuits, transportation, and overall independence, leading to a decreased feeling of self worth. These factors are what differentiate surviving ABI and learning to live with one.

Other survivors of ABI are integrated into their communities and live productive and fulfilling lives. These individuals appear to redefine themselves, releasing concepts of their former selves and developing new identities. These individuals have a sense of optimism, empowerment, and contentment in the face of continued physical, cognitive, and linguistic disability.

Models of long-term rehabilitation that focus on community integration, psychosocial needs, and family support are required in order to make an impact on the lives of survivors of ABI. Community-based programs have been shown to be effective in meeting the needs of survivors of ABI. However, critics argue they are no more effective than structured out-patient therapy services. Regardless, there remains a paucity of literature indicating the effectiveness of such programming and its ability to re-integrate survivors of ABI back into their communities.

A number of factors have been reported that influence QOL for survivors of ABI. Community integration, positive affect, and social support have been shown to improve QOL, while injury-related difficulties such as cognitive, emotional, and
communication dysfunction are associated with lowered QOL \(^{17}\). Steadman-Pare and colleagues report a need for ongoing supports for survivors of ABI many years post-injury to help integrate them into their communities, provide them with emotional support, and give them opportunities for work and leisure \(^{18}\).

While clinical investigations such as these have provided us with significant evidence outlining the issues associated with successful recovery from ABI, they fall short of providing us with a holistic perspective of the individual’s trials and tribulations in the immense struggle to live a productive and satisfying life. Narratives, first accounts of an individual’s experience, provide the reader with a glimpse into the physical, psychological, social, and economic impact of an injury and how that injury impacts the individual, their family, and their community \(^{19}\).

Hinckley examined published narratives to answer the question, “What does it take to live successfully with stroke and aphasia?” \(^{20}\) Four major themes emerged from Hinckley’s analysis; they include the need for social support, adaptation of perception of self, life-long goal setting, and taking charge of communication improvement. She concludes that “the stories” that emerged from these narratives can provide clinician, client, and community member alike with an enhanced sense of understanding the rehabilitative process.

The use of narratives in the clinical process is nicely summed up by Hinckley when she states,
"Narrative is a framework and a technique with which we can explore the difficult-to-define moments of interaction within the clinical process that have the power to become incorporated into our life stories. These clinical moments hold lessons that we abstract and repeat to ourselves. When shared with colleagues and students, these stories are potential learning moments for others."

The purpose of this investigation is two-fold. First is to establish and report the shared characteristics of survivors who have demonstrated successful recovery from ABI, who indicate that they live productive lives, and who report a high QOL. Second is to determine the impact that a community-based model of post-rehabilitation has on survivor success and community re-integration. By increasing our understanding of successful long term recovery from brain injury, as professionals, steps can be taken during therapy to prepare survivors for their future.

Prior to presentation of the methodology and results, definitions of acquired brain injury (ABI) and quality of life (QOL) will be provided. In addition, the characteristics of a community-based model of ABI rehabilitation will be summarized.
Acquired brain injury (ABI) is any injury that is manifested through cerebral vascular accident (stroke) or traumatic brain injury (e.g. motor vehicle accident or blunt trauma to the head). These injuries result in sequelae that have long term affects on behavioral, cognitive, communication, emotional and physical aspects of life for the individual. Most of these resulting deficits are not visible, thus resulting in many misunderstandings by both the survivor and others about the long-term effects of brain injury. Knowledge about ABI and its short and long term effects on individuals has increased in the past ten years based on increased mortality rates, increased longevity and better diagnostic tools.

**Stroke**

A cerebral vascular accident (CVA), or stroke, is defined as any form of disruption to the blood supply of the brain. Like any other organ, the brain requires oxygen and nutrients that are supplied by the vascular system. When this flow is disrupted, tissue is destroyed resulting in impaired function associated with that region of the brain. Strokes can occur in two forms; ischemic or hemorrhagic.

Ischemic strokes occur when there is some form of blockage that occludes arterial blood flow. They account for the majority of strokes (80%), and can occur in two forms; embolic and thrombotic. Embolic strokes occur when deposits of blood and vascular
‘debris’ travel from their site of origin (e.g. heart of larger blood vessel) to a smaller point in the vascular system, occluding the flow of blood to the brain.

Thrombotic strokes occur primarily as the result of arteriosclerosis. Major supplying arteries such as the carotid, vertebral or basilar arteries, which supply a large amount of blood to various regions of the brain, are occluded. These “turbulent areas” in the vascular system are prone to blockage due to a combination of high blood flow volume and anatomical layout 

The second type of stroke, classified as hemorrhagic, occurs when there is a disruption to the vascular system resulting in bleeding into the brain. Hemorrhagic, like ischemic stokes, manifest in different ways depending on the location within the brain. Hemorrhagic strokes can occur within cerebral space (intracerebral hemorrhage) or within the layers of meninges in the brain (extracerebral hemorrhage). Extracerebral hemorrhage usually occurs in sub-arachnoid vasculature.

Hemorrhagic strokes often occur in the presence of hypertension that causes the walls of blood vessels to weaken at specific points. If left undetected, the weakened vessel walls will form an aneurysm. Arteriovenous Malformation (AVM), a congenital pathology resulting in a tangling of cerebral vasculature, can also lead to a subsequent hemorrhagic event.

The common indicators of stroke include: 1) numbness or weakness on one side of the body, 2) blurred vision in one or both eyes, 3) problems expressing or understanding speech, or confusion, 4) dizziness or trouble walking, 4) and/or sudden/severe headache.
Trauma

Traumatic brain injury (TBI) refers to “trauma to the brain, whether as a result of the head striking, or being struck by, an object, or as a result of impact of the brain against the skull of significant severity to cause a disruption in normal brain functioning”\(^{26}\). Acquired brain injury due to trauma occurs with an incidence rate in the United States of 95 per 100,000 \(^{23}\). Though indiscriminate, more men between the ages of 15-24 have the highest prevalence rate \(^{27}\).

TBI classification depends on how the injury is manifested to the Central and Peripheral nervous system. Blunt, penetrating trauma, or forces of acceleration-deceleration impact brain tissue, causing swelling and bleeding as well as infection fall under this definition of brain injury. Diagnostically a case of TBI occurs when one or more of the following conditions exist: an observed or self-reported decrease in level of consciousness, amnesia, fracture to the skull, objective neurological or neuropsychological abnormality, diagnosis of an intracranial lesion, or death, where the medical report indicates head injury as the cause \(^{28}\).

A non-penetrating closed head injury most commonly results from acceleration-deceleration injuries, where the body’s motion is abruptly halted and inertia causes the brain to come into contact with the skull. Motor vehicle accidents, based on the quick change in velocity compounded with the likelihood that the head will impact other objects such as the steering wheel, are a major cause of this type of injury. Blunt head force, skull fracture or deformations also result in traumatic brain injury. The brain may
have contusions, disruptions in the vascular system, swelling or sheering that causes diffuse damage that often implicates the cranial nerves.²⁷

Open head, or penetrating head injuries, manifest when force causes a foreign object to enter the skull and impact the central nervous system (CNS). Most common causes of this type of injury are gunshot and force to the head with a sharp object. The implication of infection at the entrance site is high, as foreign objects entering the skull may carry dirt, hair, and skin with them.

Currently, the incidence of open head injuries is rising as a result of blast injuries, which have become the signature of the war in Iraq. These injuries resulting from detonated improvised explosive devices (IEDs) are responsible for 60% of patients at the Walter Reed Army Medical Center there with TBI, with an estimated incidence rate of 30% of the 1.5 billion troops overseas.²⁹

Hemorrhaging can be caused by trauma to the CNS. This rupturing of healthy blood vessels results from sheering and tearing of tissue. The intimate location of the cranial nerves and brain stem in the cranial vault can also result in various sensory and motor deficits.²⁵
CHAPTER 2
QUALITY OF LIFE

In long term processes of recovery, definitions of quality of life are used to determine the overall success an individual is having encompassing: physical, cognitive, emotional, social participation, community integration and productive activities such as work, education, and volunteering. QoL is often subjectively measured utilizing questionnaires and rating scales. However, first hand accounts have been found most useful for obtaining information about QoL. Through this method the survivor can openly describe what happened to them; regardless of severity or type of injury.

Many psychological, physical and emotional factors impact life satisfaction for survivors of acquired brain injury. By examining how different aspects of life are impacted by an injury, researchers are able to shed light about how specific aspects of brain injury affect long term recovery, and subsequently what the best ways to provide the most beneficial support for these issues.

Several factors are reported in the literature that directly impacts how people rate their QoL. In a study by Koskinen, severity of the injury was found to directly impact how people rated their QoL, where the more severe the injury the lower the QoL rating. Other factors such as self esteem, relationship status and negative self concept were seen to correlate with the survivors feelings of success.

A self-perceived low QoL has multi-fold impacts on someone’s recovery and subsequent re-entry into the community. These include returning to work, performing
activities of daily living, participation in recreational and leisure activities, and interaction in social activities. Most of the investigations regarding QoL have looked at overall rating scales that combine multiple elements of this definition into a combined score. By examining the components as separate but inter-relating entities, more holistic and appropriate intervention by both professionals and the individual can be experienced.

Individual needs are an important part of definitions of QoL; where high QoL is associated with a minimal number of unmet needs. In working with ABI unmet needs are the driving force for choosing goals early on in rehabilitation. Decisions are made by a team comprised of the survivor, family members and the clinicians working with them, known in the literature as a tri-partite model. This model is used more to define therapy outcomes and set goals, however its role in long term recovery, though necessary, is less clear.

Long term needs associated with recovery from ABI involve highly personalized, multifaceted components, which makes planning intervention a complicated task. In the literature a need is defined as ‘the difference between a current state and an expected or desired state’. This definition puts the responsibility of determining what a need is on the survivor. Included in this definition is the difference between a therapy outcome and a need. The term need carries with it the following implications for the survivor: 1) there is no defined role of support from family and clinicians; 2) they focus on their own specific interests and; 3) there is no structured framework for addressing these needs.
Therefore, the assumption is that in determining their QoL, the survivor must identify and address their needs and learn to set goals for themselves in order to be “successful” in their recovery.
CHAPTER 3

THE STEPPINGSTONES PROGRAM

SteppingStones, a post-rehabilitation day program located in New England, is a community-based model for people living with ABI from trauma, tumour, or stroke. SteppingStones, like some community-based programs for post-rehabilitation of brain injury, is a paradigm shift from the medical or disease models. The mission of the SteppingStones program is to empower members to engage in a variety of functional activities that increase independence, community reintegration, and overall quality of life.

Financial barriers often limit access to extended out-patient or home-based rehabilitation services for survivors and their families. SteppingStones provides services and support to survivors of ABI and their families, many of whom have already been ‘through the system’; and have exhausted their economic resources (i.e. insurance, federal funding).

The program focuses on needs cited by survivors living in a community where few other supportive services are available. Needs assessment inquiries identified a number of factors leading to a decreased quality of life for individuals with ABI living in the New England area. Factors identified included: lack of recreation, impaired social relations, difficulty with friendships, and decreased productive endeavours such as employment, educational development, and volunteerism.
The SteppingStones model attempts to provide opportunities for empowerment through a “member-driven, member-choice” program design. Member-driven program components are based on members’ inclusion of wants, needs, and wishes through professional guidance, support and management. Members take leadership roles throughout the entire infrastructure of programming, including administrative tasks, organizing and facilitating group activities, coordinating and welcoming potential members, conducting telephone outreach to absent members, and public speaking engagements through community education. These leadership roles enable members to feel a sense of meaning, productivity, and purpose. While reports of increased functional outcomes are mixed using a client-centred approach; there is evidence to indicate that participants experience increased satisfaction with the goal setting process compared with standard clinician-mediated procedures.¹⁰ ¹¹
METHODOLOGY

CHAPTER 4

SUBJECTS

Participants in this investigation included members of a community-based, post-rehabilitation program for adults with ABI. The program provides members with an opportunity to address their long-term physical, cognitive, social, and emotional needs. The thirty-one members who participated are survivors of ABI that chose to participate in an oral history project throughout a year and a half time span. From the thirty-one who participated all the interview were group to compile the study sample. Twenty-one (68%) were male and 10 (32%) female. Their average age was 45.8 (s.d. = 13.2) years. The diagnoses included CVA = 11 (35.5%), TBI = 16 (51.6%), and other = 4 (12.9%; includes seizure d/o and tumour).

The participants had an average time post injury onset of 128.1 (s.d. = 135.8) months. They were members of the program for an average of 23.6 (s.d. = 23.7) months. The majority of participants had a high school education (N = 14, 45.2%), 1 participant had less than 8 years of school (1.5%), 3 reported 8-11 years of school (9.7%), 5 had a post-secondary degree (16.1%), 5 had a college degree (16.1%), and 3 participants reported an advanced degree (9.7%).
CHAPTER 5

INTERVIEWS

The data used for this qualitative investigation consisted of narrative life stories collected as part of the ABI program's Oral History Project. Participants volunteered to be a part of the project, which was developed as a way for members to share their stories with each other, and to educate the community about ABI.

Each oral history was conducted as a semi-structured interview between two members of the program. The interviews were facilitated by a graduate student in a Communication Sciences and Disorders program at a local university, who provided technical assistance (e.g. help with recording equipment) and facilitated the cognitive-linguistic needs of members when required (e.g. help with word-finding). Following informed consent, interview participants were provided a list of the interview questions. Any questions or concerns that they had were addressed at this time.

A unique aspect of the interviews is that they were conducted by members of the program. Therefore, members interviewed members. Interviewers were provided with a list of eight questions that served as a ‘framework’ for the interview. This provided an element of structure; however, they were free to explore other issues in further detail as they arose. The eight question framework (Appendix A) probed for information regarding the member’s life prior to their injury, what happened to them (their accident), their recovery process, challenges they continue to face, and their current goals. Interviews lasted between fifteen and fifty minutes depending on content shared.
Interviews were recorded digitally on a Sony Hi-MD™ Walkman® Digital Music Player MZ-RH910 using Microphone Madness MM-BSM-7 Binaural Stereo Microphones. The interviews were then edited to eliminate personally identifying information and/or offensive language. The edited interviews were placed on the World Wide Web and recorded in CD form and donated to local libraries for public access.
CHAPTER 6

DATA ANALYSIS

This qualitative investigation examined semi-structured interviews of members of a community-based, post-rehabilitation program for adults with ABI. Qualitative analysis was used because of its effectiveness in providing subjective interpretations of successful quality of life reported by survivors of ABI. The interviews were transcribed and analyzed for thematic content using qualitative methodology.

The authors began with a random sample of nine interviews. The analysis was conducted using an emergent coding scheme. Each transcribed interview was analyzed and extensive field notes were taken. Thematic analysis was completed using manual techniques associated with theme coding and theme grouping. The authors were able to extract 25 sub-themes from the raw data. Subsequent analysis allowed for sections of the transcriptions to be coded and grouped into major themes. A mutual agreement was reached between authors on the identification and naming of themes.

Four themes emerged from the data analysis. The first is the need for strong social support from family and the community. Second, participants indicate that the ability to cope with their situation and control their emotions was an important factor in their success post injury. Third was development of a sense of empowerment. Finally, an acceptance of the ‘new self’ was important to a successful and productive life post injury.
The authors subsequently used the four themes as a checklist, which they applied to each of the transcribed interviews. If the theme was identified in the participant’s interview, a check was placed in the column for that theme. Reliability for the presence of the theme was conducted by having each author independently review the interviews to determine if the theme was reported by the interviewee. The authors came to a 97% agreement in identifying which themes were acknowledged in each interview. The percentage of members who reported that theme was calculated for each. See Table 1 for a list of themes and the percentage of members that reported it in their interviews.
CHAPTER 7

CASE STUDIES

From the initial sample of thirty-one interviews four case studies were chosen that gave defined examples of these themes in very different individuals with highly contrasting situations. The stories from these individuals serve as ‘expert’ accounts of life following ABI and the struggle to make a successful recovery and live a productive life. In her pursuit to find out how survivors live successfully following stroke by analyzing expert accounts Hinckley states, “Stories of lives of people who are experts or particular exemplars of a quality are a persuasive way to understand how that trait or quality is manifested among individuals.” 20 (p25)

The four participants highlighted in this investigation were contacted either in person or by telephone to supply follow up information. Participants were asked to clarify statements made in their interviews and to provide demographic and medical history information. The participants provided informed consent to have individual details from their interviews published with pseudonyms.

Case-Study Participants

D.H.

D.H. was 55 years old when he suffered a left hemisphere cerebral vascular accident (CVA). Prior to his accident, D.H. was married, employed as a certified public accountant, and actively involved in his local town political system. D.H. was in a coma for three weeks and hospitalized for six months, where he received speech, occupational
and physical therapy. He continued to receive speech therapy for four years after his accident, about which he says, “There must have been a screw up with insurance for me to receive so much therapy.” However, he credits his current level of expressive language to his extended access to speech therapy. D.H. continues to exhibit expressive aphasia and hemi-paresis of the right side of his body; however, he is effective with oral communication, and he walks with the use of a cane.

D.H. has been a member of the SteppingStones program since its inception in 2000. He leads the weekly aphasia support group at SteppingStones and also facilitates a monthly aphasia support group within the greater community. D.H. has been honoured by the Aphasia Association of American for his work in advocating for individuals with aphasia. He remains married. He has recently received a grant to develop an advocacy video to educate law enforcement and emergency medical personnel on the characteristics of aphasia.

B.W.

B.W. was 25 years old when she suffered a cerebellar stroke on the day after Christmas. She had been married for one year and had recently completed a masters degree in social work. She reports, “I was in the best shape of my life at the time and was playing professional woman’s football.” She was taken to hospital for what her family thought was dehydration. A nurse in the emergency room refused to give her a wheelchair because she suspected that B.W. was “having a drug overdose.” A doctor finally diagnosed the onset of a stroke and an emergency craniotomy was ordered. B.W. reports that she was not in a coma, but she was hospitalized and received extensive rehabilitation services for six months.
B.W. became involved in the SteppingStones program after a friend of the family made the recommendation. She has been involved for four years and helps facilitate several mental health groups offered to members during the programming week. She remains married. She marked the fifth anniversary of her stroke by completing the Honolulu marathon sponsored by the American Stroke Association, an organization with which she has begun work as a stroke spokeswoman.

R.B.

R.B. was 26 years old when an aneurysm ruptured as the result of an arterial venous malformation (AVM). R.B. was bilingual (French and English) and worked as a cook and caterer for a local restaurant. He had recently begun a business selling gourmet salad dressings, which was beginning to gain him some regional attention. The day of his AVM, R.B. had planned to quit his job at the restaurant and focus all his energies on his business.

Following his accident, R.B. went through multiple surgeries to repair his AVM. He was in a coma for four weeks. When he emerged from coma he received several months of intensive rehabilitation before being sent home. His doctors and therapists informed R.B. that he would “never walk or talk again.” Four years later, he found a speech pathologist willing to address his language deficits. In the ten years since his AVM, R.B. has made significant recovery. He continues to demonstrate mild right-sided hemi paresis (upper and lower extremities) and to display expressive aphasia when speaking English, although, he ambulates independently and uses oral language to communicate. He has never regained the ability to speak French, his first language.
R.B. became involved in a local brain injury support group that was the foundation for the SteppingStones program and has been a member since 2000. He was able to go back to school and subsequently gained a degree as a Master Gardener. He works part-time landscaping gardens for family and friends. Although he reports that he is unable to work full-time because “I will lose my [federally funded] disability compensation”. R.B. facilitates several functional skill training groups at SteppingStones, including gardening and cooking.

S.M.

S.M. was 21 years old when he sustained a traumatic brain injury (TBI) in a motor vehicle accident. The driver of the car he was riding in fell asleep at the wheel. S.M. was thrown from the car and sustained multiple injuries and remained in coma for several weeks. Following his emersion from coma he received speech, occupational and physical therapy for “six months, five times a week.” S.M. continues to exhibit short term memory impairment and anomia and reports difficulty “remembering names and faces.”

Prior to his accident, S.M. fathered a son at the age of 15 years. He indicates that he did not have a good relationship with his family and he was often in trouble. “I was a bad person, I was an unhappy person,” he reports. Since his accident, S.M. now feels that he is a better father and is more involved as a family member. “I’m a much better person now; I have a better relationship with my family.” S.M. has been involved with SteppingStones for two years. He has recently gained competitive employment and moved into his own apartment.
RESULTS

Through analysis of the thirty-one interviews in the Oral History project it was discovered that the following themes presented themselves as factors for success in the majority of the cases: the support of friends and family in a social network, the ability to cope with emotions in a productive manner, participation in productive and empowering activities, and the ability to accept their injury and redefine the self after injury.

The four case-studies discussed above are being used as exemplar cases to illustrate the themes, however it should be noted that these themes were prevalent in the entire sample (Appendix 1).
CHAPTER 8

SUPPORT NETWORKS

Successful recovery from ABI is often facilitated through participation in strong social support networks. However, survivors of ABI often find that their social networks begin to weaken or disappear following their injury. Research indicates that the ability to develop close friends and socialize with others is a more common unmet need for survivors of ABI than for non-disabled individuals or survivors of spinal cord injury. In addition, adults five years post-injury have reported an acceptance of their physical limitations, yet continue to report significant problems developing social contacts and significant relationships. Survivors of ABI must rely on their friends and family for much of the assistance they will receive after they are discharged from formal intervention. A lack of resources to address the long term needs of survivors and the existence of misconceptions held by family and friends can cause a great deal of strain on these personal relationships.

R.B. reports that his support network of friends quickly dropped off following his injury. “I used to have a huge cluster of friends and now I do have a handful of friends and everybody else is an acquaintance, [be]cause I now understand I don’t know how many people thought they would come and support me in rehab and how many didn’t, not very much.”
S.M. expresses the fear and anxiety that limited his ability to maintain friendships with former peers.

Other friends I don’t like to talk to. Most people don’t understand aphasia. I’m always scared that people think I’m dumb. But I’m not. They just don’t understand about the aphasia. So I would rather not to talk with other people. It really upsets me. Sometimes with strangers it doesn’t really bother me because I’m never going to see them again. Who cares?

**Role of Family in Recovery**

Despite initial challenges faced by each of the four subjects in this analysis, they report strong bonds with immediate family and friends. Family members and social supports give survivors outlets to experiment with their abilities and go through their changes with a sense of security. In all of the interviews a deep sense of gratitude towards friends and family was seen. Survivors knew the extent of sacrifice that their loved ones made and also what they continue to do to make their life easier. Each exhibited a deep sense of understanding that it was because of this sacrifice that they were able to be where they are now.

And that was the strength of my family to be that way so after they did my operations they had to do rehabs. Well I went from Boston to Concord, they did their best... We are a strong-willed family. (R.B.)
I'm a better person because I realize that my family are the most important people. Not my old friends, not people who I thought were cool. It was my family that cared about me, that did things for me. I am different and I try to be as nice to my family as I can. (S.M.)

Two of the four participants highlighted in this investigation stated that the survival of their marriages was instrumental in their recovery. D.H. and B.W. were both married at the time of their injuries. They continue to be married today. D.H reports, “I’m grateful that we made it, and you ask me how it’s going now and it’s wonderful. We’re in love.”

Many survivors of ABI who were married prior to the onset of their injury find their marriages ending in divorce. The rate of marital breakdown within survivors of ABI varies depending on the severity of the injury. For those with severe injuries, the divorce rates have been reported to be 78%; about 50% of marriages dissolve for those with less severe injuries and better prognosis for recovery.

**Importance of Supports for Family**

The ability of spouses and other family members of these participants to provide support were influenced by the degree to which their own needs were met. Significant distress in family functioning has been documented by members of the family unit compared to norms. Involving the family in the recovery process is critical to the success of the survivor. Family members report that having knowledge about the recovery process, psychosocial supports, and access to community resources is integral to their well being and the subsequent care of the survivor.
The Support of SteppingStones

The support provided by SteppingStones has been seen as tremendously important to the success of each of these individuals. The program was designed to provide members with opportunities to build friendships, receive support, link up with valuable community resources, and explore life interests. The participants in this investigation report that the environment at SteppingStones is supportive, caring, and nurturing. Members can be themselves without the worry of social labelling or misconceptions. S.M. states, “That is the best thing about SteppingStones, people understand. To them it is just normal. You don’t have to worry. I don’t have to think about it at all. I don’t have to worry about it at all. People at SteppingStones care about you. We just understand.”

B.W. reports that SteppingStones provides an opportunity for members to share their similar experiences with each other. “I am a huge fan of SteppingStones. I do think there is something to knowing other people who have had the same experiences and having people of varying functioning levels to kind of share with you their experiences.”

In addition, SteppingStones provides family supports to its members. Recent focus group discussions have found that family members report the best part about the program is the “fellowship, sense of community, and acceptance.”

27
COPING AND GRIEF FOLLOWING ABI

After brain injury a variety of personal adjustments must be made. These adjustments often require the survivor to accept that some parts of his/her life will never go back to the way they were before the accident. This realization can produce a variety of emotional responses, such as anger, anxiety, and depression, which were prevalent in the participants of this investigation. Emotional sequelae, which has been previously reported by survivors of ABI, not only affect quality of life, but also impacts goal setting, motivation and long-term recovery. "When I first came to SteppingStones I had so much anger and frustration and I couldn’t speak much; it was really hard." (R.B.)

Coping

The participants in this investigation all indicated that adaptations in their coping styles had to be made before they achieved success following their injuries. Coping is a reflection of a variety of experiences that we as individuals have throughout our lives. Demographic characteristics, pre-injury coping skills, cognitive function, and type/severity of injury all influence how a survivor will cope with the emotional difficulties they experience after an ABI. Other factors involved include coping strategies and reduction of negative thought processes, most prominently ideas of wishful thinking, self-blame and the avoidance of issues. Insight into the strategies that individuals self-employ can help guide therapists in creating more effective intervention.
R.B. reflects on his ability to instil a positive attitude following his injury, "I've been to the bottom of the pit and to the top of the pit...I just try my best and think positive and if it doesn’t [work] there is a reason I can’t; so I can stop and try something totally different."

An ABI creates changes in lifestyle and personal abilities that can result in a wide variety of emotional responses including depression and anxiety. Coping can be either positive or negative, and people with ABI are often more limited in the 'how' aspects of the coping method that they use. Choosing methods that address actual issues are more effective than avoidant methods such as substance abuse that can lead to further emotional decline. Memory, behavioural sequelae, and impaired attention all act as barriers for successful coping. Therefore, in addition to coping with change, these individuals must reinvent or change the way in which they cope. "I used to drink too much. I was not happy so I would drink. Now I do not at all. I don’t want it because I don’t want to be who I used to [be]." (S.M.)

**Grief**

The subjects highlighted in this study reported a progression though several stages of grieving before they were able to accept their post-injury self. This progression must take place in order for the survivor to understand the emotional procession of accepting the changes in his/her life. Kubler-Ross outlined five stages of grief that an individual experiences following any type of loss; these include denial, anger, bargaining for change, depression and acceptance. Each stage has certain characteristics that influence not only the emotional state of an individual, but also the types of strategies they use to cope. "I thought for at least a year that I, um, everybody else, they were
either faking or they were, um, it wasn’t me and it was a dream; or something is wrong with them.” (D.H.). “Well it took me almost three years to fully embrace and understand that this is my life now.” (B.W.)

In addition, participants also reported a period of withdrawal from social situations. “After my accident I didn’t want friends because I have aphasia and I don’t know how to say words. It was very difficult and I felt dumb being with other friends. So I didn’t want to spend time with other people.” (S.M.)

The final acceptance of injury is a gradual process. This stage may also develop an understanding of the specific coping mechanisms that were employed by the individual and allow cognitive processing and insight into his/her situation to occur in a more intrapersonal way 60.

SteppingStones attempts to address the grief that members face; and help them develop coping skills for long-term success. Members and family have opportunities to attend several “emotions” groups that guide them through issues they may be facing; and provide them with opportunities to meet their challenges. “The emotions groups give you an opportunity to express your thoughts and feelings. You can also feel better knowing that others are going through similar experiences.” (S.M.)
Another common theme identified in the interviews of these four participants was the concept of injury acceptance and redefining the self. Survivors of stroke and head injury display negative concepts of self following their injuries. For many people, the redefinition of self is an arduous and emotional process. Survivors don’t have the luxury of easing into their new lives; the changes that ABI brings are abrupt and unexpected. Since these changes take time to fully emerge, a longer adjustment time is needed for both the survivors and the family. D.H. indicates that he suffered a long emotional battle before coming to accept his situation:

And it took me a long time to realize that wait a minute its been a long time now, maybe I am maybe something is wrong. Then I got a lot of depression, as you know, it takes…. Well it’s been one two three four five six, six and a half years that it’s been since I had my stroke. And it is getting better, sometimes I can see different things, but it’s not and I don’t think it’s ever going to be perfect you know. But that you know. But the other thing is I finally realized that that’s okay you know, I have to do, I have to; I can’t just sit here and um and um on a log.

The personal adjustment to the psychological and social changes brought on by ABI can be made following adjustment of several factors. These include providing a
sense of purpose, establishing emotional connections, and developing new goals and ideals for their lives.

The individuals in this investigation sought new meaning by developing aspects of their lives that they neglected for one reason or another before their injury. S.M. talks about how he is a nicer person now and a better son as well as father to his own son. He now highly values his role within the family. He also realizes that this role has changed as a result of his injury (e.g. reduced ability/desire to participate in activities that took him away from his family role pre-injury).

In addition, participants in this study were able to accept themselves for who they are now. Furthermore, they have come to accept that they are not who they used to be.

When it came to everyone else I was fine. I didn’t have any prejudices... But me being disabled is a whole different ball of wax. Looking at what I had previously and dealing with being disabled was all negative. All of my thought processes were, oh, if I’m disabled that means this whole slue of things... That means being ‘weak’; that means being ‘lazy’. And understanding changing my perception and of what that means for me; that has been a tremendous feet for me. I’m still going through it. (B.W.)

These participants acknowledge that they have new roles to play, new goals to achieve, and their sense of “self” differs greatly from who they were before. In reaching this stage they have found a way to fit their new selves into their lives. “I will never go
back to the old [R.B.]. That [R.B.] died when they did the operation. I'm a whole new
person, I'm more able and more stronger that I never thought I would get.” (R.B.)

…but I present pretty well and I think that that can fool myself and other people,
definitely myself. I don’t think it has probably been until the last month or so that I
have really embraced the difficulties I still have and that has been a really, well it
took me almost three years to fully embrace and understand this is my life now.
(B.W.)

By including a focus on goal setting, emotional adjustment, and social integration
eyearly on in therapy, survivors of ABI can be equipped with the proper tools for long term
aspects of adjustment.
In the last ten years the mental health literature has explored what aspects of life lead to feelings of empowerment. Three major categories emerge that define empowerment: self-esteem/self-efficacy (redefining self-concept, developing independence, overcoming societal misconceptions), actual power (being assertive and learning new skills) and community activism ('giving back' to the community and ABI advocacy).

**Developing a Sense of Independence**

The participants in this investigation consider themselves to live independent lives. Each has re-integrated into their communities, they drive themselves, and they set their own goals for achievement. However, the early stages of the recovery process was challenging as decisions were often made by family members, schedules were determined by therapy routines, and there were often choice limitations based on their functionality. For many survivors who face such swift and drastic changes, it is unsurprising that regaining independence in daily living tasks and living arrangements, and recapturing practical aspects of life--such as getting back a driver's license--are often at the forefront of an individual's personal goals.
Yes, I'm living alone. My mom and dad wanted me to live back with my mom and dad. I love my mom and dad but I can be such an opinionated person I said I wanted to live alone. So I can get this way if I have my family and my mom will say and do anything my mom will do this for me, so what am I going to say, “mom will do it, mom will do it,” so I can just sit and relax so everyone can give me pity; no I'm not like that. (R.B.)

The SteppingStones program, with its member driven design, allows for members to explore activities and set their own goals within the infrastructure, and then with support, integrate themselves out into the community. For B.W., being able to use her social work background to lead some of the mental health groups in the program was a key component to her empowerment. From there she was able to begin working as a spokesperson for the American Heart Association. “I have actually been trying to manoeuvre into being a spokesperson for stroke. So far I have probably done 15 different speaking engagements through SteppingStones and through the Heart Association and through Train to End Stroke, kind of a little bit of everything.” (B.W.)

Her initial work at SteppingStones allowed her to build her self-esteem as she recovered. From there she was able to set goals for herself, make independent decisions, and redefine her self-concept.

**Procuring Employment**

Finding and sustaining employment is one of society's final measures of successful independence and self-empowerment. Successful return to work has been
shown to be determined by several factors, including management of pain and depression and development of effective coping strategies. Survivors who were employed prior to their injuries, especially in professional or managerial roles, are more likely to return to work following their injuries.

Well it was very busy. I was a um a planner [financial planner]...at night I was the counsel head of the counsel of Newmarket. I was very busy almost one two three four five six seven days a week. I was very involved with the mills. They were going to close; they did close, so it was like what are we going to do with these mills? So I was in one two three four five six seven eight nine years I was involved with the mills and the um the um closure. And so I was very involved so I didn’t have, and I also built my house, so I was really I was very busy and then all of a sudden nothing. (D.H.)

The four participants in this investigation were employed to some capacity pre-morbidly. All have returned to productive endeavours. However, only one currently maintains gainful employment (S.M.). None of the four participants has returned to his/her pre-injury profession. “I will never, quote, work. It’s too hard for me because I get tired in the afternoon so I tried to work and um I wanted to be independent and I’m really hard. I like to do hard work and stuff, but I now know my ability that I can do, not disability. But there is no job out there for me to have a “normalish” job.” (R.B.)
The most difficult thing before my stroke, I would say that 100% my belief had always been a career woman and that was kind of my ideal. That is why I went from high school to college to grad school all right in a row because I was always going to work and then when it became time my husband was going to stay home with our children…. Whereas before, a couple months ago, I never said I’m not working. I just said I’m not working right now, you know I’m volunteering, I’m busy doing all this stuff, and that is true, but I don’t see working in my future.

(B.W.)

Despite not all being “gainfully” employed, these four individuals consider themselves to live significantly productive lives. It has been shown that return to work may be a benchmark that misrepresents survivors perspective on productivity following ABI. Involvement in “productive” activities has been defined as participation in gainful employment, school, or volunteer work. Involvement in the SteppingStones program may indeed play an instrumental role in facilitating this level of productivity. Studies with survivors of ABI who were involved in milieu-based and comprehensive day-treatment approaches have been shown to live highly productive lives as previously defined.

**Driving**

Regaining the ability to drive a vehicle has been described as one of the major sources of empowerment for survivors. It has been shown that the ability to resume driving is one of the greatest factors in a survivor’s ability to procure employment post-
injury. Furthermore, survivors of ABI who resume driving post-injury effectively integrate back into their communities more often than those who do not resume driving. All four participants in this investigation have resumed driving.

For a year I didn’t drive. That was horrible. I just really, I have always been a driver. As people know now that I have my license, I was never a passenger. I never liked other people driving. I get car sick pretty easily and over that year I had to ask for other people to drive and wow that was just really hard, accepting other people’s, I’m not very good at asking for help either. I had no choice, I had to ask for help and not only that but asking for help but in the same breath being frustrated. (B.W.)

**ABI Advocacy and a Need to Give Back**

Each of these individuals has had to find a way to meet past vocational pursuits within post-injury abilities. This has taken different forms, all of which involve getting highly involved in providing support for other survivors. This not only empowers each of the participants, but it also gives each the opportunity to support the ABI community.

The SteppingStones program has given survivors this unique opportunity to go back and support the ABI community in ways that are empowering to both the individual and the group as a whole. B.W. does this by facilitating several emotions groups, R.B. facilitates gardening and cooking groups, S.M. has been active in music groups, and D.H. facilitates several aphasia support and strategy groups.

D.H. discusses his desire to give back to the aphasia community:
I says I gotta do something. I mean I didn’t expect that... I mean, I says what can we do? Look at the people, the people that came that just had a stroke and have aphasia. I want to start a foundation, so when we came to home we said let’s do it. So we um, I got people that had aphasia, I had a therapist, pathologist, I have doctors that will help.

D.H. now runs the Aphasia Advocacy Foundation both within the SteppingStones infrastructure and as an independent organization that provides support and education at the community and state levels.

The desire to contribute, advocate, and give back has empowered each of these individuals. It has given each a sense of purpose and a sense of belonging. R.B. concludes his interview by offering to extend the same support to others that was provided to him by SteppingStones, “SteppingStones has helped me so much. I’m so grateful to be here and would gladly be here to support anyone else who needs support.”
DISCUSSION

The four exemplar cases in this study represent a sample of individuals who have made remarkable progress during their recovery from ABI. Analysis of the interviews conducted with these survivors identifies several themes congruent with each that were influential to post-injury successes.

Each participant indicated the importance of familial and social support during the recovery process. The role of family and marriage were significant in providing each with the needed encouragement to be successful. The participants indicated that they lost many of their friends following their injury. However, they report that their bonds with relatives strengthened following their injuries.

The literature on this point, reports that the stress placed on both primary and secondary caregivers is often straining to both family and friend bonds. Furthermore, survivors of brain injury are placed at a high risk of significant decrease in friendships and social support and lacked the opportunity to successfully procure new social connections.

The two exemplar cases in this study that were married pre-injury remained married and worked through the strain on their relationship. The two participants that were not married have not established romantic relationships since their injury; however, within their community at Steppingstones have been able to create new friendships and social interactions.

The participants in this investigation were able to implement coping strategies successfully into their lives. The ability to cope and to grieve allowed these individuals
to deal effectively with the emotional strains associated with their injuries. Reliable coping mechanisms gave them the ability to accept their loss of self and provide an opportunity to 'redefine' themselves. Previous research supports our findings that development of effective coping strategies reduced emotional distress and contributed to increased quality of life for the participants in this investigation\textsuperscript{56,60}.

The motto of the post-rehabilitation, community-day program that the participants in this investigation belong to is, “You are not who you were; be who you are.” This sentiment is lived by each of these participants. They have accepted their injuries, coped with their losses, and they have redefined who they are now. Previous research has indicated that survivors of ABI exclude brain injuries from their identities in order to create a “shared meaning of self in society”\textsuperscript{78}. The participants in this investigation have embraced their injuries and accept them as a part of who they have become. “When I’m at [the ABI program]; one I’m a nicer person. But I’m just a normal person with them. We all have our problems; from an accident or a stroke. But when we are all there together everyone completely understands...” (S.M.). “I am 180 percent another person. I’m much more calm; I don’t have anger anymore; I don’t have fits. For awhile, I just wanted to get back to my old self [and] my little life; and just be normal again. Well, I will never be normal; I don’t want to be normal. I like the person who I am.” (R.B.)

“Everything has done an about face. And part of my changing has been accepting the fact that I do have a disability and what that means in my life.” (W.B.)

The participants in this investigation have achieved a number of accomplishments that have empowered them to become independent, resourceful, and eager to give back to their communities. In addition to living independent lives and being able to drive, the
participants indicate that their lives are productive and fulfilling. This sense seems to stem from their advocacy of brain injury awareness and their desire to help others who have gone through similar experiences. Current literature supports these findings, specifically in reference to the importance of procuring meaningful and productive vocations, and a return to driving.\textsuperscript{74, 75}

The issues raised in these interviews may serve to inspire other survivors and provide them with hope and motivation as they progress through the recovery process. Narratives have been successfully used to empower survivors of psychiatric disorders.\textsuperscript{31} Furthermore, needs assessments indicate that survivors of ABI and their families require continued information/education about brain injury and the recovery process and empowerment strategies.\textsuperscript{54} The use of narrative stories from survivors may be able to provide other survivors and their families with insight to ease their fear, answer their questions, and provide an element of hope while they cope with their many challenges.

In addition, it has been demonstrated that the attitudes and beliefs about ABI recovery held by practicing clinicians were significantly different after listening to interviews of ABI survivors.\textsuperscript{79} In particular, the researchers found that clinicians' attitudes and beliefs about the recovery process significantly improved with regards to the psycho-social and vocational challenges of the survivors. Poor attitudes and beliefs held by clinicians about the patient's ability to recover have been linked to poor outcomes.\textsuperscript{80, 81}

Clinicians should be assiduous in sharing such stories of recovery with their patients. Clinicians can help survivors and their families to identify useful suggestions offered in these narratives and apply modifications that will enable their greater success.
By inspiring and empowering survivors and their families through increased education, and improving the attitudes and beliefs of ABI held by health professionals, survivors of ABI will improve their rehabilitation process and experience a higher quality of life.
CONCLUSION

This investigation highlights the major themes shared by thirty-one survivors of acquired brain injury through four exemplar cases. The following themes appear to have had an impact on their successful post-injury accomplishments.

- Development of support networks
- Learning strategies to cope with emotional issues
- Acceptance of injury and redefinition of the self
- Empowerment

These findings also indicate that a "community-based program, such as SteppingStones, for adults with acquired brain injury helps provide members with opportunities to address each of these long-term issues. More research is needed to examine the characteristics of such programming and determine specifically how these programs meet the long-term needs of survivors of acquired brain injury.

Many survivors of ABI are not as fortunate as the participants highlighted in this investigation. However, stories of inspiration such as these may serve to provide hope and motivation to others as they progress through the recovery process.
REFERENCES


09-Apr-2007

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Portsmouth, NH 03801

IRB #: 3972
Study: Definitions of Quality of Life in Survivors of Brain Injury
Approval Date: 29-Mar-2007

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study as Exempt as described in Title 45, Code of Federal Regulations (CFR), Part 46, Subsection 101(b). Approval is granted to conduct your study as described in your protocol.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, Responsibilities of Directors of Research Studies Involving Human Subjects. (This document is also available at http://www.unh.edu/osr/compliance/irb.html.) Please read this document carefully before commencing your work involving human subjects.

Upon completion of your study, please complete the enclosed pink Exempt Study Final Report form and return it to this office along with a report of your findings.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or Julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,

Julie F. Simpson
Manager

cc: File
Fraas, Michael
Table 1: Major Themes Leading to Successful Recovery from ABI and Subsequent Productive Lives as Reported by Study Participants

<table>
<thead>
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<th>Theme 2 Coping &amp; Emotions</th>
<th>Theme 3 Acceptance of new self</th>
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Table 2: Case Study Subject Demographics

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<td>2003</td>
<td>3 wks</td>
<td>12</td>
<td>S</td>
<td>6 mos.</td>
<td>2004</td>
</tr>
</tbody>
</table>

Diagnoses: LCVA (Left cerebral vascular accident), CCVA (Cerebellar cerebral vascular accident) AVM (Arterio-venous malformation), TBI (Traumatic brain injury), MVA (Motor vehicle accident); Edu (Years of education); MS (Marital status: M-married; S-single); Rehab (Time in rehabilitation); SS (Year the participant joined the SteppingStones program).
Appendix A: Oral History Questions

1. Could you tell me about your life before your injury?

   employment
   family
   goals
   education
   friends
   social life
   Religion

2. Describe your injury.

   How long ago it happened?
   Where if happened?
   What happened to you?

3. What was your rehab experience like?

   What types of therapy did you have?
   Where did you have therapy?
   What was beneficial/non-beneficial during therapy?

4. What changes have occurred since your injury?

   Physical
   Emotional
   Communication

5. How has life been since your injury?

   Social
   Family
   Vocation
   Financially
   Religion

6. How has your communication been effected since your injury?

7. What goals are you currently working towards? Or what would you like to achieve in your life now?

8. How has [the ABI program] played a part in your life?
