

Returning to “Status Quo”?

Multiple Perspectives on Community Reintegration and

People with Brain Injuries

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## ABSTRACT

Brain injuries (BI) are the leading cause of death and disability among people under the age of 45 (Ontario Brain Injury Association, 2004). With improved survival rates, more individuals each year return to the community with impairments and disabilities caused by their injury (Smith, Magill–Evans, and Brintnell, 1998). Adjusting to these impairments may affect the individual’s subjective well being; therefore, attention to community reintegration by researchers, policy developers, and health care providers is important. Using qualitative research methods and systems theory as the theoretical framework, the purpose of the study was to examine community reintegration from the perspectives of three key groups: individuals with BI, community based agencies, and primary care physicians regarding the meaning attributed to “successful reintegration”, as well as the key characteristics and barriers experienced during reintegration. “Successful” reintegration appears to be an individually derived concept. Participants consistently identified the need for information about the process of community reintegration, and resources available both during rehabilitation and after discharge from the hospital as being both a key aspect of community reintegration, as well as a barrier experienced during the return to community.

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## CHAPTER 1

### Introduction

A brain injury (BI) can happen to anyone, of any age, at any time: Canadian information shows that BI are the leading cause of death and disability among people under the age of 45 (Ontario Brain Injury Association, 2004). An acquired brain injury (ABI), also known as a traumatic brain injury or simply a head injury, is defined as damage to the brain that occurs after birth, and is not caused by a congenital disorder (cerebral palsy, autism) or a progressive degenerative disease (Alzheimer's disease, multiple sclerosis; Ontario Brain Injury Association, 2003). In general, brain injuries are caused by traumatic events (falls, assaults, and sports injuries) or medical problems and diseases that cause damage to the brain (strokes, brain tumours, aneurysms, or meningitis).

Using Statistics Canada census data, the estimated prevalence of traumatic brain injury (TBI) in Canada is 74 per 100,000 among those 15 years of age and older (Willer, Ottenbacher, & Coad, 1994). The Ontario Brain Injury Association (2003) estimated that the incidence of brain injury in Ontario is 115 per 100,000 persons and that 24 per 100,000 persons annually require neurorehabilitation. Canadian statistics indicate that in 1996 there were approximately 45,600 reported brain injuries; 37,000 of these people were admitted to hospital for their injuries, and the remaining 8,600 were dead on arrival. Approximately 34,500 of the 37,000 admitted to hospital were ultimately discharged



from hospital care; 21% or approximately 7, 300 people were discharged to rehabilitation programs (inpatient and outpatient) (Willer et al.).

Numbers in the United States (U.S.) show similar statistics: *The Incidence of Traumatic Brain Injury in the United States*, a Disability Statistics Abstract of the U.S. Department of Education (1996), stated that a person receives a traumatic brain injury every 15 seconds in the United States. Over 2 million such injuries occur each year, with 25% of injuries severe enough to require hospital admission. Between 75,000 and 100,000 Americans die each year from brain injuries which are the leading cause of death and disability in children and young adults. Two-thirds of all persons sustaining brain injuries are under 30 years of age (VSA Arts, 2002). It is important to note that these statistics reflect only diagnosed cases of BI – many brain injuries go undetected, and many other people receive misdiagnoses of mental illness. People who are undiagnosed, or receive a misdiagnosis, subsequently receive no treatment or services for their brain injury (Ontario Brain Injury Association, 2003).

Smith, Magill–Evans, and Brintnell (1998) indicate that with improved survival rates of people with BI, more individuals each year return to the community with impairments and disabilities caused by their injury. Adjusting to these disabilities and impairments may affect the individuals' ability to resume meaningful roles within their community and their perceived life satisfaction; as such, attention to community reintegration by researchers, policy developers, and health care providers is important. In addition to increased survival rates and numbers of individuals readjusting to life post BI, several other factors make this an important area of study. Please see Table 1 for a summary of these factors.

Table 1.

*Summary of Factors that demonstrate importance of area of study*


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Decreased Length of Hospital Stay	<p>Bullock and Morris (1991) indicate that As a result of fiscal tightening, the average length of stay in hospitals has decreased and patients go home sooner, in many cases before they are ready or at least by the standards of only 10 to 15 years ago. “Patients are discharged today when they are medically stable, not necessarily when they are socially, emotionally, or even physically ready” (p.28).</p> <p>Hospital based community reintegration programs provide people with the opportunity to develop and practice the skills necessary for community living before they are discharged home; including functional skills such as decision making, money management, and social skills (p.3).</p>
Real World Advantage	<p>According to Venzie, Felicetti, and Cerra–Tyl (1996) “much of the increase in community integrative programming is based on a general understanding that advantages to brain injury rehabilitation occur when it is performed in an environment that is as close to the real world as possible” (p. 52). Ideally, rehabilitation in real, not simulated environments provides functional relearning of skills and reduces problems associated with generalizing skills from clinical to home settings.</p>
Independence for Lower Functioning Clients	<p>For lower functioning individuals, a community reintegration program may increase quality of life in an environment that encourages independence while providing support and ensuring maximum safety (Venzie, Felicetti, and Cerra–Tyl, 1996).</p>

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Despite knowledge of the importance of reintegration support for people with BI, research and published work has primarily focused on the issues and barriers experienced by people with spinal cord injuries. Burleigh, Farber, and Gillard (1998) indicate that the concept of community reintegration related to BI has had relatively limited exposure in the literature. Community reintegration is a relatively new concept that has emerged in rehabilitation over the past 10 to 15 years. The term typically describes the primary aim of rehabilitation after serious trauma, which is attempting to prepare the patient for discharge, and consequently, return to their community (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993). This is especially true in the literature on serious BI where, in spite of good prognosis for the recovery of most physical and some cognitive functions, recovery of community integration skills usually remains poor (Willer et al.).

Research articles alternatively refer to the process of returning to the community from rehabilitation as *community reintegration*, *community reentry*, *community integration* or *return to productivity*. One researcher referred to the process as *community (re)integration* (Dijkers, 1998). Although the terminology is different, each publication refers to the process of individuals with brain injuries returning to the community. Many researchers have generated definitions of community reintegration based on a set of similar characteristics; (a) an individual returning to society and family life after injury, with the ability to live independently in one's community, (b) performing expected roles and responsibilities, and (c) participating as a contributing member of society in paid employment, avocational activities, and unpaid work (Miller, Burnett, & McElligott, 2003).

Kreutzer and Wehman's (1990) book on community reintegration divided the literature into three general areas: vocational, family, and community. The term *community*, according to Kreutzer and Wehman, could be described as integration into a social network. They further contend that integration into a home like setting should be defined as active participation of the individual in the operation of the home. Social integration or participating in activities outside the home is a second area of community reintegration identified by Kreutzer and Wehman; which refers to all types of activities, including shopping, leisure activities, and visiting friends; another aspect of social integration is reflected in aspects of interpersonal relations such as having a best friend and participating in social activities with people without disabilities. The third identified area of community reintegration is the regular performance of productive activities; including the extent to which individuals gets out of the house during the day (Burleigh et al., 1998).

Further to the study of productive activity, Fuhrer, Rintala, Hart, Clearman, and Young, (1992) examined the relationship of impairment to quality of life for individuals with spinal cord injuries, a population that experiences similar barriers to community reintegration as people with BI. They found that the strongest relationship existed between social integration and life satisfaction. In studies focusing on people with BI, it was determined that return to work and education are other critical measures of independence, community reintegration and quality of life. In an evaluation of people two years post hospitalization with BI, Webb, Wrigley, Yoels, and Fine (1995) found that employment was a strong contributor to improved quality of life. Overall, the research

on community reintegration indicates the importance of successful return to community settings for people with BI.

Adults with BI and their families “want the same things other people do: a place to live, a job, an education, recreation, friendships, and family life” (Racino & Williams, 1994, p. 39). There have been few in depth studies of individual responses to living with a BI; and in some research, the perceptions and experiences of the people with the injury are often viewed with skepticism (Racino & Williams). The information collected from participants with BI is often viewed as unreliable on the assumption that impaired cognitive functioning precludes the ability to provide accurate information, or comprehend the questions (DiDonato & Schaffer, 1994). However it is important to obtain a first person perspective from people with BI because, although their daily activities may be contrary to what society generally believes makes a person happy, they may be satisfied with their lives (DiDonato & Schaffer).

Mactavish, Lutfiyya and Mahon (2000) conducted the Lifespan and Disability Project emphasizing the inclusion of the perspectives of individuals with intellectual disabilities on the concept of social integration. This study, built upon the presumption of participant creditability, utilized multiple data collection strategies, qualitative interviews, focus groups and verification meetings to collect meaningful and reliable insights on how the participants viewed social integration. Presumed credibility means that researchers provide supports or processes to enable people to “tell their story,” with the assumption that participants have credible and valuable information that they are willing and able to share. Although the participant group differs, many of the assumptions are based on the resulting cognitive impairment, and therefore, relevant to the current proposed work. The

work of Mactavish et al. clearly show that studies with concrete strategies and methods can elicit information from participant groups previously viewed as either unreliable or incapable of contributing to discussions.

Racino and Williams (1994) emphasize the role of the person with a BI in lifestyle decision making. The field of rehabilitation has only recently recognized the expectations of persons with a BI to be involved in the process of reintegration and community membership. This recognition is reflected in guiding principles,

it is important to reinforce and build on the knowledge persons already possess about themselves, their strengths, what they want to do with their lives, and what they want their lives to be. The opinions and views of the person's family members and friends must also be considered. When the opinions and views of the person with a traumatic BI differ from those of others, the ultimate question must be: Whose life is it?" (Racino & Williams, 1994, p. 37).

Studies show that with appropriate tool design, interview techniques, and patience, quality information with validity and credibility can be obtained (Burleigh, et al., 1998; Johnston & Lewis, 1991). Additionally, the research conducted by Karlovits and McColl (1999) indicate the rich data that can be collected from people with BI. Using a qualitative approach, Karlovits and McColl interviewed 11 individuals with severe BI on coping strategies and stressors of community reintegration, and reported successful and useful results.

### *Research Purpose and Objectives*

While there is a significant body of literature regarding community reintegration pertaining to people with BI, limited attention has been paid to the perspectives of

individuals with BI; the researcher found no studies that had compared multiple groups' perspectives on community reintegration. In this research, community reintegration was examined from the perspectives of three key groups: individuals with BI, community based advocacy groups that support these individuals, and their primary care physicians. The purpose of this study was to identify similarities and differences in perspectives between these informant groups on issues related to community reintegration.

Specifically, the research objectives were:

1. To identify key characteristics of community reintegration for people with BI;
2. To enhance understanding of what "successful" reintegration means from the perspectives of each of the informant groups; and,
3. To identify and understand the barriers (factors that constrain) experienced by people with brain injuries when reintegrating to a community setting.

### *Key Terms*

*Community reintegration.* Community reintegration is thought to encompass return from hospital or rehabilitative care into three areas: home, social network, and productive activities. Individuals with or without disabilities elect to balance their lives in a manner that may produce greater integration in one area over another and therefore, a complete picture of the individual's level of community reintegration is some combination of all three areas of reintegration.

*Person with a brain injury.* A BI is defined as damage to the brain that occurs after birth, and is not caused by a congenital disorder or a progressively degenerative disease. In general, brain injuries are caused by traumatic events or medical problems and diseases that cause damage to the brain.

Impairment levels vary depending on the severity of the injury, the part of the brain that was injured, the age, and general health of the person. Typically, people with moderate to severe BI have more problems with cognitive deficits than people with mild BI. A history of several mild BI may however, have a cumulative effect, causing a similar level of cognitive deficit as a severe injury (MD Consult, 2003). A person who is considered high functioning, generally, has a lower level of impairment, and conversely, a person considered lower functioning generally demonstrates higher levels of impairment in activities of daily living.

*Community agency.* Community agencies involved in this study are organizations based in the community that are dedicated to providing services and supports for people with BI and their families.

*Primary care physician.* Primary care physicians are professionals who have not registered as a specialist through the College of Physicians and Surgeons of Manitoba (Manitoba Health, 2002). Primary care physicians are responsible for providing comprehensive health care to any individual seeking medical care; they function as a generalist whereas other health providers (specialists) limit access to their services based on age, sex and/or diagnosis. Primary care physicians are involved in all aspects of health care; their relationship with patients not only deals with episodes of illness, but



also includes long-term care, rehabilitation, preventive care and health promotion (Forkosch, Kaye, & LaPlante, 1996).

## CHAPTER 2

### Literature Review

Creswell (2003) recommends that qualitative researchers review the literature and incorporate the information in one of three ways: (a) include the literature in the introduction, using it to frame the problem; (b) review the literature in a separate section; or (c) include the literature in the final section of the study, comparing and contrasting the study findings and the literature. Each of Creswell's approaches to the use of literature is commonly used in all types of qualitative research, although different types of studies will generally present the literature in a different way. Creswell states, "In grounded theory studies, case studies and phenomenological studies, literature will serve less to set the stage for the study" (p. 30). Rather, the literature becomes an aide at the conclusion of the study, once patterns and categories have been identified in the study data.

Literature for this study was incorporated using a combination of Creswell's (2003) recommended methods. Literature was presented in the introduction chapter, assisting the researcher in framing the research questions, reviewed in a separate chapter of the presented work, and included in the discussion chapter of this work to compare and contrast study findings with existing information.

This chapter is separated into two distinct topic areas: first, a discussion regarding the various perspectives on community reintegration in the literature; including the conceptualization and goals of community reintegration, examples of its application, and the instruments/tools used to assess the impact of community reintegration. The second section addresses these related concepts (quality of life and life satisfaction) and the theoretical framework of systems theory as they relate to the research.

## Role and Definitions of Community Reintegration

### *Role of Community Reintegration in Rehabilitation*

“Only about half of all persons with moderate brain injury will return to school, work, and independent living within 1 year of injury” (Burleigh et al., 1998, p. 49).

Statistics such as this exemplify the need for health care professionals and community agencies to assist people with BI prepare for life after hospitalization and rehabilitation.

Seaman, Roberts, Gilewski and Nagai (1993) state that “head injury rehabilitation is a relatively new field and community reintegration as a treatment technique has only been performed in rehabilitation centres for approximately 15 years” (p. 13). These topics, as they relate specifically to BI have had limited exposure in the literature (Burleigh et al., 1998) and there has been limited consensus in the development of a singular definition of community reintegration.

In the past, the term reintegration was seldom found in rehabilitation literature; however, when survival of the person with BI is assured, return to normal living is often seen as the ultimate goal. “Most professionals would argue that, overall, they wish each person with a BI to resume “living” his or her life as normally as possible, within the constraints of disease or the aftermath of trauma. In this sense, “living” obviously involves functional performance” (Wood–Dauphinee, Opzoomer, Williams, Marchand, & Spitzer, 1988. p.583). Therefore, reintegration to normal living could mean the reorganization of physical, psychological, and social characteristics so that the individual can resume well adjusted living after illness or trauma (Wood–Dauphinee et al.).

Willer et al. (1993) stated that the term community integration is frequently used in the literature to describe the primary aim of rehabilitative services after serious trauma.

This practice is especially true in the literature on serious BI where, in spite of good prognosis for the recovery of most physical and some cognitive functions, recovery of community integration skills usually remains poor. These researchers define community integration as effective “role performance in community settings” (p. 76) and empirically identified community integration and its components, including home, social, and productivity (work, school, volunteer).

Venzie et al. (1996) noted the need for community integration programs for individuals with BI, while Bullock and Morris (1991) advocated for the continuation of treatment services during the transition between hospital and community, stating that this is required if persons with a BI are to attain the highest levels of wellness and independent functioning in their home communities. A bridge is needed between the acute care and community setting that involves active, responsible participation in family, leisure, and vocational activities. Goggins, Hall, Nack and Shuart (1990) discussed the benefits of community reintegration programs, identifying the provision of opportunities to increase decision making skills, self responsibility and initiative in persons with a BI prior to discharge.

Clinical experience indicates that prospects for a smooth and successful transition to outpatient status are substantially enhanced by the implementation of a community reintegration program before discharge from the inpatient rehabilitation setting. At the time of transition between hospital and community, a therapeutic community reintegration program seeks to augment recovery by providing a coordinated set of hospital based training activities and community-

based practice sessions designed to supplement standard inpatient rehabilitation efforts (Goggins et al., 1990, p.343).

### *Issues in Defining Community Reintegration*

Other researchers have identified additional definitional concepts regarding community reintegration. The term community reintegration has been used in human services fields to refer to being part of the mainstream of family and community life, living independently, performing normal roles and responsibilities, and being an active and contributing member of one's social groups and of society as a whole (Dijkers, 1998; Tate, 2001).

Several factors (e.g., independent living or reduced dependency on others, return to productive activity, and leisure participation) are used to indicate if a person has been reintegrated to the community from inpatient hospital care. Among these factors the most frequently cited indicator of community integration is return to competitive employment, as employment status lends itself well to measurements and is important for the individual and society (Willer et al., 1993). In many cases, however, return to competitive employment is not feasible. For this reason, a number of practitioners have suggested a broader focus on productive activities that includes avocational activities and unpaid work (Willer et al.).

### *Benefits Associated with Community Reintegration*

The mission of a community reintegration program for people with BI is to help them restructure their lives so they can re-enter the community (Venzie et al., 1996). A community reintegration program has many potential benefits; it allows the therapist to assess the behaviour of the individual with a BI or family behaviour before discharge;

determining if the individual and family has sufficient skills for independent living. A community reintegration program also “helps to reestablish a degree of patient autonomy before discharge” (Goggins et al., 1990, p.343). The routine in the acute care setting allows the person with a BI minimal control over his or her daily routine; while a gradual return to community enables the person with a BI to overcome the fears, depression and dependency that they experienced. This gradual return to community also provides time for the person with a BI, family and others in the social network to make the psychological adjustment from injury related roles (patient) to more conventional community roles such as spouse, parent, neighbor (Goggins et al., 1990).

Community reintegration programs that provide individuals with the ability to regain their sense of productivity through work and leisure have reported outcomes that vary tremendously. Published community reintegration programs have demonstrated varied levels of success with patients, and suggest that designing a program for such a heterogeneous population is very difficult (Seaman et al., 1993; Venzie et al., 1996).

For lower functioning individuals, community reintegration programs may increase quality of life while encouraging independence and maintaining support and safety. Additionally, rehabilitation activities conducted in real, as opposed to simulated environments, provide opportunities for functional relearning of skills and may reduce problems associated with generalizing these skills between clinical to home environments (Venzie et al., 1996).

### *Community Reintegration Approaches and Programs*

Brain injury rehabilitation and community reintegration programs specifically have received little attention in the rehabilitation literature until recently. When

community reintegration programs are identified in the literature, there are typically two approaches: single discipline hospital or community based programs, and interdisciplinary residential or day treatment programs. The goals of community reintegration programs are diverse, ranging from preparation for community functioning to obtaining gainful employment (Seaman et al., 1993). Interdisciplinary programs that are reported in the literature occur primarily in residential facilities and employ behaviour management techniques in assisting individuals with brain injuries prepare for community reintegration. Seaman et al. stated that “single discipline hospital community reintegration programs are often conducted by Occupational Therapists (OT); and training in community skills were included among activities of daily living (ADL) and other OT tasks” (p. 6). Some OT organized programs may include or provide opportunity for other disciplines to provide input or feedback.

For purposes of exemplification, this section outlines a few studies that have examined key concepts of community reintegration. These examples outline key concepts such as quality of life, independence; but also show the design, goals and outcomes of community reintegration programs.

*1. Community Reintegration Program (CRP).* Bullock and Morris (1991) outline the benefits of a community reintegration program facilitated by a therapeutic recreation specialist (TRS). A TRS uses activity modalities to treat or maintain the physical, mental and emotional well-being of people they serve. The interventions help individuals remediate the effects of illness or disability, achieving optimal independence. Therapeutic recreation specialists work as members of an interdisciplinary team; developing individual treatment plans and programs that are consistent with client need, abilities and

interests, with the goal of improving physical, cognitive and social functioning (American Therapeutic Recreation Association, 2004). Bullock and Morris indicate that special consideration for the needs of the TR professional as well as the opportunities for this program to fill the gaps between hospital and community services is required to provide well-rounded rehabilitation services.

In the Community Reintegration Program (CRP; a three year funded qualitative pilot study; 1991), discharged persons with a BI were included in a project that continued therapeutic recreation services through the transition phase between hospital and home. Prior to discharge, a comprehensive plan was developed to identify the service needs of people with BIs to increase their quality of life. Many disciplines were included in the development of the discharge plan, including clinical TRS, transitional TRS, and the traditional health care team. The CRP partnered with community-based services such as vocational training, the Independent Living Program, and home health services in the area to ensure that services were not duplicated, and efficient use of resources occurred.

The CRP included a standardized protocol that was completed by all members of the reintegration process, including referral to the CRP by the clinical therapeutic recreation specialist in which the participants would commence the formal leisure education process. At the time of discharge, the TRS introduced the person with a BI to the transitional therapeutic recreation specialist (TTRS) who would lead the person with a BI through the discharge process and continue the leisure education model in the community. Upon completion of the leisure education model, the TTRS would complete the discharge process and follow up at regular intervals.



The CRP data showed that creative, practical, and cost effective implementation of recreation programs could be used to facilitate rehabilitation of recently discharged people with BIs; and that recreation motivated the participants to reengage in their communities. Bullock and Morris (1991) state unequivocally that therapeutic recreation services must be started in hospital and continue to the homes and communities of discharged persons with a BI as a community based treatment service.

Bullock and Morris' (1991) study indicates the need for quality community reintegration programs both in hospital and rehabilitation settings, but emphasizes the continuing needs of persons with disabilities once they have returned to the community. The Community Reintegration Program used transitional therapeutic recreation specialists to facilitate continuing community reintegration.

2. *The Cedars – Sinai Medical Centre Community Reintegration Program.* Seaman et al. (1993) outline a community reintegration program that they developed and implemented as rehabilitation professionals in the Department of Physical Medicine and Rehabilitation at Cedars Sinai Medical Centre. These practitioners developed a community integration intervention in their facility, combining the comprehensiveness of a residential interdisciplinary program with the benefits of an early intervention hospital-based program. This program was designed to,

1. Improve persons with a BI's physical, cognitive, social, and linguistic functional outcomes from a structured to an unstructured, dynamic community environment,
2. Provide an organized, educational approach for persons with a BI and family members regarding deficits and compensatory strategies, and

3. Enhance team cohesiveness and effectiveness by establishing interdisciplinary team goals.

Participants were included in a seven phase community reintegration process based on their medical (as evaluated by the physician), behavioural, and cognitive status. The program used modules that progressed from simple tasks in quiet, hospital-based activities to complex tasks in stimulating environments performed away from the hospital. Each discipline involved in the rehabilitative care contributed individual focused goals that were consistent with the seven-phase model and as a result successful implementation was reported (Seaman et al., 1993). The authors also noted that the seven-phase community reintegration program could be used at any point in the continuum of care; although designed for persons with traumatic brain injuries, the program has been applied to groups with other types of neurological impairments such as cerebral vascular accidents, cerebral tumors and aneurysms.

The study outlines the benefits (social, psychological, and functional) of community reintegration programming from the perspectives of the authors and team members. Case study presentations displayed the process of community reintegration using the program format, and identified positive outcomes for the participant, but the authors do not present formal evaluation data to support these findings. In addition, the authors fail to represent the perspectives of participants; which supports the purpose of the presented research, obtaining key participants perspectives of the reintegration process.

*3. Self Directed Learning for Physiatrists and Rehabilitation Professionals.* In *Archives of Physical Medicine and Rehabilitation*, a leading rehabilitation medicine journal, Miller

et al. (2003) presented a self-directed learning module of clinical and educational activities that outline the expected learning objectives of practitioners and trainees in physical medicine and rehabilitation. The article highlights the cognitive and psychosocial adjustment aspects of brain injury and focuses specifically on evaluation and treatment of mood and behavioral impairments after brain injury, treatment of cognitive impairments, efficacy of cognitive rehabilitation, and psychosocial impact of a BI on families and resources available for community reintegration.

A clinical educational activity presented to the readers was as follows: “Six months after traumatic brain injury, you are following up with the 40 year old father who was formerly employed as an engineer. Identify the components needed for successful community reentry” (Miller et al. 2003 p.S16). The authors identify four basic components that will enhance successful community reentry: neuropsychological testing, a driving evaluation, a functional capacity evaluation and vocational rehabilitation. There was limited mention of social variables other than employment and mental well-being in this educational activity; and should be flagged as a potentially limited view of successful community reentry. This view of successful community reintegration would benefit from comparison to the perspectives of other groups (family physicians, people with BI and advocates).

*4. Return to Productive Activity after Traumatic Brain Injury.* Wagner, Hammond, Sasser, and Wiercisiewski (2002) conducted a study designed to identify the factors associated with successful return to productive activity (RTPA) one year post hospitalization for traumatic BI. The authors also wanted to determine the relationship between successful RTPA and other measures of impairment, disability, handicap, and

integration into the community. For the purposes of this study, “return to productive activity” was defined as a return to pre-injury comparable work, full time school or homemaking. Returning to pre-injury work and education are critical measures of independence and community reintegration after BI, also indicating quality of life (Wagner et al.).

This study used the Community Integration Questionnaire (CIQ) and the Disability Rating Scale as outcome measures with 105 participants. Wagner et al. (2002) found that approximately 75% of participants returned to productive activity within one year post injury; and suggest that the CIQ social integration subscales may be useful predictors of successful return to productive activity.

The study points to the need for efficient and effective community reintegration for people with brain injuries. With approximately three quarters of people returning to home, community and productive activities, the value of community reintegration, from the perspectives of stakeholders should be explored further.

***5. Characteristics of Facility-based Community Integration Programs for People with Brain Injuries.*** A study funded by the National Institute on Disability and Rehabilitation Research collected information regarding the quantifiable characteristics of community reintegration programs available to adults with brain injuries in the United States. In an attempt to understand similarities and differences between post discharge community reintegration programs available, Glenn, Goldstein, Selleck and Rotman (2004) conducted telephone interviews with 49 representatives of facility based reintegration

programs across the country. The authors defined facility based as “nonresidential program for which clients come to a facility for services” (Glenn et al., p. 484).

An initial focus group consisting of people with BI, their caregivers, and other “experts” guided the development of the Community Integration Program Questionnaire (CIPQ), which is a tool designed to gather information during a telephone interview about certain characteristics of community integration programs. The identified 8 community integration skill areas that the researchers focused their data collection on included whether or not the program worked with their clients regarding the following skills:

- 1) navigating in the community (travel outside the home)
- 2) shopping
- 3) participating in leisure activities
- 4) visiting friends or relatives
- 5) banking
- 6) education
- 7) employment
- 8) volunteer activities

The researchers found that there was tremendous variability in community reintegration program characteristics, with a high proportion of the programs surveyed indicating that they treated clients in three or more of the eight skill areas, and almost all of the programs indicated that they worked with their clients on employment skills.

The authors used the CIPQ to collect information regarding client populations, time spent in team meetings, length of stay in programs and time spent in group versus

individual therapy sessions. The authors indicate that ultimately, they would like to refocus their tool and assessment process to gather information regarding program delivery and assess client outcomes.

*6. Community Integration and Life Satisfaction After Traumatic Brain Injury: Long – Term Findings.* A study conducted by Burleigh et al. (1998), used the social integration subscale of the Community Integration Questionnaire, which included items about visiting friends and relatives, the quality of their friendships, leisure activities with friends, and banking and shopping in the community. The participants also completed the Life Satisfaction Index (Neugarten, Havighurst, & Tobin, 1961), which is an 18-item scale that documents life satisfaction.

The study was designed to address two questions:

- 1) Is there a relationship between life satisfaction and the long term community reintegration of persons with traumatic brain injury?
- 2) Is there a relationship between life satisfaction and home integration, social integration and productivity integration of persons with traumatic BI?

Burleigh et al. (1998) found that participants with higher social integration reported a greater satisfaction with life. Therefore, the hypothesis that life satisfaction has a positive relationship to social integration was supported. They state “the findings of this study demonstrate a low, but significant, relationship between social integration (subtype of community integration) and life satisfaction” (p. 49). The findings of Fuhrer et al. (1992) and Heinemann and Whiteneck (1995) support these results.

It was found that many persons with BI lose their pre injury social network, and without the skills necessary to develop new relationships, they become socially isolated and dissatisfied with their level of social integration. This dissatisfaction may cause secondary psychological disabilities. These findings may be particularly relevant for persons with severe BI; impairments in judgment, self awareness, social and sexual disinhibition, egocentricity, and other behavioural problems make it difficult to remain socially integrated in society (Burleigh et al., 1998).

6. *The Community Reintegration Group II*. Dryovage and Seidamn (1992) developed and implemented an intervention called the Community Reintegration Group II. The authors state, “an important aspect of the rehabilitation of traumatic brain injured individuals is community reintegration” (p.12); creating a program to address the needs of higher functioning persons with brain injuries by providing them with the opportunity to participate in a group that focused on the skills necessary for successful community participation. The goals of the Community Reintegration Group II are outlined in Table 2.

Table 2

*Goal of the Community Reintegration Group II Intervention*

Program Goal	Implementation Strategies and Activities
Promotion of successful community participation by providing and practicing strategies in...	Leisure planning and organization Budgeting skills Problems solving and decision making skills Functional memory and orientation Safety awareness and judgment
Provision of opportunities to improve communication skills in relation to...	Phone skills, conversations, and interactions Nonverbal communications Pragmatics/social skills

Assist in successful return to  
community activities through...

Presenting concrete practical experiences to  
promote independence  
Providing support and feedback  
Assertiveness training  
Creating opportunities for people to  
experience rewarding interactions  
Education regarding need for the  
compensatory strategies for deficits  
Developing resources in the patient's  
community

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A unique facet of this program was the co-facilitation by two professionals from separate and distinct disciplines; Speech Language Pathology and Therapeutic Recreation. This enabled the blending of distinct approaches/foci that led to improved quality of treatment for this group; which was demonstrated by the majority of people with BI who made significant progress toward their goals through the course of the program (Dryovage & Seidamn, 1992).

The Community Reintegration Group II clearly outlines some of the key activities and skills required by persons with BI to promote quality of life and community integration. This overview provided the researcher with key question areas to discuss with participants to determine if these activities and services were available, who was or should be responsible for these activities, and what role key organizations should play in these activities.

#### An Instrument/Tool for Assessing the Impact of Community Reintegration

Professionals interested in the experiences of people reintegrating to their communities have developed many tools that help measure and define the requirements of the experience and the effects on participants. Many of these tools measure functional



ability (Krefting, 1989), work performance, life satisfaction (Neugarten et al., 1961), and role performance; but are not comprehensive, only examining one aspect of social recovery. Willer et al. (1993) outline in detail the Community Integration Questionnaire with respect to its development, applications and content. The CIQ is a commonly used and referenced standardized tool in the field of rehabilitation and community integration; examining the process of community reintegration holistically including home, social, and productive activities.

The development and field-testing of the CIQ began with a general definition of community reintegration. For the purposes of evaluating the impact of rehabilitation in the model systems program on individuals with BI, community reintegration was divided into three related but separate aspects of integration based on Kreutzer and Wehman's (1990) book on community reintegration. This commonly accepted distinction divides the community reintegration literature into three areas: vocational, family and community. The term community, according to Kreutzer and Wehman, could also be described as integration into a social network.

Willer et al. (1993) outline each of the three distinct aspects of community reintegration. The first is integration into a home like setting and actively participating in the operation of the home. The second area of CI is social integration, which refers to participation in a variety of activities outside the home, including shopping, leisure activities, and visiting friends. Other aspects of social integration reflected aspects of interpersonal relations such as having a best friend and participating in social activities with persons without disabilities. The third area of CI is regular performance of

productive activities, which includes the extent to which the individual leaves the house during the day.

Community integration in the general sense was seen to encompass integration into each of the three areas of home, social network, and productive activities. It was also determined that individuals with or without disabilities elect to balance their lives in a manner that may produce greater integration in one area over another... A complete picture of the individual's level of community integration is some combination of all three areas of integration (Willer et al., 1993, p. 78).

The CIQ does not assess the extent of control or satisfaction the individual feels over integration outcomes; although control over one's life is extremely important to life satisfaction. Some questions do ask whether the individual participates in important life activities such as managing personal finances, but control over the activity is merely implied rather than assessed.

In summary, this review of the community reintegration literature substantiates the importance of programs and services in this area, the need to enhance knowledge about the links between life satisfaction and other factors (e.g., social integration) that promote successful reintegration, and the need to include the perspectives of persons with BI. Although many of the reviewed studies included people with BI as study participants, none of the articles clearly outlined the strategies used to ensure that the participants' perspectives were included and accurately reflected in the study. By using specific data collection techniques the perspectives of people with BI can be included and collected with confidence. Mactavish et al. (2000) discuss the techniques used to include the perspectives of people with intellectual disabilities, a group that experiences similar

barriers or constraints as a result of impairments in cognitive functioning. The study discusses the assumption that all perspectives on an issue are inherently valuable and used data collection processes that facilitated inclusion of their participants' perspectives in the study. Specific adaptations included using multiple and intensive data collection strategies such as developing rapport and the use of intensive interviews with probing, prompting and cueing helped participants respond to questions asked in an interview.

With the exception of the self-directed learning module in the physical medicine and rehabilitation journal, the researcher found limited mention of physician (physiatrists or family physicians) involvement in the process of community reintegration. One study mentioned health care professionals as members of the community reintegration process, but no articles discussing community reintegration as it relates to primary care were found.

Many of the reviewed studies indicated that multiple factors determine the ease of transition between hospital and community. These factors included: multidisciplinary input in to the community reintegration process, the provision of continued services through the transition phase, return to productive activity, and perceived responsibility for the injury.

### Quality of Life and Life Satisfaction

Three overarching and related concepts in the general construct of subjective well being; quality of life, life satisfaction, and health related quality of life (Diener, Emmons, Larsen & Griffin, 1985) were identified as particularly relevant for this study. The literature shows that these constructs have relevance to the discussion of community reintegration and people with brain injuries.

The term quality of life has been conceptualized in many different ways, although the majority of these conceptualizations centre on “how good life is” for people (Raeburn & Rootman, 1996, p.16). Schumaker, Anderson and Czajkowski (1990) define quality of life as “an individual’s overall satisfaction with life and general sense of personal well being” (as cited in Smith et al., 1998, p.131). Renwick and Brown (1996) define quality of life as “the degree to which a person enjoys the important possibilities of his or her life” (p. 80). The focus on the “important possibilities” of life provided the researcher with an item of conceptual framework for this study as the research questions centred around the key characteristics and barriers perceived and experienced by participants.

When quality of life is assessed and measured in clinical settings and rehabilitation research, it is typically viewed as a component of functional status of overall health and assumed to be in existence or enhanced as the individual’s level of function performance improves (Renwick & Friefeld, 1996, p.26). Fuhrer (1994) asserted, however, that evaluation of the outcomes of medical rehabilitation services should be considered incomplete if the subjective well being (i.e., individually held expectations versus externally defined criteria) of the individuals being served has been ignored (Corrigan, Bogner, Mysiw, Clinchot, & Fugate, 2001).

The term life satisfaction refers to a cognitively oriented, subjective judgment of one’s current life situation in relation to one’s own expectations; it is noteworthy that studies’ focusing on life satisfaction among persons with disabilities has occurred more frequently in populations of people with physical impairments rather than individuals with disability caused by cognitive impairment (Corrigan et al., 2001). Most notably, among persons with spinal cord injury, higher life satisfaction has been associated with

better perceived health, greater social support, more social activity, and a greater sense of control over one's life" (Smith et al., 1998). Research on the life satisfaction of persons with BI however, shows an association with characteristics such as employment, marital status, functional memory capacity, bowel independence, family satisfaction, and perceived responsibility for their injury (Corrigan et al.). Corrigan et al. suggested that the experiences of individuals with BI are sufficiently different (i.e., when compared to people with spinal cord injuries and other forms of impairments) in areas to warrant separate consideration; they also noted that there is a need to examine life satisfaction from the individual's perspective; although some common factors affect life satisfaction, disability specific factors may have a determining role.

An additional quality of life concept, *health related quality of life* is defined as "a person's subjective perceptions of his or her physical, psychological, and social well being after taking into account the impacts of disease and treatment" (Wood et al., 1992, p. 7). Other researchers (Fuhrer et al., 1992) however, found that life satisfaction was not related to the extent of impairment or disability but was associated with dimensions of social participation such as participating in social roles, accessing support services, as well as home and family functioning (Smith et al., 1998).

### Depression

The BI literature identifies depression as a significant clinical concern (Seel et al. 2003); and it is further recognized to be a consequence of BI that may extend from the acute phase to more than 3 years post injury (Berg, Palomaki, Lehtihalmes, Lonhqvist, & Kaste, 2003). Functional aspects often associated with depression include severity of injury, physical disability, and functional impairments; however, full understanding of

the link between cognitive deficits and depression require further investigation (Berg et al.). Researchers have identified many possible social risk factors that may contribute to depression or are linked to depressive symptoms. These risk factors include: living alone, having few social contacts, marital and family disruptions; as well as the inability to return to work, and the resulting financial impacts (Berg et al.; Seel et al.).

Researchers (Seel et al.) have been unable to determine the frequency, distinguishing features and factors associated with depression after a BI, but commonly reported symptoms include sadness, poor concentration, sleep disturbances, memory dysfunction, and psychomotor retardation. This literature is particularly relevant for the present work. Researchers state that increased rates of depressive symptoms are found in the unemployed and impoverished, which may emphasize the importance of prompt vocational assessment and rehabilitation, and referrals to community support programs (Seel et al.).

People with BI have many of the same types of stress as others without disabilities; additionally, they face unique stressor caused by their disabilities and barriers found in their physical and social environments (Karlovits & McColl, 1999). Community reintegration is recognized as a significant stressful event requiring considerable adjustment as it has an effect on the individual's finances, employment, and relationships (Karlovits & McColl). Mumma (2000) states that adjustment to disability may require the individual to come to terms with their various losses, and that adapting will depend on the individual's ability to develop new patterns of living. Berg et al., (2003) stated that personal coping abilities, as an adaptation factor, may be more important in the later stages of recovery.

Karlovits & McColl (1999) define coping as a process in which a person manages stressful situations and emotions. A study conducted by Frank et al. (1990) compared coping strategies and perceived family functioning between patients with brain injuries and a control group; finding that information seeking was the most dominant coping strategy (cited in Karlovits & McColl). Other researchers (Willer et al.) identified increased involvement in family decisions, seeking support from others, and use of memory and organizational aids, as well as participating in activities outside the home as coping strategies employed by people with BI.

### Caregiver Stress

The process of community reintegration does not only affect the person with a brain injury. Much of the rehabilitation literature has identified the burden placed on family members (caregiver stress) as a key factor in determining physical as well as psychosocial reintegration of people with BI (Hauber & Testani-Dufour, 2000; Liss & Willer, 1990; Perlesz & O'Loughan, 1998). Caregivers and family dynamics have been described as a mechanism for assisting the reintegration process, and literature in this area also examines the effects that 'caring' may have on the caregiver. Research shows that "with the passage of time family members may develop a greater intolerance for the individual's limitations" (Liss & Willer, p. 312). Such increases in stress levels and feelings of burden for family members regardless of physical improvements that occur with time; implies that the physical 'symptoms' of a person with a BI are only one of the factors contributing to caregiver stress. Other factors that contribute to feelings of stress in caregivers include psychosocial aspects such as: lifestyle changes, feelings of loneliness and isolation, and depression (Liss & Willer; Perlesz & O'Loughan).

## Systems Theory

From a systems theory perspective, human interactions with one another in different environmental contexts and situations are viewed as distinct yet interconnected systems. Interactions between and among these systems are reciprocal, which makes for a complexity of functioning that exceeds what might be understood if viewing systems as a collection or sum of different parts (Johnston, 2004). Consistent with this interpretation of systems theory, Ackoff (1981) offered three elements that define the nature of systems:

- 1) Each participant group has an effect on the functioning of the whole;
- 2) Each participant group is affected by at least one other participant group in the system; and
- 3) All possible subgroups of participants also have the first two properties (p. 15-16).

Buckley (1967) also identified four general, but key principles of systems theory:

1. Tension is an ever present, normal and necessary aspect of any social system;
2. The nature and sources of variety (those aspects that fall outside the considered norm, and where they originate) in a social system are areas of foci.
3. Attention is paid to the selection and inclusion of participants at all levels of the system, and alternative participants in the system are identified.
4. The interpersonal characteristics of the system are considered to be the framework for larger structures; interactions of exchange, negotiation, and bargaining are the processes from which stable social relationships emerge.



In qualifying each of these principles, Ritzer (1992) noted that although the four principles generate a level of dynamism in the system, systemic dynamism, with accommodations and adjustments, the system remain stable over time (as cited in Ritzer).

Systems theory has become increasingly popular in social work, mental health research, and the behavioural sciences (Laszlo & Laszlo, 1997) as it is well suited to interdisciplinary applications. Systems theory is a good fit within the context of the present study as the process of rehabilitation, discharge planning, and consequently community reintegration activities are conducted and experienced by many health related disciplines and interested persons. Systems theory was used as a point of reference to guide the conceptualization of the study methods, as well as helping guide question development and data interpretation. The researcher was interested in the perspectives of groups that fit within the social systems of persons with BIs in the reintegration process. The researcher gathered information from the participants regarding Ackoff's (1981) principles in an effort to determine who was a participant in the system, what constitutes the "environment" for the social system, and the extent of the participant groups' interactions and relationships.

Under the properties defined by Ackoff (1981), if the participant groups were to constitute a "system", the three informant groups in this study would have an effect on the functioning of the whole group. Each group of participants would interact and fulfill their roles based on the actions of the other participants (e.g., the actions of the physician are affected by the adherence of the person with a BI to the prescribed treatment plan). Subgroups included the person with a BI and the physician, the person with a BI and the included service agencies, as well as the physician and the service agencies.

System theory suggests that the individual and the system are equal and cannot be studied out of context, and in the case of this research, the perspectives of people with BI, primary care physicians, and service agencies were collected and interpreted as being of equal value, contributing to a collective perspective of community reintegration.

This study examined the interactions between the three participant groups from the perspective of systems theory, focusing on the interactions between members of the system (persons with a BI, service agencies and family physicians) as well as paying attention to the effect that actions/activities or events from the environment have on the system holistically as well as at an individual participant level. Environment in systems theory has generally been referred to what is outside of the system and relegated to a secondary or residual role (Bailey, 1998). For this study, environment was determined to be all the other social service and health related programs, as well as members of participant groups that were not directly related to this study's participants' interactions.

## CHAPTER 3

### Research Methods

This chapter includes a description of the qualitative research paradigm and the study methodology. A detailed description of the study setting and participant groups is also included, containing recruitment procedures, inclusion criteria and participant specific descriptions. A detailed description of the research design, including data collection procedures and tools, as well as data analysis techniques is outlined in this chapter.

#### The Qualitative Research Paradigm

Qualitative research has a long established history in the social sciences. Initially used in disciplines such as anthropology (fieldwork) and American sociology this approach has expanded to social/behavioural sciences such as education, medicine, social work, nursing, and history (Denzin & Lincoln, 2000).

Qualitative research involves an interpretive, naturalistic approach to the world by investigating social situations, people and events in a natural setting, and attempting to bring meaning of these events through the researcher's interpretation (Denzin & Lincoln, 2000). Questions posed in a qualitative inquiry seek understanding about how social experience is created and given meaning by the participants. Qualitative researchers study a variety of materials: case studies, life histories, archival information, and observations. Generally there is a commitment to utilizing more than one interpretive activity in a study. Qualitative research is distinguished by unique characteristics (Table 3) that are inherent in its design.

Table 3

*Characteristics of Qualitative Research*

	Characteristic
1	Occurs in natural settings, where human behaviours and events occur.
2	Uses multiple interactive and humanistic methods.
3	Captures and gives voice to the participant's perspective of the event or occurrence.
4	Emergent – the research focus and data collection methods may change and develop as the researcher learns and refines the boundaries of the study.
5	Fundamentally interpretive and descriptive. The researcher interprets the data for themes, working toward a conclusion or broad interpretation of the event.
6	Researcher reflects on their role in the inquiry and is sensitive to the effect their perspective may have on the results.
7	Researcher adopts and uses one or more strategies of inquiry as a guide for the procedures.

*Note.* Adapted from Creswell (2003) and Rossman & Rallis (1998).

### Research Design

The present research, grounded in a qualitative approach was conducted in two distinct phases. The first included an integrated case study, linking the perspectives and experiences of three interrelated participants; a person with a BI, a representative of the community service agency that they receive services from, and their primary care physician. The second phase of the research consisted of a series of key informant interviews with representatives of the three participant groups.

The original study method was designed to be a cross case comparison between three integrated case studies (a triad) consisting of a person with a BI, their primary care physician, and the community agency from which they were receiving services/programs. Difficulties in recruiting complete triads resulted in a modification to the research design.

The original integrated case study design was amended to consist of one integrated case study and a series of six in-depth interviews with individuals from the identified participant groups.

### The Case Study Research Design

In the early part of the 20<sup>th</sup> Century, much of the literature regarding case study methodology came from the University of Chicago department of Sociology (Tellis, 1997). Social scientists, in particular, have made wide use of this qualitative research method to examine contemporary real life situations and provide the basis for the application of ideas and extension of methods. “A case study is both a process of inquiry about the case and the product of that inquiry; the ‘case’ is the focus of the investigation; the unit of analysis,” (Stake, 2000, p.436).

A case study is generally organized around a small number of thematic or issue based research questions (Stake, 2000). Case study design allows the researcher to explore in depth a program, an event, an activity, a process, or one or more individuals. The cases are bounded by time and activity and researchers collect detailed information using a variety of data collection procedures over a sustained period of time (Stake, 1995). Case studies are particularly valuable when the evaluation is intended to capture individual differences or unique variations from one program setting to another or from one experience to another. This study used a collective case study design, as well as a series of interviews to understand the phenomenon of community reintegration for persons with BI.

### In Depth Interviews as a Method of Qualitative Inquiry

Qualitative indepth interviews have been described as “a conversation with a purpose” (Kahn & Cannell, 1957, p. 149), and are considered an excellent way to obtain detailed information regarding an individual’s perspective on an event (as cited in Marshall & Rossman, 1999). An interview also allows the researcher to seek clarification from the participant. This depth of information, combined with researcher observations (although not always linked) helps the researcher “understand the meanings that people hold for their everyday activities” (Marshall & Rossman, p. 110).

Interviews as a method of data collection can have limitations as they are based on self-reports and personal interaction between researcher and participant. To offset these potential pitfalls, the interviewer must have excellent listening skills, be skilled in personal interaction, question framing, and gentle probing (Marshall & Rossmann, 1999). The participant’s willingness and comfort level sharing personal experiences may affect the depth of the information collected. Strategies to address these potential limitations include developing rapport between researcher and participant, and using techniques to ensure data trustworthiness, such as member checking and triangulation of data. It is important to note however, that all research that involves people’s perceptions, or people more generally, may have similar limitations.

Patton (1990) identifies three typical approaches to conducting interviews:

1. the informal conversation interview;
2. the general interview guide approach, and;
3. the standardized open interview.

These three approaches typically differ in the extent to which the questions are developed and standardized prior to data collection. This study used the general interview guide approach which involved identifying general topic area that would be explored during the course of the interview. As Patton indicates “an interview guide is prepared in order to make sure that basically the same information is obtained from a number of people” (p. 283); the interviewer is free to build conversation around the topics, and the guide acts more as a checklist, helping the researcher ensure that all of the necessary topics are discussed with the participant.

### Bounding the Study

#### *Setting*

This study occurred in Winnipeg, Manitoba; a Canadian urban setting with a population of approximately 650,000 people. The identified urban setting has several acute rehabilitation facilities, and community agencies that provide services to people with brain injuries.

#### *Participants*

The participants in this study were individuals with brain injuries, community agencies and primary care physicians that provide services to people with brain injuries. The researcher recruited (see participant recruitment approaches, p.43) an integrated case consisting of three participants: “Bill” a person with a BI, the community service agency Bill accessed services from, and the Bill’s family physician. The researcher also recruited and interviewed six additional individuals; two from each of the respective three participant groups. Please see Table 4 for a summary of participant characteristics.

Table 4  
*Summary of Participant Characteristics*

Participant Group	Characteristics
<u>Person with a BI</u>	
Bill	59 year old male, married, two children, with a history of two strokes within four years and currently accessing services from two community agencies
Lisa	50 year old female, married, two children, with a history of two brain aneurysms and accessing services from community based support programs.
Tom	60 year old male, married, with a history of multiple brain injuries dating back into his 30s and was currently accessing services from at least two community based service agencies.
<u>Physician</u>	
Dr. Brown	A primary care physician, currently in private practice. Had experience in a salaried environment; and has admitting privileges at a tertiary care facility.
Dr. Richards	A family physician practicing in a teaching environment.
Dr. Johnson	The new physician practicing in a teaching environment.
<u>Community Agency Representative</u>	
Patrick	A graduate of a social service degree program with experience working with people with various types of disabilities. Currently the executive director of a community agency that provides services to persons with brain injuries and their caregivers.
Kendra	An allied health practitioner that had worked in a variety of rehabilitation settings and had moved to manage a new initiative, developed in an attempt to unify and coordinate the post discharge service delivery for people with brain injuries.
Margaret	A long time professional associated with the community agency that provides support, education and resources to persons with brain injuries and their caregivers.

*Note. All participant names and identifiers were changed or removed to protect their identity. The names included represent the manner in which they referred to themselves and each other.*



Morse (1994) suggests that investigators use a minimum of six participants when trying to understand the essence of an experience. If new information continues to be discovered however, additional interviews should be conducted until theoretical saturation occurs – in other words, until no new information, or only minor variations emerge (Morse). For the purpose of this study “theoretical saturation” was reached when new information added only minor variations in the themes and patterns developed from the interviews.

Morse and Field (1995) state that in qualitative research the number of participants included in a study is necessarily small, and random sampling is not necessary. The researcher used purposeful–criterion based sampling, (Patton, 1990) selecting participants who are willing to talk, have established relationships of trust with the researcher, or who are in key positions and have a special knowledge of the phenomena. The intention of this study was to conduct a holistic comparison of perspectives regarding community reintegration; as such the individuals and groups that have experienced community reintegration and those that have expertise in facilitating this process were the preferred participants for this project. The participant groups included persons with a BI, health care consumer advocacy agencies and health care professionals were identified as being key players in the reintegration process and were included as such.

*People with brain injuries – inclusion criteria.* The individual with a BI is the user of community and health care services. Inclusion criteria: Individuals who had a non-traumatic (e.g., caused by tumours, strokes, aneurysms) BI, had received rehabilitation services and were accessing programs and services from a community based agency were

invited to participate. All study participants were required to be over the age of 18 years, and able to communicate fluently in English. Additionally, individuals not considered medically stable, or having behavioural issues that may inhibit their participation were excluded from the study group. In addition, any person deemed/assessed as “legally incompetent” was excluded.

*Community agencies – inclusion criteria.* Community agencies act as the voice of the public; those who lobby for change; and take a leadership role in the advancement of services and treatment of people with BI.

Agencies that are currently providing services to people with recently acquired and long term neurological impairments, have acted as a liaison with governing bodies, and have knowledge of policy development and/or practice guidelines regarding community reintegration for people with ABI were invited to participate in the study.

Agencies that were contacted regarding potential involvement in the study included: the Manitoba Brain Injury Association, the Stroke Recovery Association of Manitoba, the Occupational Rehabilitation Group of Canada, Heart and Stroke Association of Manitoba, the stroke rehabilitation units at various Winnipeg based health care facilities, the Society of Manitobans with Disabilities, the Winnipeg Regional Health Authority, and Age and Opportunity.

*Primary care physicians – inclusion criteria.* When people with BI leave an acute/active rehabilitation setting and return to the community, a family physician resumes the provision of primary health care. Primary care physicians were purposely selected for their provision of primary care services to the people with BI.

### *Participant Recruitment Approaches*

For the collective case study portion of the research, the researcher initially provided the recruitment materials for the person with a BI to the community service agencies after the agency had agreed to participate. The community organization provided the materials to potential participants, indicating that if they were interested in participating that they should contact the researcher directly. Upon receiving the completed participant information form (see Appendix A, p.129), the researcher contacted the identified primary care physician and invited them to participate.

Difficulties in obtaining a sufficient number of participants required the researcher to make amendments to the recruitment strategies. The modifications changed the initial point of contact with the person with a BI from the community agencies to an interested physician's clinic. The researcher contacted the Director of Research for the Department of Family Medicine, and the Medical Directors at the teaching clinics for the Department of Family Medicine at the University of Manitoba to obtain permission to approach the academic physicians regarding their potential involvement in the research. Upon receiving approval from the Department Head and Medical Directors, the researcher sent a letter of invitation to all family physicians via the Medical Directors. Upon receiving confirmation that the physicians were interested in participating, the researcher provided participant packages for people with BI.

For the individual key informant interviews, the researcher contacted purposefully selected participants from each participant groups. For the primary care physician, the researcher asked a thesis committee member to assist in the identification of potential physicians that may be interested in participating. To identify community service

agencies, the researcher contacted one community agency, explained the purpose of the research and asked for assistance in developing a list of potential community agencies to contact. From this list, the researcher contacted the executive director or program lead at each agency to explain the research and invite them to participate. To obtain participants with BI, the researcher explained the criteria to the representatives of community agencies, and asked them to contact potential participants, providing them with the researcher's contact information. Interested persons with a BI contacted the researcher directly to hear more about the study and schedule an interview if interested in participating.

#### Research Ethics

To protect study participants, the study adhered to the following ethical considerations. Please see Appendices for samples of materials provided to participants.

- 1) The research proposal and subsequent revisions were submitted for approval to the Education and Nursing Research Ethics Board (ENREB), at the University of Manitoba for approval prior to initiation of the project.
- 2) Among other documents, a cover letter was included in the recruitment materials. This letter explained why the research was being performed, outlined the research activities, and why participants were being asked to voluntarily participate. This letter also provided the name and telephone number of the researcher that they may contact regarding the questions or concerns.

- 3) Participants were provided with the name and telephone numbers of the researcher's academic advisor, as well as the ENREB contact information should they have any concerns about the research.
- 4) Participants were informed that the research was voluntary and required informed signed consent. Requirements, benefits and potential costs of the research project were outlined in a consent form, of which they signed two copies, returning one copy to the researcher.
- 5) Only the researcher and her academic advisor viewed individual participants' responses; participant identifiers (included real names) were removed for all resulting reports.
- 6) Participants deemed legally incompetent were not included in the study. This information was collected from the participant themselves, or from their family physician prior to starting study activities.

#### Data Collection

Mactavish et al. (2000) provided support for the study method of using an interview guide to collect data. An interview guide is designed prior to the intervention, and includes a series of questions that will be explored. This method lent structure to the interview while creating an environment that was relaxed and conversational, which is essential for establishing rapport. Topical questions and relevant probes were included in the interview guide; ensuring similar types of information was gathered from all participants. This interview technique also ensures that the interviews covered all the topic areas required, and allowed the interviewee sufficient time and freedom to respond (Morse & Field, 1995).

The researcher carefully developed the interview guide from the reviewed literature, with feedback from her graduate committee. Each question pertained to only one aspect of a topic and included prompts to elicit further information as necessary. In addition, a pilot test of the interview instrument allowed the researcher to analyze the quality of the interview questions, format and collected data. Revisions and additional questions were added, as necessary, to ensure that gaps did not occur in the questions.

The overall purpose of this study was to identify similarities and differences within the case and between informant groups on issues related to community reintegration.

Therefore, three main categories of questions were posed to the participants:

- 1) What does “successful reintegration” mean to you? What would the process of community reintegration optimally look like? Who would be involved in this process? What are the roles of these identified people/organizations?
- 2) What barriers or constraints do people with acquired brain injuries experience when reintegrating to a community setting?
- 3) Based on your experience, what are the key characteristics of community reintegration for people with acquired brain injuries? What domains of life are of primary concern for someone reintegrating to the community?

A fourth summary question that is specific to each participant was included at the conclusion of the interview. Please see Appendix A to C (p. 129 – 147) for copies of the individual interview guides used in the case study interviews.

*Data Collection for Phase I: Case Study*

Upon receiving approval from the Education and Nursing Research Ethics Board at the University of Manitoba, the researcher commenced recruitment of the service agency participant group. The researcher met with representatives of the identified service agencies and provided them with recruitment packages for distribution to appropriate (as per the provided exclusion and inclusion criteria) clients. These recruitment packages contained an introductory letter, and participant information form (Appendix A). This information form asked for the potential participant's name, address and telephone number. A yes or no question asked the participants if they currently had a family physician; if the participants stated "yes", space was provided for them to write the name of their physician and clinic. This form clearly stated that by allowing the researcher to contact their physician, they were not yet part of the study group, and no discussions with their physician about them would occur prior to their interview with the researcher.

The researcher received a participant information form from an individual with a BI that was interested in participating, and contacted the identified primary care physician (Dr. Brown). In this initial contact, the physician was told they were identified as Bill's family doctor, provided an overview of the study, as well as an outline the inclusion and exclusion criteria for both the physician and participant with a brain injury. After reviewing Bill's chart, the physician was asked to contact the researcher stating whether or not they were able to participate in the study. In an attempt to protect the individual with a brain injury's privacy, the physician was instructed to (if appropriate) to decline participation without stating their reason.

After the physician agreed to participate, the researcher contacted all the connected participants (Bill, Patrick and Dr. Brown) to schedule interviews and sign consent forms. More details about the consent form can be found in the Ethical Considerations section of this chapter and a copy can be found in Appendices A, B, and C (p.130 – 148).

The researcher conducted an in-depth individual interview with each of the three interconnected participants, starting with Bill, then interviewing Patrick and Dr. Brown. In an effort to ensure the comfort of the participant, while decreasing possible interruptions and unwanted distractions, the interview location was of each participant's choice. Settings included private offices, quiet public settings, and conference rooms located at the interviewer's workplace. All interviews were audio taped with the participant's permission.

#### *Data Collection for Phase II: Key Informant Interviews*

In response to difficulties in recruitment for additional integrated case studies, the researcher modified the research approach to include a second phase, consisting of a series of key informant interviews. These interviews were conducted with two individuals from each participant group for a total of six interviews.

The researcher conducted an in-depth individual interview with each participant that lasted between 40 and 70 minutes. These interviews also occurred in a location of each participant's choice. All interviews were audio taped with the participant's permission. Please see Appendices D through F (p. 149 – 160) for copies of the Key Informant Interview Guides.



## Data Analysis

This research project, using a qualitative method, contained two phases: an integrated case study, and a series of key informant interviews. The researcher used the same data analysis procedures for both phases, seeking understanding of the data and analyzing for key themes regarding the meanings attributed to the community reintegration process, and the key characteristics and barriers experienced. The primary difference between the analysis of the case study and key informant interviews existed in the development of a detailed description of one individual's (Bill) experience of community reintegration using the case study participants' own words prior to key theme analysis.

Data analysis was a descriptive and interpretive process consisting of 6 steps which are outlined in table 5. Each interview was analyzed separately, identifying possible key themes, and noting commonalities and discrepancies in participant responses across the interview data. This iterative process helped the researcher develop key themes which were compared and contrasted between the participant groups.

Table 5

*Data Analysis Process*

Step	Description of Analysis Activity
1.	Data were organized and prepared for analysis, which included developing the list of researcher preconceptions and assumptions, verbatim transcription of interviews, and typing the researcher's field notes. A table containing participant responses to the research questions, information from the researcher's field notes, and researcher preconceptions was generated.
2.	Generating the table in step 1 allowed identification of each respondent's perspective in relation to the questions posed and facilitated comparisons for identification of consistent and distinct views. This table was reviewed and the data evaluated using the field notes and preconceptions to determine if the data were in the appropriate column. The researcher also used this table to determine if additional interviews were required to reach "theoretical saturation".
3.	Each interview was analyzed separately, identifying potential themes by reading and re-reading the interview transcriptions; taking note of commonalities and discrepant information. This iterative process helped the research develop the key themes.
4.	The researcher further developed and refined the descriptions and themes identified from the case study and the key informant interview data by using the table generated in step one. The researcher determined connections between the themes, creating sub themes and noting relationships between themes. Verbatim narrative sections were identified and selected to support, exemplify or clarify the themes reported in the findings.
5.	The researcher compared and contrasted the key themes within participants of each study phase, and between participant groups. The researcher then compared the themes between the case study and key informant participants.
6.	This step involved relating the presented themes to existing literature and the theoretical framework. Additional questions and future research directions were identified.

## Accuracy and Trustworthiness

Accuracy and trustworthiness in qualitative research is important and comparable to the concepts of validity and generalizability in quantitative research. Although having different meanings, accuracy and trustworthiness aid researchers in ensuring that the themes developed by researchers are credible and reflective of participants' perspectives. Creswell (2003) indicates that qualitative researchers use reliability checks to determine if themes developed are accurate or credible, and consistent with the data from which

they are drawn. Validity is seen as strength of qualitative research, but it is more often used to refer to the accuracy of the findings from the perspective of the researcher, the participant, or the audience (Creswell, 2003) or how well the study findings represent “reality” (Morse & Field, 1995).

The researcher utilized the following strategies, as identified by Creswell (2003), to ensure the accuracy and trustworthiness of the findings:

1. *Triangulation of data sources* - Data were collected from different sources – health care consumers, advocacy agencies and primary care physicians regarding community reintegration. Multiple perspectives clarified meaning, verifying the consistency of the interpretation, and enabled the researcher to build a coherent justification for the emergent themes (Creswell, 2003; Stake, 2000).
2. *Selection of the Participants* – A purposefully selected sample (Morse & Field, 1995) was recruited in order to collect data from individuals with knowledge and expertise on community reintegration based on lived experiences.
3. *Member checking* - Taking transcribed materials back to participants to be checked for accuracy assisted the researcher in ensuring the data were accurate. Each participant was provided with an opportunity to provide input of this nature, although the majority of participants declined this opportunity.
4. *Present negative or discrepant information* - The researcher presented data that was not necessarily consistent with the key themes. It has been suggested

(Creswell, 2003) that providing and discussing information in this way adds to trustworthiness of the study results.

The researcher presented a thickly detailed description of setting and actors, providing details regarding the methods, data analysis techniques and results (audit trail). The audit trail provides context for the readers, allowing them to make connections to their own experiences, determining if the findings can be extrapolated to contexts, individuals and situations beyond those studied in the research.

The qualitative researcher acts as an interpretive element or tool, and needs to ensure that their preconceptions and assumptions are held in check. Some researchers (Creswell, 2003) suggest that openly acknowledging researcher assumptions and preconceptions and presenting them to readers, is imperative to an open and honest narrative. Other techniques for addressing preconceptions include consciously noting these assumptions and placing them aside, and framing the questions in a deliberately neutral format (Lincoln & Guba, 1985). In the presented study, the researcher developed a list of her preconceived ideas and assumptions regarding the research questions prior to any data collection (Appendix G). The field notes and memos were used to identify if these preconceptions and assumptions were evident during data collection and analysis. This was particularly important for the data analysis and interpretation phases, as it ensured that themes presented were in fact identified by participants rather than an extension of the researcher preconceived ideas. A review of the transcribed interviews was conducted by the researcher prior to data analysis as a final technique to ensure that the participant's expressions and intonations are included for analysis.

## CHAPTER 4

### Perspectives on the Community Reintegration Process

Although data collection and analysis techniques may be similar across different forms of qualitative research, the way data are reported is diverse (Lofland, 1974; as cited in Creswell, 2003). Narrative display is one of the most commonly utilized processes whereby the findings are presented using the participants' words to "tell their story". The findings of this study are presented in a naturalistic, descriptive format; displaying the study participants' diverse perspectives on community reintegration in their own words, creating a holistic representation of the experience.

The results of this study are presented in two sections: the first contains findings from the case study, and the second chronicles findings from the key informant interviews. The objectives of the research are used in both sections as the organizing framework.

- 1) To identify key characteristics of community reintegration for people with brain injuries;
- 2) To enhance understanding of what "successful" reintegration means from the perspectives of each of the informant groups; and,
- 3) To identify and understand the barriers (factors that constrain) experienced by people with brain injuries when reintegrating to a community setting.

#### *Integrated Case Study – Bill's Community Reintegration Experience*

This section of the results chapter includes a detailed account of Bill's community reintegration experience – the majority of the presented information was collected from Bill himself, in an attempt to "let him tell his own story". Information that contributes to

the contextual details of Bill's experience were added from the other participant interviews, the perspectives of Dr. Brown (primary care physician) and Patrick (community service representative) regarding Bill's experience however will be presented in a separate section.

“Bill,” a 59 year old male, married for 26 years to Donna, with two adult sons from a previous marriage. Bill had two strokes within the last four years; the first at home; which he described as a very sudden occurrence:

Well, see, it was a Friday. And I took my wife out for lunch and I came home. My wife had taken a day off and she was downstairs doing laundry. Around 3 o'clock in the afternoon I parked the car and I came downstairs and all of a sudden I fell over. And that was it. I did not experience anything, any problems whatsoever. I didn't experience any of the symptoms of a stroke.

At the time of his first stroke three years ago, Bill was admitted to a tertiary care facility. Upon discharge, Bill moved to an inpatient rehabilitation program, where he received approximately four months of intensive rehabilitation that included physiotherapy and occupational therapy to help him regain strength and function in his affected limbs. During his stay in the rehabilitation facility, Bill was aware of other programs available to persons with brain injuries, such as therapeutic recreation; but did not request involvement until after his discharge from the facility. His request was refused as the therapeutic recreation programs were not available on an outpatient basis. Bill expressed disappointment at not being able to access these services and programs.

As a condition of his discharge from the rehabilitation facility, Bill's physiatrist (a physician specializing in physical medicine and rehabilitation) required him to make

modifications to his home, including building a wheelchair ramp to the front entrance of his bungalow style house. “And she (referring to his psychiatrist) told me, she was not going to release me until I had a wheelchair ramp made. So I had to get my brother-in-law to make me a wheelchair ramp so I could get on home on weekends.” After a period of “weekend passes” from the rehabilitation unit to home, Bill was discharged and instructed to make an appointment with his primary care physician (Dr. Brown) for follow up care.

Dr. Brown was aware of Bill’s admittance to both the tertiary care facility and the rehabilitation hospital, which he indicated was not necessarily typical for physicians of persons with BI. He stated that notification of admittance is often based on a variety of factors, including admitting privileges at the hospital, staffing levels in tertiary care facilities, medical resident protocols and staff awareness (nursing and medical residents) of physicians.

At the Vic, yeah, if someone is admitted, and they know that I am their physician, then I am notified; if they are not, I don’t find out about it until after they are discharged. Occasionally I will be called by a resident, but generally it is because they have to get corollary information... someone will call me up for info but normally I don’t expect to be contacted by anybody to give me information.

When asked about the communication processes after a person with a BI is discharged from a rehabilitation program, Dr. Brown indicated:

If they are in the rehab I generally get an excellent and incredibly detailed, long summary of everything that went on – and they are generally appropriate, a lot has gone on – once you know how to read them, you can typically read through

them very quickly and get the information you want. So the rehab facilities are excellent in that way – if they are discharged directly from the hospital, or their injuries are such that they only require outpatient physio or outpatient OT or whatever, I don't get anything.

After his discharge from the rehabilitation hospital, Bill continued to access outpatient rehabilitation services (physiotherapy and occupational therapy) on a daily basis, which helped him regain his mobility and decreased his use of mobility aids such as a wheelchair and/or walker. Bill told the interviewer about the daily walks that helped him regain his strength and ability to walk. He talked about the recovery process as being a frustrating experience, but one he saw as a challenge that he met and beat – until a year ago, when he had a second stroke. He attributed his ability to return home to his attitude:

It was tough at first because I was in a wheelchair. And then I switched to the walker. And I had to go for walks every day. I went for walks every day. And I think the walking and my attitude was perfect. It was the thing that gave me a, gave me the, um, the will to get forward, go forward. And not stay stuck in a rut. Not stay there.

Interestingly, Bill didn't see his process from rehabilitation to home as "reintegrating" - he viewed it as a challenge in his life: "So I'm not sure what you mean by integration. I didn't see it integrating. I saw it as a challenge. That's what I saw it as. And I took over that challenge and I beat it."

Bill described his second stroke as a mild one, which affected his speech and ability to walk. As a result of his unsteady gait, he was using his cane again, and walking



very slowly. Bill was referred to a speech language pathologist, whom he saw on an outpatient basis, once a week. Bill indicated during his interview that he was very frustrated with, and self conscious about his speech impediment and was working hard to improve his speech and communication abilities; “I get so mad at myself, frustrated because I can’t speak perfectly. And I just get so mad at myself for that, you know, I got to, and when I get talking, I talk so fast that the words seem to run together”. Bill described his speech therapist as being very good, but that he was finding the process of “relearning” difficult. In his rehabilitation, Bill had a clear goal in sight:

I find I have to slow down a lot, you know. Like she says, you have to slow down a lot. And I say well I agree with you but how to do it? I’m in process now of stretching out my words. You know like I - bought - a - car (enunciating each syllable slowly), that kind of thing. And so I think with the practice, and that kind of attitude, you know, with that kind of therapy I should be able to, when it comes to July, I should be able to give a speech to my son. That’s what I’m aiming for.

One of Bill’s sons was getting married in the summer, which was a source of both excitement and trepidation for Bill. He expressed a significant amount of concern about whether or not he was going to take his wheelchair with him on the trip; saying that he worried about being on his feet for long periods of time, but could not express precisely why he did not want to take the wheelchair with him. When probed for additional information about this “quandary” – his words – Bill talked about the pressure being exerted by his family to convince him to take his wheelchair to the wedding. Everyone (Donna, his brothers, and his sons) thought he should take the wheelchair - he may get

tired and need it as an opportunity to rest, but Bill did not feel that he would need the chair. He was aware of his abilities and limitations, but did wonder if he should agree, in an effort to appease his wife.

Before his second stroke, Bill was employed as a manager of a credit collections agency; a position that required extensive verbal communication. As a result of his difficulties with physical functioning (mobility), and speech/language problems, he was unable to return to his career. He was receiving long term disability benefits which he stated cut his annual income by approximately 75%. This was extremely frustrating for Bill, as he was sure he was going to recover fully, regain his functional abilities and return to work, and the decrease in household income has had significant financial implications. He reported that Donna continued to be employed full time as they could not afford for her to not work.

When it was realized that Bill was not going to be able to return to his previous career, he was put in touch with a not-for-profit association that works with persons with disabilities to find employment opportunities. This community based program provides a wide range of services including: career exploration services, information about training initiatives, assistance in job search planning, resume preparation assistance and referral to potential employment opportunities. Through his involvement with this program, Bill gained part time employment in a community agency that provided support and assistance to people with brain injuries. This was his first exposure to this community agency and he began working with/for the association to develop and practice skills that he may require for future employment. In addition to the opportunity to gain post injury

work experience, Bill began to utilize some of the support services that the agency provided.

The executive director of the community agency, Patrick, indicated that there was a very long time lag between Bill's BI and his access to and utilization of the community agency and their support services. It is also important to note that Bill accessed the organization, programs, and services through his association with another community program. If Bill had not had the second stroke which resulted in the functional limitations that precipitated his involvement with the first community association, he would not have accessed the participating agency and the support programs he was utilizing. Patrick outlined the organizational philosophy of the community agency:

To provide support to the family and to the stroke survivor so that they can become a positive and constructive member of society again. That they can feel this within themselves -to become self-regulatory, valued. Because when the crisis like this happens, you're so devalued. You've lost your job. You're paralyzed on one side... Society perceives you, maybe alienates you in a way, you know, they perceive you as being disabled, different. Because when you're dependent on society or dependent on something else, somebody else for everything in your life, it really takes away from your feeling valued yourself. So if we can give that feeling of being valued back and guiding him to become self-sufficient again, that's what creates that self-esteem and, uh, I guess the reintegration process back into society.

Patrick also indicated during his interview that there were many programs in their agency that could have been useful for Bill early in his reintegration process whether it be physiotherapy, or group support programs.

In conversation about activities of daily living, Bill outlined several changes in his regular activities and responsibilities. Prior to the BI, Bill and Donna were very active in the community with many leisure pursuits - a bowling league, square dancing, as well as camping and other family oriented recreation activities. As result of his BI, they have had to renegotiate the recreation and leisure pursuits in which they engage. When asked to outline his typical day, Bill indicated:

I get up at 11 o'clock. Between 10 and 11. I do dishes. Read the paper til 1 o'clock. I just go for a walk between 1 o'clock and 2 o'clock. I haven't because it's been cold out, you know, and really cold and I haven't been able to keep the wind, the wind blows me off, blows me down. And then I make supper. And then I watch a little TV for an hour. Donna comes home. And that's it, that's my day. Well, we watch TV together. And then we usually spend about half an hour, 45 minutes talking about her work. You know, first thing we do is turn off the TV and she talks, tells about her work, her day. And I tell her about my day, you know. And all that kind of stuff. And, uh, and the TV comes on again and we usually watch TV again from 8 to 10 or actually 8 to 11.

Additionally, Bill and Donna have some regular weekly activities that include coffee dates with friends, and visiting Donna's mother. Bill has some standing medical appointments, massage and speech therapy sessions and a weekly day of work at the community agency office.

When asked about his participation in home responsibilities, Bill indicated that as a result of his mobility difficulties, Donna had to assume more of the household maintenance activities including housework, hauling firewood, and financial management. As a result of cognitive difficulties (particularly around decision making and reasoning) Bill was not been able to independently manage the household finances, as was one of his primary responsibilities previously. He talked about one particularly disastrous example - the “loss” of a significant amount of money (approximately \$30,000) when he miscalculated the penalties on a sale and trade in of a truck and RV. As a result of this miscalculation, Bill and Donna realized that he was not able to independently manage the household finances, and developed what Bill calls “a team effort” approach that consists of a check and recheck process by each of them regarding bill payments and budgeting. Bill was aware that this activity was a “chore” that Donna did not enjoy doing, but was required to assume as a result of his BI. Additionally, he indicated that his responsibility for the household accounting was a source of pride for him and the loss of ability frustrated and saddened him.

Looking forward, Bill said that Donna would have to work until she was 65, then they would collect their pensions and renegotiate what would happen after that. In the meantime, he thought that he would continue with what he was doing, and beyond that, “play it by ear”.

#### *Other Perspectives of Bill’s Community Reintegration Experience*

Patrick and Dr. Brown indicated that the process of community reintegration was extremely difficult and frustrating for Bill, with many obstacles to his recovery. The areas identified to be frustrating included: 1) regaining functional abilities, 2)

communication difficulties caused by speech problems, and 3) not being aware of how difficult the recovery/reintegration process would be. Each of the participants described the experience of Bill's reintegration from their perspective.

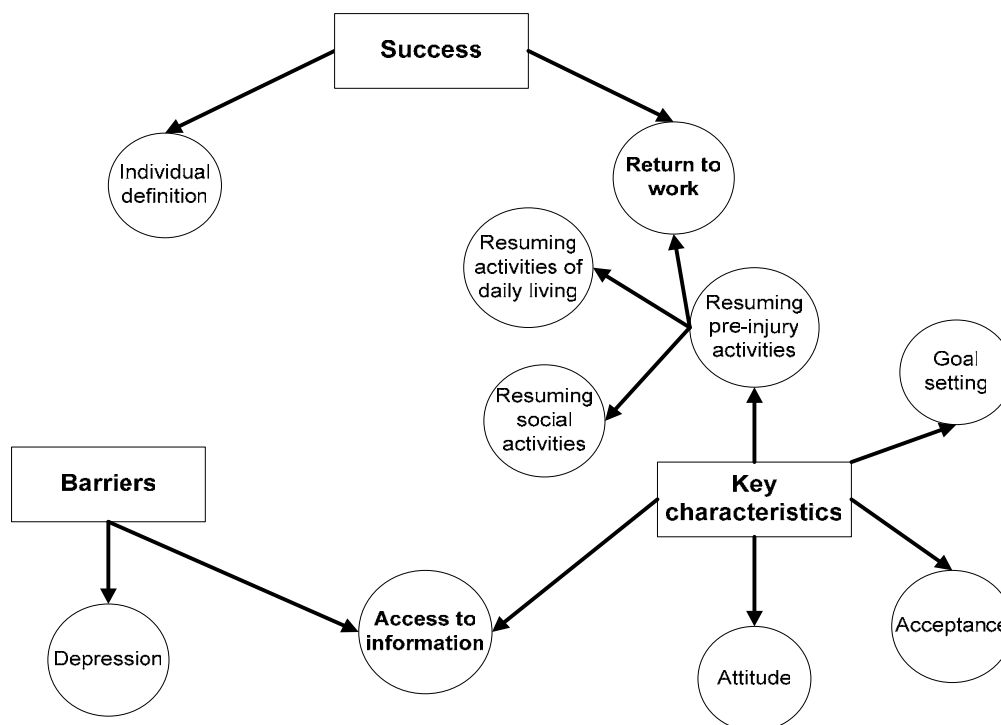
Dr. Brown's perspective focused on Bill's functional (mobility) recovery. He shared Bill's continuing health issues and functional abilities, but had limited knowledge and/or awareness of the social aspects of Bill's return home. He stated that Bill was aware of how much worse things could have been, and was generally happy with how well he had done. He also commented that Bill thought very highly of his rehab therapists and was grateful for the services he had received. Dr. Brown felt that the major sources of frustration for Bill surrounded his inability to go back to work, and his inability to "do the little things anymore, like take out the garbage, or stuff like that..."

Patrick (the executive director of the community agency) acknowledged that he had limited knowledge of Bill's brain injury, medical care, and rehabilitation process, however, Bill told him it was a very frustrating experience. He commented primarily on the lack of information and support Bill received during rehabilitation and discharge, with only Donna for emotional support. He also noted that it took Bill a long time (almost 3 years) to become aware of, and access his community agency.

Each participant in the integrated case study was asked specific questions pertaining to the stated objectives of the research. Please see Appendices A through C (p. 130 – 148) which contains the interview guides for each participant group. Presented in this chapter are the key themes developed from participant responses to the research questions. Figure 1 depicts the case study key themes for each research question and the relationships between these key themes. This figure demonstrates the research areas

(boxes): definitions of success, key characteristics of the process and barriers experienced as well as the subsequent themes (circles) for each research questions. Two connections are highlighted by the figure. The first connection is the relationship between success and return to work. Successful reintegration for Bill included an individually derived definition, and his return to work. Return to work (a sub theme of resuming pre-injury activities) was also noted to be a key characteristic of community reintegration for Bill. Thus, in the case study results, return to work is connected by arrows to the research questions, Success, and Key Characteristics. A second and similar connection existed between the research areas of Key Characteristics and Barriers. Access to information was a key characteristic of reintegration for Bill, but was also noted to be a barrier he experienced. An arrow, therefore, connects this theme to each of the research questions.

*Figure 1 Case Study Key Themes*



*What does “successful” reintegration to the community mean?*

Participants’ information contributed to the development of two sub-themes; a) success is individually derived, and b) return to work. Only Dr. Brown explicitly indicated the individual nature of trying to derive the meaning of “success” in the context of community reintegration, as he said, “I think the best judges of that are the patient and/or caregivers. I am there to provide services and provide the support I can, but I think that is pretty much up to the patient.” He did however; present his own perspectives on community reintegration by saying: “he has a very successful time from my standpoint, given his disabilities, his reintegration... in my opinion; he has had a very successful reintegration and thinks he has done well, and he is very grateful for the services and how well things are going.”

All of the case study participants agreed that return to previous employment would have indicated successful reintegration for Bill. As Dr. Brown said, “to him, a successful reintegration would be that he would be able to go back to work. That would be his definition of successful reintegration.”

*What are the key characteristics of community reintegration for people with BI?*

Five key characteristics were essential in the process of community reintegration: a) *acceptance*, b) *goal setting*, c) *attitude*, d) *resuming pre-injury activities*, and e) *access to information*.

*Acceptance.* People with BI need to recognize and accept that their lives are not going to go back to normal; there is a role for people and programs to help individuals and their families as they go through this transition process. A community support program can help people work through the stages of acceptance:



Everybody goes through stages; I guess the stages of reintegration or acceptance of your crisis or your, your injury or your stroke, whatever it was. You either, some accept it and have decided in their mind already at the stage that we see them that life's going to be different. And there's people that don't accept it. They're still in denial. And how we approach is the support groups, for example, help with that because you're with other people that are going through the same thing as you. And that's a wonderful resource 'cuz, you know, you talk about things like that. Denial, acceptance and all that type of thing. So stroke survivors are helping other stroke survivors who are new get through that process. So it all depends on where the person is at. Some people, like I said, accept and know that their life's going to be different and other people, other people don't, so they need more support that way. (Patrick)

Neither Bill nor Dr. Brown identified acceptance as a key characteristic of the community reintegration process; however, their numerous references to Bill's frustration and anger would suggest Bill had not accepted the functional limitations caused by his BIs, and his changed lifestyle. Bill recognized that his life was different as a result of his BI, but seemed reluctant to "accept" what that meant for him in the future. Bill, reflecting on his return home, primarily expressed frustration with his progress regaining functional skills and abilities. He did indicate that he felt he had received good rehabilitation services, but that he was striving for constant improvement.

*Goal setting.* Bill was the only participant that identified having goals as a key characteristic. He suggested that having a goal to focus on during the recovery process made it easier to continue working toward recovery. Bill talked about continually facing

challenges with a positive attitude, and keeping his personal goals in mind. Referring to his son's upcoming wedding he talked about his determination and its impact on his speech therapy: "And so I think with that, that kind of attitude, you know, and that kind of therapy I should be able to, when it comes to July, I should be able to give a speech to my son. That's what I'm aiming for."

*Attitude.* Bill and Patrick identified attitude as a key characteristic of successful reintegration. Bill stated:

It's attitude. That's all it is. Attitude. If you're very up, you know, if you have a positive attitude in other words, you can make it. But if you have a bad attitude, you know, a down attitude, no, you're not going to make it. There was a chap in my room, when I was admitted to Victoria 2 days after me. Had the same thing I did. Stroke. But he wasn't talking. He wasn't walking. And I kept, coaxing him, you know, to walk at least. And he did walk. But then he just fell back, you know, his attitude fell back and he never walked again after that. He went home and that was it.

Patrick also identified having the right mindset as essential to the community reintegration process, noting that Bill has "the mental attitude. He has that fight in him that some people have and some people don't... But if they do have that attitude, that enhances their capabilities I guess of reintegration. Having that mental toughness."

Bill also made several references to maintaining a positive attitude, saying that he continually worked at it and engaged in positive self talk to overcome the depression that resulted from all of the changes in his life:

I just tell myself I know this is going to be a good day. That's it. Like I said, the glass is always half full, you know. And of course, pills help too. I'm on Effexor, you know which relaxes, you know, that sort of thing. And, uh, well you see I don't know how I'm doing it. In some days I get really depressed and I cry a lot. Other days I can't wait to get out to walk to the store. And see the world, I mean see the sunshine. I have more of those than I do the depressed days.

Dr. Brown, when probed for additional information regarding emotional aspects of the community reintegration process, suggested that most of his patients with BIlleave the rehabilitation program with a positive attitude: "for the most part, when people come out of the program, they seem to have an incredibly good attitude toward things, sure there are disappointments about not being able to retain certain functions and so forth, but for the most part, I find people coming out of these programs really quite optimistic."

*Resuming Pre-Injury Activities.* All triad participants identified resuming pre-injury activities as essential to the reintegration process. Patrick identified several key elements about resuming activities for people with brain injuries in general; and Bill's experience in particular:

You may not be returning to your employment or your job. But just returning to feeling like you are a productive member of society. (Returning to previous life) is not a reality. And that's something that, that has to be, that's part of accepting having a brain injury or a stroke. You know, your life's going to be different. And that's just a reality of it. That was one of the biggest things that (Bill) had difficulty with. He told me today he couldn't do some, he couldn't do a lot of the same things he did before. And that was the hardest obstacle that he had to face.

*Resuming pre-injury activities* contained three sub-themes: i) *returning to work*, ii) *resuming activities of daily living*, and iii) *resuming social activities*.

*Returning to work.* Return to work was identified as being the most important aspect of community reintegration for Bill. All the case study participants recognized return to work as an essential characteristic for Bill and communicated it throughout the interviews.

*Resuming activities of daily living.* All of the triad members identified resuming activities of daily living as important in the process of community integration. These included independent mobility, self care, and household tasks such as cooking and cleaning. Included as well, were activities such as independent transportation (driving and use of public transportation), house and yard work. Bill repeatedly identified these activities as critical and seemed to measure his functional performance on these tasks or activities as an indicator of successful “recovery”. An additional component that should be noted in this sub-theme is Dr. Brown’s emphasis on the importance of functional improvements, “I think physical functioning is number one because making a person become independent and getting as much physical independence as possible, whether it be physical movement or physical ability to speak, that is going to help more than anything else.”

*Resuming social activities.* Bill indicated that prior to his brain injuries, he and Donna were very active in the community with a wide range of recreation and leisure pursuits that they both enjoyed. Bill reported a cessation of these activities, with an increased amount of time spent at home or in low physical exertion activities such as coffee dates with friends or family as a result of his physical and communication

impairments. This was contrary to the perceptions of Dr. Brown, who noted that people generally return to “status quo” after their brain injury. Dr. Brown did note, however, that people with BI and Bill in particular, may not resume all of activities they were previously engaged in, but assumed that people will independently “find a way around that,” and did not spend any primary care visit time on these types of topics or issues:

Most people, if they were well functioning socially when they went in, they continue to be well functioning with their network of friends tends to rally around them and they continue to do well. If they were not particularly well functioning socially, they continue to not function very well socially... everything seems to be status quo – where everything started is where they end up. Different activities again, this goes back to the physical independence, certainly people may miss out on particular activities, like curling or camaraderie that comes from around that, but again if they have a good social network, and if they are socially very functional to begin with, they seem to find a way around that... um... if they weren't before, then they continue to be poorly functioning socially. Um... that hasn't, that typically hasn't come up.

*Access to Information.* Bill did not fully understand what leaving the rehabilitation unit and returning home after his BI would be like; he would have adjusted more easily if he had more information:

I wish I had known how difficult it would have been. Like, I can't do these things. Can't do it. It's a lifestyle change. If I had known that I could have adjusted a lot easier. I think I thought that everything would go back to normal.

Patrick noted that having information about community reintegration was essential, and that Bill was not provided with sufficient information prior to his discharge from hospital. Patrick also stated that the information should address the process of community reintegration, as well as supports and resources available. Without accessing all the available resources, “your chances of reintegration are less likely than if you had exhausted all the possible resources. If you are able to access all the resources necessary, the chances are very high, highly likely that they’ll reintegrate.”

Dr. Brown suggested that while access and use of resources that maximize independence is important, this must be balanced with promoting independence and limiting potential reliance on services: “maintaining as much independence as possible, and limiting the need for services as much as possible, maximizing his function while at the same time providing services that allow him to be as independent as possible.”

*What are the barriers (factors that constrain) experienced by people with BI when reintegrating the community?*

The barriers a) *lack of information*, and b) *depression* also reflect many of the key characteristics of community reintegration for Bill;

*Lack of information* related to two aspects of Bill’s experience. First, he indicated that he would have liked to receive more information from rehabilitation practitioners regarding translating the learnings from rehabilitation to home and community; and second, he would have liked more information about the available programs and resources available in the community. Bill said, “I wish I had known how difficult it would have been. Like, I can’t do these things. Can’t do it. It’s a lifestyle

change. If I had known that I could have adjusted a lot easier. I think I thought that everything would go back to normal.”

Bill did not receive formal community reintegration programming while in hospital. Participating in this type of program may have addressed Bill’s difficulty translating learnings from the rehabilitation facility to home. He provided an example:

I couldn’t go downstairs. That was main focal point for us, you know. We were always downstairs, but I couldn’t go down. It took months to go down there. I looked at those stairs and I said ‘I can do this- Oh no, no, no, maybe not.’ But, you know, the stairs at rehab, I could do those...

Patrick also identified *lack of information* as a barrier for Bill, specifically focusing on the lack of information regarding services available post hospital discharge:

He didn’t have the proper knowledge when he left the hospital. So if you can imagine that a crisis is happening to you. You’re in the hospital for 3 months. And then you’re discharged and there’s nothing basically. He would have liked to have been provided the information at the time he was discharged. More information more service information, maybe more referrals to external community.

There was also a long delay in Bill’s access to Patrick’s association; he only became aware of the community agency when he was referred by another community program for support and part time employment. Patrick talked at length about the “hit or miss” nature of people in rehabilitation hospitals receiving information about the community agencies, and the work needed to overcome this problem:

Sometimes it's just word of mouth. Some people know us and other people don't. I am not sure if it's the social worker or a nurse, but somebody knows us or doesn't know us... It's either hit or miss. Other people don't know that we exist. They either do or they don't. Basically it depends on what hospital or organization... But I know that there needs to be more education there, more of a direct process I guess of referrals. So that's going to take work on our part and work on the other end to, to kind of come together.

This barrier appears to be partly a result of the lack of a formal community reintegration program at the rehabilitation facility. Additional information provided by other members of the community agency (not direct participants) suggested that providing information to people with BI at discharge from hospital is insufficient – people leave the hospital thinking that they are going to recover fully, and it is only when they realize this is not possible, or caregiver stress precipitates it, that people with BI access community supports.

Dr. Brown recognized that knowledge of and access to community support programs was important in the community reintegration process, but indicated that he did not spend any clinical visit time discussing this with Bill. He assumed that Bill possessed all the information he needed regarding available supports, resources and community programs: “I don't think I have actually done that with Bill. He has spent a lot of time accessing resources and getting info from his rehab people, and so he is quite well informed, and has made a good use of resources.” There seemed to be a disconnect regarding the importance of having information about community based programs and



resources with the question of who is responsible for disseminating this information to the person with a BI.

Both Bill and Patrick identified *depression* as a barrier. Bill related the he was experiencing high levels of stress; as a result, he had difficulties sleeping and was taking anti-depressants. Corollary information collected from Dr. Brown suggested that he was aware of Bill's depressive state. During interpretation of the data, questions unanswered by participants arose: was depression a barrier that in some way precluded Bill's community reintegration process, or rather, was it an indicator that Bill was not "successfully" reintegrated?

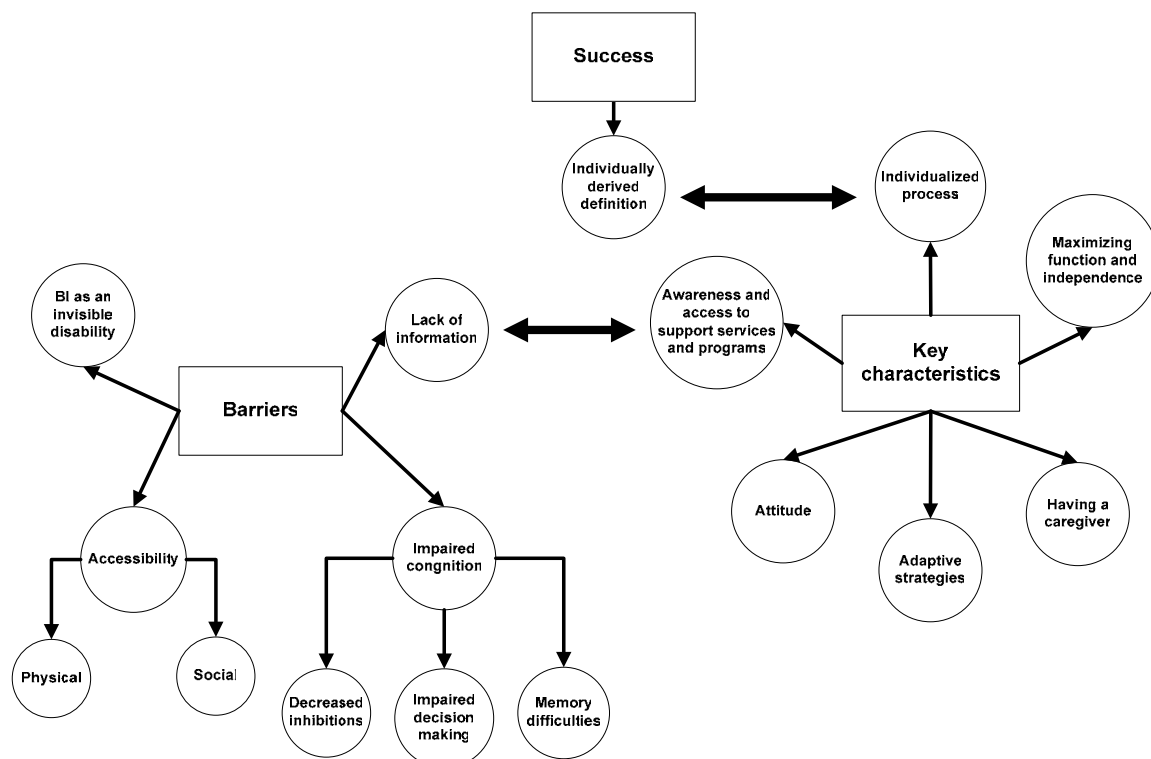
The data from the case study interviews provided a comprehensive perspective on Bill's community reintegration process. There were, however, limitation to this information as both Patrick and Dr. Brown lacked full knowledge of all aspects of Bill's reintegration experience. Dr. Brown had little, to no knowledge regarding Bill's social and emotional needs, and Patrick was only able to speak to the emotional aspects of Bill's reintegration, as he had no information regarding Bill's health status, and social challenges.

### *Key Informant Interviews*

The second phase of this study included a series of key informant interviews. These interviews were designed to collect additional participants' perspectives on the research objectives of interest. The researcher asked each key informant (i.e., 2 individuals with BI, 2 community service agency workers, and 2 physicians) questions specifically pertaining to the stated objectives of the research. Please see Appendices D through F (p. 149 – 160) which contains the interview guides for each participant group.

The next section of the chapter discusses the themes developed from the participant responses to these research questions and their interrelation. Figure 2 is a visual representation of the relationships between the themes and sub themes (circles) developed for the research questions (boxes) – definitions of success, key characteristics and barriers. Two particularly interesting connections are highlighted in the figure. The first connection exists between the themes under Success and Key Characteristics. Successful reintegration was determined to have an individually derived definition, which the researcher determined to be parallel to the theme individualized process as a key characteristic. This relationship is therefore demonstrated by an arrow connecting these two themes and research areas. A second connection existed between the themes *awareness and access to services* and *lack of information*. Awareness and access to support services and programs, a theme under Key Characteristics, was noted to have similar aspects as the perceived Barrier, lack of information. This connection is also denoted by an arrow connecting these themes. Information pertaining to these connections and further detail regarding all the themes are subsequently presented.

Figure 2. Key Informant Interviews Key Themes



*What does “successful” reintegration to the community mean?*

Participant responses focused on the concept of an individually derived definition of “success”:

I think that’s really a question that only the client can answer for themselves. And I don’t think it’s a black and white answer. I think there’s different degrees of community reintegration or re-engagement as it would be from our perspective but also from the client’s perspective...and have we helped make any gains in terms of their level of satisfaction over the course of intervention and involvement?

Further, Margaret stated that the meaning of community reintegration was individually determined and that individual characteristics also contribute to a person being successful”:

Success rates is an independent thing as well. Just like a brain injury is. It depends on where your brain injury is, where the defects are. It also depends on your support systems. I truly believe that if you had two people with the exact same injury in the hospital. Number one they're not going to feel the same way right off the bat because of their own personal genetics. But also, their state of mind. If you've got one person with the exact same brain injury who is totally supported by family, friends and everybody cares about them, you got another guy in the bed next to him with no family, no friend, no support system. Who do you think is going to make it. So that's, that would be my answer. I think that it would be, um, it varies on individual circumstances and whether or not there are supports there for that person.

Tom also stated that “success” was individually defined:

An outsider may think that I've successfully reoriented. I'm given a full time job and a marriage. All I know is the struggles that I have every day in time to try to keep a positive attitude. Like I do occasionally mentally wander and, makes you wondering what, think about why, why might have been, why... now ideally each person can only give their own understanding. Can only express their own success... it's hard to come up with anything that you would define what success is. I guess, success would be personal, personal appreciation of self worth would be a success.

According to Lisa, people could be “successfully” reintegrated, but it is a gradual process:

I’m going to be honest and I’m going to say I think you can be successful. But don’t think it’s going to happen in a three-week study period. I’m many years into this injury and things are still changing. The way you look at yourself is so important. It just, you know, you can’t put a day on it. You don’t know when it’s gonna end but I think if your experience is such that you can see it changing or that you’ve got people supporting you through it, then you can get through it.

When the physicians were asked about the meaning of “successful reintegration” Dr. Richards responded “I think you can determine if someone is “adequately reintegrated”, noting that access to the required resources may be indicators of success.

Dr. Johnson suggested that, given the nature of their interactions with the person with a BI (physical health care focused), an absence of issues may be an indicator of successful reintegration from a physician’s perspective “but I think you do because hopefully one would be able to identify when a patient is not successfully integrated in the community because you need more services. And the fact that they would come in repeatedly...”

This is a particularly interesting concept, as it points to the philosophy that medically stable and physically healthy people with brain injuries have been “successfully reintegrated,” and that an absence of “illness,” indicates “wellness.”

What are the key characteristics of community reintegration for people with BI? The analysis yielded six themes that capture key characteristics; a) *individualized process*, b) *maximizing function and independence*, c) *attitude*, d) *awareness and access to support*

*services and programs* and e) *adaptive strategies*, and f) *importance of having a caregiver* that are considered to be key elements of the community reintegration process.

*Individualized process.* Representatives from the community agencies stated that community reintegration is an *individualized process*, in which the nature of the process, and the meaning and outcomes derived from it are individually determined or defined. Kendra, in an overview of what community reintegration meant from her agency's perspective, said; "It's a gradual process of resuming activity that he or she was involved with prior to their illness or disability. I think it's a process of providing support for an individual to return and participate in those chosen life activities. Re-establishing community relationships, and re-establishing community activities."

Margaret, a representative of a community agency offered the following as a response to the question, "what areas of life are most important in the community reintegration process?"

From my perspective, I think what the most important areas are comes back to what's most important for the client. And as much as possible, we want to be client-centered and find out from the client what is most important. My take on their situation may be very different and it's not appropriate necessarily to determine that for the client. So I think we want to be client-centered and start off with finding out from the client, and most certainly getting their history, finding out what their limitations are, what their strengths are. What is most important for you to achieve right now? What are your goals? If we can help the client identify their goals, we'll know what's most important.

*Maximizing function and independence.* Two participants identified *maximizing function and independence* as a key characteristic of community reintegration. Kendra and Dr. Johnson indicated that the focus of their interactions with patients is on resuming function or improving skills. Kendra indicated that this was one of the founding principles of the agency she worked with:

It came about through the home care program itself, um, recognizing that clients don't always improve in level of function following hospital discharge. They may actually decline or they may plateau. Is there an opportunity to help them become a little bit more independent, more functional, rather than putting in as much or the extent of home care services that we do that will just provide assistance to the clients. Is there an opportunity here to improve their level of function so that we don't need to put in as much home care?

Dr. Johnson said that physical health and functional performance were of primary importance in the care of persons with BI, regardless of the patient's priorities:

From the physician point of view, the first things that I would be asking would be, you know, are you having any headaches? Watching for any visual changes, you know, kind of reviewing medical, doing physical assessment and making sure that I've covered everything in terms of their physical health care. I'd probably; I would probably do that before I addressed some of those issues that, that might be probably more important for the patient. But from my point of view, if something's going on physically with them - that could be very serious. And so, although it may not be the most important issue for the patient, I think that it's my job just to make sure that I cover the physical, you know.

*Attitude.* Tom and Lisa, the two interviewees with BI, identified a set of attitudinal traits that they viewed as essential in the process of community reintegration: having a positive attitude, having a sense of humour, acceptance, and putting/keeping the BI in perspective. Both participants indicated that having and keeping a positive attitude was important to them, but something that they struggled with everyday. As Tom said, “all I know is the struggles that I have every day in time to try to keep a positive attitude”.

Lisa also identified the need for a sense of humour in the experience of having a brain injury. In discussing adaptive/compensatory strategies, Lisa talked about the humour in hiding and retrieving gifts in a “safe place”:

For people who do routines, it might take you one time, two times, maybe three times to learn the routine. With a brain injury, 10, 15, 25 times’ til it sticks, you know. That’s what I do. And when times of the year are a little bit less stressful, it’s a little easier. I think because your mind isn’t working as hard. Like at Christmas, I’m a nut case. I make a list. I start shopping. I put things away in a safe place so I know where the list is. Now I go to go shopping again, I can’t remember where the safe place is -like you better have a note for a note, you know. Put it in a safe place. OK. But where’s my safe place? I don’t know. I can’t. So I try not to get all excited. I will go through the cupboard when nobody’s around, pull all the gifts out, make a list, OK, that’s for so and so, that’s, OK, that could be for so and you get through it...

If you don’t learn to laugh about it...A fellow in our association, said one time. He said, you know, having a brain injury isn’t all that bad. He said, you



know, you're some of the few people that you're ever going to know that could have fun hiding our own Easter eggs...And he's right. I would hide my kids Easter eggs. I had to make a list. OK, one here, one there. OK. And then when the kids would run around trying to find their stuff, I'd have my little list. OK, there's something else. Otherwise, it could be there for 6 months until I pulled it out and I wouldn't know where it was.

Both participants with BI identified acceptance (self-acceptance and being accepted by their spouse) as a key element in the community reintegration process:

When somebody says, it isn't your fault. What does that mean? Well this is what it means. It means that you're doing the best you can. And it means that you're coping. And you know what? When you get mad cuz everybody gets mad and everybody gets frustrated. It's not just you with your brain injury or. Brain injury is a, it's an explanation. It's a, it's the reason why, but it's not something to be ashamed of or to hide from or to be. It's the way I am...And he (husband), learnt to accept it. And that was even after people saying to him, I don't know how you put up with her. I couldn't do that. You know, like I would have walked away a long time ago. What do you do that for?

Tom and Lisa identified the need to put or keep the BI in perspective. For Tom, it was the realization:

The people with the brain injuries you can tell that they're, they've had some damage somewhere and somehow. That there's been an impact on their life. But they've got more life than the <name> Association, uh, members are in a way

worse shape. And because I'm dealing with both those things on my own. Here I'm thinking brain injury is the worse thing in your life. No way man.

For Lisa, recognizing that there were some positive aspect to her BI helped her put it into perspective, "I accepted that my life was never going to be the same again. In some ways it's better. I feel like I have more empathy, more. I can understand people's frustrations. But I can see it, you know, more than I ever could before. It's just because I've been there."

It is important to note that although depression was not identified directly as a key characteristic or barrier, both Tom and Lisa mentioned that depression was an aspect of their lives after their BIs.

*Information.* The need for *information* was identified by all participants as being an essential aspect of the community reintegration process. Tom and Lisa suggested that having more information would have allowed them to prepare and adjust before the experience. Lisa had a positive experience that she felt showed how important this was:

First of all, one of the nurses, when I had the bleed in January and I'm hospital and they're going to let me go home.... She said to me, when you go home and take some time. She says, go and get yourself a wig. Because when you come back for the surgery, they're going to shave all your hair off. So when you leave here, you won't have hair. Get yourself a wig. You've got time, you know. So I did. I found a wig that was my hair color, so it was exactly the shape of the cut I had. And I was so happy because when I left that hospital, I still felt like a woman. Because somebody took the time.

At the time of Lisa's first BI, the community agency that she now accessed was not in existence; therefore she did not have access to the resources she feels are necessary. Tom confirmed the need for information, and resources in general, and the community agency he accesses, "It'd be important to be able to lower our own barriers to try and reach out and see if there was something out there that could help us. So being able to ask for, to see if there are organizations or associations..."

Lisa identified an additional element to the need for information; suggesting that information about BI is needed for the community at large to increase the acceptance level, "both your family and people around you learn and some strangers don't. But that's OK. They can be educated, you know, to learn about what it can be like to live like that".

Kendra and Margaret responded that people with BI need more information about all of the resources and programs may be available to them, not only in their own agency, but in the community in general. Margaret indicated that she spent a large amount of time working with her clients in this area:

A lot of times what happens is when people are released from hospital, there are no more services and that's why they end up coming to <name of association> because we're able to provide them with some resources. And we try and support them in finding other community resources that they can afford that are either free or minimal charge so they can continue whether a social worker or if it's a one-on-one peer support that they're looking for because they don't have that family. That kind of thing. So that's where we spend a lot of our time is just trying to determine which would be a really good fit for them because of the programs we run.

Kendra's program was aware of the need of people with BI to have information about and access to other community programs, and that their program relies on a case coordinator to provide that type of information to their clients:

We would be aware in a sense that, um, that may have been recommended to the client while they're in hospital. It may be recommended by the case coordinator herself while client is receiving services in the community or it may have been recommended by the therapists who are seeing the clients in the community. And we do have that information kind of communicated to the different groups. So, yes, I think, you know, not to say that in all situations will we know of every service or agency that the client is receiving, but that would be our hope. And That as much as possible we can be advocates for the client. And there's a recognition that perhaps they need more support, peer support, education, somewhere to transition to once the rehab phase is through, that we can make those recommendations, give them the contacts and so forth.

Drs. Richards and Johnson also agreed that information for their patients was important in the process of community reintegration; but they noted that physicians also require information regarding their patients' involvement and progress. Dr. Richards indicated that having all the information regarding the patient's experience would make it easier to identify resources and services for referral: "I would want to know what kind of deficits they have, both cognitively and physically would probably be the most important thing because I think you need to guide resources based on that..." Primary care physicians may receive a discharge summary from the rehabilitation program and would often rely on their patients for additional information regarding the social aspects of their

lives. Dr. Richards also stated that primary care physicians on the whole would typically refer their patients to others for information regarding community resources, “Well I don’t think any of us know a lot about community resources. I mean we know a little bit but, uh, I think we depend very heavily on social workers that we know. And so we know where to direct them such that those issues could be addressed.”

Dr. Johnson recognized the importance of having information about the patients’ experiences, and indicated that “I think it’s important that we had a sense of their social contact in their lives for patients, you know, beyond just their medical issues. Because I don’t think. I don’t think you can really separate them as well.”

*Adaptive strategies.* *Adaptive strategies* were identified by people with BI and community agency participant groups as being particularly important in the process of community reintegration and for resuming regular activities. Each participant with BI identified different strategies, but the commonality was the need for the adaptive/compensatory strategies to be individually derived based on their deficits. Lisa said that she and her husband had to work together, with no outside information or resources, to develop the adaptive and compensatory strategies that allowed her to function independently at home. One such strategy included a household schedule that outlined the housework to be done on each day of the week, which compensated for her inability to remember what tasks she had completed:

When I did my household chores on the weekend, I’d make a list for the heck of it and I’d just cross it off. OK I did the vacuuming, because I loved the feeling of the accomplishment. Like that’s dumb - but that’s the way I did things. When I had the brain injuries, I did that because I had to survive. I couldn’t. When

[husband name] told me, OK, if you're getting it organized, you're getting the housework stuff done, he says, write it down. And we'll make you a schedule, you know, write it all down. So I made my schedule, I did all this stuff. Now I get up in the morning, OK, what day is it? I couldn't figure out what day it was. I had to get a newspaper. I'd look - OK, it's Monday.

Lisa also talked about the adaptive strategies that she has developed with her physician:

If I go to his office and he tells me, OK, [Lisa], this is what's wrong with you, what you have to do, whatever, or I'm going to make an appointment for you. He will come out to the front desk with me and he will say to his receptionist. I want you to make an appointment for [Lisa] for this. I want you to do this. And so she gives the card. Otherwise, I walk out to the front and especially if I get nervous, it's like, whoa, and it's gone. It just, there is a little click in my head and it's gone. And I don't remember that stuff. So he makes sure. And she gives me all the forms and everything. Like I really, really appreciate those couple extra minutes that he takes to do that because then I know where I'm going.

The community agency group participants also work with their clients regarding adaptive or compensatory strategies. Kendra identified that her agency's perspective is one of working with the client to develop adaptive strategies, but focusing on empowering the person with BI to problem solve and develop strategies for themselves:

As much as possible initially, we're helping the person regain as much function, as much movement, etc. as possible so they can re-engage in those desired life activities. And if that's not possible, then certainly how can they compensate for their level of disability, their impairment and resume some of those activities

perhaps in a modified manner. One-handed golf, um, using a mobility aid. Having to use Handi-Transit as opposed to driving themselves. Things like that. So figuring out how they can resume activities again. I think a big responsibility we have too with community reintegration is empowering that client and helping them problem solve. So we're not just telling them how they can re-engage back into community activities but working alongside with them and trying to empower them to figure out how can they re-engage back into the community. Because we aren't here for a long time they need to be able to move on from what we can provide to then figuring out all the remaining many other problems that they're going to be faced with so...empowering the client, empowering the caregiver.

*Having an informal caregiver.* Having a caregiver was a key element in community reintegration. Lisa indicated that having a spouse that was involved in the health field as an allied health professional was an advantage for her: "I had a husband who had worked in the medical field so he had that advantage and he could make some contacts, ask some questions you know... Because I had a husband that was involved in all that stuff, that's what made the difference", and "it took a husband with a lot of guts and who was willing to stand by me and not walk away from me. And not get frustrated with me...".

Both participants with BI indicated that changes in lifestyle were not only felt by the person with a BI, but rather has a ripple effect, reaching their spouses, friends, and children. Both Tom and Lisa talked about the strain that their limitations placed on their families, and in Tom's situation, led to a divorce. Lisa related: "don't think for a minute

that he hasn't had more than one time when he hasn't said to himself, 'I'm outta here. I can't do this any more - Lisa you're driving me nuts'. I don't know many times he said, 'I don't want this any more. I can't - you know, you're driving me nuts.'"

The community reintegration process can have a profound impact on caregivers. Margaret outlined a scenario that demonstrated this impact:

When people with brain injury end up in the hospital, when the doctors feel that they're fine, they basically let them go and then maybe have some outpatient relations with them to continue with some rehab or some counseling. But as far as taking the time to train the family members if this person's going home with their spouse or their other family members, the family needs to be shown more hands-on what to do, what to expect, and maybe even begin the trial period in, when they're in the hospital still to provide that service for their loved ones so they know exactly what to expect when they get home. Too many times, people have been sent home with family and three months later, the family member's so distraught, so stressed out, they're begging for respite services. They're having trouble getting them because respite is so few and far between. And they end up getting sick themselves. Unable to care for this person any more. And begging the hospital to please take'em back.

In Kendra's program, it was recognized that "limited family support is a big one in terms of what we can expect or what the client may be able to achieve;" but also said of their outpatient – home based rehabilitation program: "I think it's a good opportunity to work with the caregivers as well. So hopefully perhaps decrease the burden on the caregiver if we can help that client readjust to life after stroke."



One physician (Dr. Richards) indicated that he would typically be interested in knowing how the family of the person with a BI is coping, and related it to being able to guide resources and services to the person with BI and their family:

Is their family struggling because of the health issues or the deficit issues? And, and even though they're getting along, do they know that respite is available, you know. Well they may not, you know. And so, yea, they may be hanging in there in the community and be accessing adequate care but probably not all the resources that they could that would, you know, benefit them further, more so than what they have in place at the time.

*What are the barriers (factors that constrain) experienced by people with BI when reintegrating the community?*

From the analysis of the key informant interviews, barriers were noted in five key theme areas: a) *impaired cognitive abilities*, b) *accessibility*, c) *lack of information*, d) *BI is an invisible disability*.

*Impaired cognition.* *Impaired cognition* was identified as a barrier for people with BI; including memory difficulties, impaired decision making, and decreased inhibitions. Participants with BI reported difficulties with the memory, ranging from a need to use adaptive strategies to having no short term memory. Tom discussed his impaired decision-making and the impact that it had on his life: "I would sometimes make a decision and then find that shortly after this that either I hadn't thought about all the factors that I could have to make the proper decision or I'd missed, miscounted." As a result of his impaired decision making abilities, Tom invested in a bad business venture, losing his savings.

At that point, I also had dreams of being a businessman, when you've had a brain injury, your dreams are all over the place. I took a small business development course and tried to open a street food vending machine for the Expo in Vancouver. It turned out to be a disaster. I picked a bad location, and I don't know if it was compounded by a bad product but it's primarily a bad location because there was no, no foot traffic. I barely sold anything after a couple of weeks and a real waste of money. Then, then I declared bankruptcy because I'd wasted all my money taking the course and doing that.

Lisa reflected on the impact her memory impairments had on her ability to resume her regular activities:

I could start doing the laundry say. I'd go upstairs. Get the laundry. Bring it downstairs. Sort it. Put something in the washing machine. And then come back or continue on with my day. Two days or three days later my husband says, where is all our clothes? I don't know. They're downstairs. Stuff is just sitting in the washing machine wet - the other stuff still sitting on the... In those minutes that I would leave, it was gone. I only lived for the moment.

Lisa also identified *decreased inhibitions* as a problem she experienced as a result of her BIs, and the negative responses she would receive:

Apparently I would say things that were just off the wall. Because it's what I was thinking for that minute, there's no inhibition. You just said it... And the other person that's receiving this stuff is looking at you like, who are you? Why are you saying that to me? You know, when you got the brain injury you don't even know that you're thinking like that. You don't realize it.

Many of Margaret's clients had difficulties due to memory impairments:

I have members that get kicked out of their apartment because they don't remember to pay their rent, they're always late. And because they look perfectly normal from the outside, the company doesn't understand that they have a brain injury and that short term memory loss is a huge problem for him or her. And, so, you know, three strikes you're out. And sure enough we've got people who, who move around three, four times a year because they can't maintain a place.

People forget to eat sometimes depending on their brain injury. We have members who've lost, like I have one in particular that's lost over a hundred pounds because the brain does not tell her to eat. So she basically starved. Oh yea. And then you have other people who overweight. Or they eat the wrong foods.

Neither primary care physicians talked about altered cognition and the potential effects on people with BI.

*Accessibility.* The researcher identified two sub-themes to the key theme of *accessibility*, a) physical accessibility and b) social accessibility. Physical accessibility was described as the person with a BI's ability to move about their home and community, and access all facets of their environment. Factors that may constrain physical accessibility included mobility impairments, transportation issues, and climatic barriers.

Margaret and Kendra identified physical accessibility issues as being a barrier for their clients, one which required the community agency's attention:

I think wherever possible we try to figure out what are the barriers to improved function or what are the barriers that are interfering with the client achieving their goal. And sometimes it's the physical environment. And we look at, OK, how can

we influence change on this, that physical environment, to make it more possible for the client to achieve their goals? Is there some equipment that they could be using in the home? Is there some modifications that could be done to the home? Is there alternate methods to get around some of those barriers? There's some aspects of the environment that we can't control or influence that much, the weather. The snow, the ice, you know, our climate, our bumpy sidewalks or icy sidewalks are certainly big barriers.

Social accessibility referred to the ability to access and engage in social aspects of the community. Lisa outlined the social isolation she felt as a result of her BI, indicating that it took her a long time to realize the need for and benefits of social outlets:

I've learned that you have to do that. You have to have some fun. And you have to have some time for you which is no different. Like I go to some exercise things now. I run with a friend. That's my way of getting out. Sometimes when I leave the house or I go away or whatever - that's the thing that gets me away from my frustrations that I have.

Both Dr. Richards and Dr. Johnson said that they would like to be aware of difficulties that their patients were experiencing, but they would likely only access this type of information if it were in context of primary health care or self reported by the person with a BI. Dr. Richards also suggested that patients may have an expectation of communication between health practitioners and service agencies: "they probably do expect more communication between physician and wherever they've been involved. Because in my experience, they're often surprised that I haven't heard about their admission and/or discharge for instance."

*Lack of Information.* Participants in the key informant interviews also identified lack of information as a problem people with BI experience upon return to the community from hospital. Lisa said that she needed more information about what to expect when she left the hospital: “nobody said to me, you could have trouble remembering things. You could have trouble organizing things. You could have trouble, cooking. Nobody told me that - It was just this physical stuff.”

Additionally, people with BI need more information about community programs and services that provide assistance and/or support to people with BI and their caregivers. Margaret speculated that people with financial resources, whether it was personal or third party insurers, fared better in accessing services, and that those without, have limited access:

It depends on who their financial providers are has a huge impact on what kind of services that they can, they can afford and get. And if there's none available to them, then they a lot of times end up here. So under the age of 18 you're covered by Manitoba Health and all the services are provided through the Children's Hospital. After the age of 18, if you had a brain injury and you left, and you no longer qualified for services unless you had a very good strong corporate funder that's funding you, there's nowhere for you to go. You're lost. There's no services.

Dr. Richards and Dr. Johnson agreed that there is a need for people with BI to have information regarding community resources and services, but that they would refer their patients to other more knowledgeable professionals for that information:

Well I don't think any of us (physicians) know a lot about community resources. I mean, we know a little bit, but I think we depend very heavily on the social workers that we know. And so we know where to direct them such that those issues could be addressed.

A third aspect of this theme is the lack of information that is provided to, or accessed by the primary care physician. Primary care physician participants indicated that they typically received limited information regarding the person with BI's experience, and what they receive was usually long after the BI and rehabilitation process. As Dr. Richards said:

I would suspect that in the system currently, they could probably go through an entire rehabilitation program and I would never know... Even if we got a discharge summary (from the rehabilitation program), I think it would contain only a minimal amount of that information. I don't think it would, for instance, list the type of resources that that patient is accessing after discharge. They may say patient discharged to wherever. But that probably would be the extent of their discharge plan that we would receive.

Dr. Johnson added to this by saying that as a primary care physician, there is a desire to have more information, but many factors make it difficult:

It would be great to have more information. It's one of the frustrations of family medicine, being expected to be the primary care contact and the one who's directing the care not to have all of the information is frustrating. And the amount of time it takes to get all of that information, It's tough to decide, you know, what is really important for me to know or what can I manage without knowing all the

details. I don't have the time to try to collect all that and neither do your staff. But if it were set up within the system that we would receive updates from physiotherapy or occupational therapy. That would be great.

*"Invisible" disability.* Two participants (Lisa, and Margaret) identified the "invisible" nature of the cognitive impairments that accompany BI as a barrier to reintegration. Very often there are no visual cues to others in the community that the person with a brain injury has a disability. As Lisa described:

You know if I had walked over to you and I was dragging my leg or I was limping, people around here would say, oh, this girl's got a problem, right. Maybe that explains why she does this or why she does that. I don't have that. I walk around and I talk and I can make sense - sometimes I repeat myself. It happens... and people don't understand.

Margaret describes this phenomenon from the community agency perspective:

It's really tough for these people because it is seen as an invisible disability. If you have a slight limp or something with your brain injury and maybe a slight slur right away people think there's an alcoholic in the community, you know, stuff like that. We have members like that as well who are fighting that community stigma. Someone who is in a wheelchair almost is better off than someone with a brain injury. Yes they have the physical limitations but they can advocate on their own behalf. They can think for their own. They can still tell people what they need and be understood and not be judged quite as easily as someone with a brain injury.

Lisa refuted this suggestion however, by stating that she was lucky to not have a physical disability as well:

But I'm, I'm lucky, I don't have any physical disabilities. There's people in the association that have these mental things that they deal with and on top of that they have physical disabilities. I don't have that. My only problem is when you see me wandering on a street. Stop me and say, do you want a ride because I know you lost your car because I can't find it. I can't remember where it is...

In conclusion, key informants provided a significant amount of information regarding the meaning of “successful reintegration”, the key aspects and the barriers experienced by people with BI from a global perspective as contrasted to the case study information.

#### *Similarities and Differences between the Integrated Case Study and Key Informant Interviews*

Participants in the case study and key informant interview phases of the research provided information about the meaning of successful community reintegration, the key characteristics of this process and the barriers encountered.

*What does successful community reintegration mean?* Participants from both phases of the research stated that definitions of “success” are individually derived. A physician key informant however suggested that it may be possible to determine if someone is “adequately” reintegrated; the other physician key informant suggested that considering the nature of their relationships with the person, they may view the absence of medical issues as “successful.”



*What are the key characteristics of community reintegration?* The case study triad, with their focus on a single individual's experience, identified a narrower scope of characteristics than the key informants with descriptions of *acceptance, goal setting, attitude, resuming pre-injury activities, and information*. From the key informant interviews, key characteristics in the theme areas of, *individualized process, maximizing function and independence, attitude, information, adaptive strategies, and having a caregiver* as essential in the community reintegration process. The most notable similarity between the groups was the identification of *information* as a key element in the process of reintegrating to the community.

*What are the barriers experienced by people with BI during reintegration?* The key informant interview group provided a greater breadth of information than the case study triad. *Lack of information* was noted by both the case study triad participants and the key informants as being a problem that people with BI experience. Key informants noted problems with *impaired cognitive abilities, accessibility and the "invisible" disability nature of BI*.

#### *Similarities and Differences between Participant Groups*

All participant groups identified barriers that may be experienced during community reintegration. Participants with BI always presented information in a personal, lived experience way, supported with anecdotes and personal experiences. Community agency representatives focused on the systemic aspects of the process, with emphasis on emotional aspects. These participants were also much more focused on meeting their clients' expressed needs, typically based on individual goals. Interviewed

physicians related all research questions back to the individual's medical/physical health needs, with little knowledge of, or regard for the persons' social and emotional priorities.

When speaking about "successful" reintegration, participants provided a fairly consistent perspective regarding the question. Similarities and differences could not be determined within and between participant groups. However, all participants, and participant groups did contribute information that helped the researcher identify the sub-themes presented in the results.

Most physicians involved in this study did not mention the attitudinal traits of their patients with BI, and how they related to the research questions. Dr. Brown did suggest that Bill was generally optimistic and had a good attitude; which is in conflict with Bill's self reports of sadness and prescription use of antidepressants. Bill did indicate that he chose to focus on the positive, but provides contextual information about his frustration, anger and stress that would suggest that he is not generally optimistic. Community agency representatives and the participants with BI often focused on the attitudinal traits when discussing key characteristics, meanings of "successful" reintegration and barriers experienced. Additionally, by focusing on the physical functioning of their patients, information presented by physicians could be interpreted as clinically detached from the lived experiences of their patients.

## CHAPTER 5

### Linking to the Existing Knowledge Base

Through the data analysis/interpretation stages of this research, and in the process of linking the findings to the pre-existing knowledge base, it became apparent that the key characteristics and the barriers identified did not occur in isolation; they occurred simultaneously and were interrelated. The information presented in this chapter relates the themes developed from the interview data to the existing literature, the identified conceptual grounding, and the theoretical framework. Additionally, this chapter will address the results as they relate to practical implications and future research; discussing the limitations and significance of the presented research.

The case study portion of the presented research was designed to generate a holistic perspective of the community reintegration experience. What was noted from collecting multiple perspectives on a single individual's experience was the consistent mention of depression as an aspect of Bill's reintegration experience. Two participants identified depression as a barrier for Bill, and through corollary information presented in the interview (prescribing antidepressants and inquiring about potential suicidal ideation), the researcher noted physician awareness of Bill's depressive state. Additionally, the key informant interview participants with BI identified depression as an element of their community reintegration experiences. The consistency of this concern and its relationship to the conceptual grounding in the quality of life and subjective well being literature, suggests that depression may be used as a lens through which the presented study results can be viewed.

Depression is a significant clinical concern for people with BI (Seel et al., 2003); which may extend from the acute phase to 3 or more years post injury (Berg et al., 2003). Many functional and social factors were found to be associated with depression. Functional factors identified in the literature included: severity of injury, physical disability, and functional impairments; and social factors included living alone, having limited social contacts, marital/familial disruptions and the inability to return to work (Berg et al.; Seel et al.). Depression, specific to these factors and the impact they may have on a person with a BI's experience reintegrating to the community are particularly relevant to the presented study. This section of the discussion will focus on the themes of *having a caregiver, maximizing function and independence, accessibility, impaired cognitive abilities, lack of information, individualized process, and attitude* as they relate to the concepts of depression.

*Having a caregiver* was identified a key characteristic of community reintegration. For the participants with BI, their caregivers were their spouses. The aforementioned risk factor of living alone, therefore, was not relevant for the participants with BI. Participants did, however, discuss the effect their BI had on their caregiver and the impact on their relationships as a problem experienced during their reintegration experience. Most participants with BI were aware that their injury had changed not only their life; but their spouse's life and their patterns of interaction, roles and relationship, which relates to the demonstrated link between family disruptions and depressive symptoms.

For the majority of participants in this study, resuming social activities was identified as a sub theme of *maximizing function and independence*. Participants

discussed the importance of resuming pre-injury activities, with emphasis on a) activities of daily living, b) return to work, and c) social activities, which reflects the work of Berg et al. (2003) regarding contributing factors to depression.

Activities of daily living were most closely related to an individual's desire to regain their physical functionality, with the identification of personal and household tasks as being most indicative of a return of skills and functional abilities. Most participants viewed regaining physical function as being the most important characteristic of reintegration. The return of these abilities signified a "recovery" for participants with BI. It may be supposed, that resuming these activities suggested a return to "normalcy", whereby not every aspect of life was affected by their BI. The recovery of functional abilities allowed them to focus their attention on other areas of their lives such as employment and social activities.

Return to work is an important topic in the area of community reintegration; as "work performance is an important aspect of an individual's daily occupational life and supports the sense of meaning and productivity essential to health and well being" (Holzberg, 2001, p. 245). In the context of the present study, all of the study participants with BI indicated that employment had significance for them; both as a contributor to personal identity and allowing them to support themselves and their family. This is supported by the work of Holzberg, who outlined the benefits of vocational rehabilitation, saying that work helped "to form one's identity, structure one's day, and provides a means to support oneself and one's family" (p. 245). Holzberg suggested that vocational rehabilitation had the potential to improve quality of life while decreasing government health care spending. Willer et al. (1993) indicated that return to competitive

employment is one of the most commonly cited indicators of integration as it is easily measured and is important for the individual and society. Other health practitioners suggested a broader focus should be used to measure/assess return to productive activities such as avocational activities and unpaid work. None of the participants with BIs identified these as indicators of success although many of them were engaged in what would be perceived as “productive” activities. Participants in the integrated case study agreed that return to previous employment would have been an aspect of successful reintegration for Bill, which was supported by the data collected from the key informants. It is important to note that Bill was unable to resume his previous employment; the depression literature indicates that the inability to work and the resulting financial implications contribute to depression, which was identified by most participants as a barrier to community reintegration. This is reflective of the findings of Seel et al. (2003) as they stated that the increased rates of depression in the poor and unemployed emphasize the need for timely rehabilitation and referral to appropriate community support agencies.

The topic of resuming social activities and the increased risk of depression, relates to *accessibility*. Key informants talked about what could be divided into two sub-themes; a) physical accessibility and b) social accessibility. Physical accessibility was described as the ability of the person with BI to move about their home and community, with the ability to access all areas of their environment. This included constraining factors such as mobility impairments, transportation issues, and climatic barriers. Social accessibility referred to the ability to access and engage in social aspects of the community. Burleigh et al. (1998) found that people with BI who had higher levels of

social integration reported a greater satisfaction with life. The authors stated “the findings of this study demonstrate a low, but significant, relationship between social integration and life satisfaction,” which is supported by the work of Fuhrer et al. (1992) and Heinemann and Whiteneck (1995). The presented study findings represent a mixed perspective on this sub theme. Participants emphasized the importance of staying active and engaging in social activities; but indicated that their social contacts had decreased significantly after their BI, and that they had not resumed their previously enjoyed social activities. The reported reduction in social activities and the potential relationship to depression are supported by the work of Berg et al., stating that “living alone and having few social contacts have been found to contribute to depression” (p. 138).

Commonly reported symptoms of depression include sadness, poor concentration, sleep disturbances, memory dysfunction, and psychomotor retardation; however “researchers have generated few consistent findings regarding the frequency, distinguishing features and factors associated with depression after BI” (Seel et al., 2003, p. 177). All of the participants with BIs and many of the other participants discussed some aspect of the key theme *impaired cognitive abilities* as a barrier to community reintegration. Participants with BIs reported difficulties in memory ranging from a need for adaptive strategies to having no short term memory. Other areas of difficulty included impaired decision making, and decreased inhibitions. As Seel et al. (2003) state “evidence also indicates that depression can greatly affect daily functioning and exacerbate cognitive impairments arising from brain dysfunction,” (p. 183). Reflecting on the literature, the question was then raised: are the reported cognitive difficulties

attributable to the BI, or did the identified depression exacerbate the cognitive affects of the BI in this study's participants?

Holzberg (2001) in a study that examined best practices for gaining and maintaining employment, noted that cognitive deficits such as difficulties in learning, perception, and memory were often negatively associated with acquiring work related skills, which demonstrates an interrelation of the psychological symptoms of depression to the study themes.

The *decreased inhibitions* sub-theme is of particular relevance in relation to the depression and community reintegration literature. Lisa clearly articulated her experiences with decreased inhibitions and the impact this had on her ability to exist in her pre injury social network. She was able to determine when she had said something that others found disconcerting by their reaction, and subsequently began withdrawing. Realizing the importance of social activities, Lisa made the concentrated effort to engage in activities with friends. Her experience is reflected in the literature; Burleigh et al. (1998) found that many persons with BI lose their pre injury social network. Without the skills necessary to develop new relationships, they become socially isolated and dissatisfied with their level of social integration. This dissatisfaction may cause secondary psychological disabilities. These findings may be particularly relevant for persons with severe BI; impairments in judgment, self awareness, social and sexual disinhibition, egocentricity, and other behavioural problems make it difficult to remain socially integrated in society (Burleigh et al.).

*Lack of information* was determined to be a barrier experienced in the community reintegration process. Participants indicated that they would have liked more information



from the rehabilitation practitioners about how to translate the learnings from rehabilitation to home and community. They would have liked more information about the programs and resources available within the community. A community agency representative (Patrick) felt this was a systemic problem, presenting Bill's long delay in accessing his association as an example. Bill was only made aware of the community agency when he was referred by another program for supports and part time employment. This barrier appears to result in part, from the lack of a community reintegration program at the rehabilitation facility. Anecdotal information also suggested that providing information to people with BI at discharge from hospital is not sufficient. People believe they are going to recover fully. It is only upon the realization that functional limitations are not going to improve, or caregiver stress precipitates accessing external services, that people with BI seek out community supports.

Dr. Brown although stating that knowledge of, and access to, community support programs was important in the community reintegration process, indicated that he did not spend any clinical visit time discussing this with Bill. Rather he assumed that Bill possessed all the information he needed regarding available supports, resources, and community programs. There is an apparent disconnect between the participants' recognition that having information regarding community based programs is important and determining who is responsible for dissemination. All the participants identified that it is ideal for people with brain injuries to receive this information before they are discharged from the facility, but if they do not - who is responsible then?

None of the participants with BI received formal community reintegration programming while in hospital, although the literature clearly states that this is an

important component of the rehabilitation process. According to Venzie et al. (1996) “much of the increase in community integrative programming is based on a general understanding that advantages to brain injury rehabilitation occur when it is performed in an environment that is as close to the real world as possible,” (p. 52). Ideally, rehabilitation in real (not simulated) environments, provides functional relearning of skills and reduces problems associated with generalizing skills from clinical to home settings.

The themes of *attitude*, *adaptive strategies*, and *goal setting* relate to the literature regarding depression and adaptive strategies as coping mechanisms. Berg et al., (2003) state that “adaptation factors, such as personal coping abilities, may become more important in later recovery” (p.142). This is particularly relevant for people with BI reintegrating to the community. Included in *attitude* were three related sub-themes: *acceptance*, *positive attitude* and *having a sense of humour*. *Acceptance* for participants with BI meant realizing and accepting that life was different after the BI. *Positive attitude* was something that people with BI identified as being a conscious choice, and something that they continually worked at. One participant with a BI emphasized the importance of having a *sense of humour* when living with a brain injury.

*Goal setting*, a key characteristic of community reintegration, provides individuals with BI a focus in the recovery phase. A community reintegration program implemented by Goggins et al. (1990) used goal setting to develop community skills training or practice opportunities around functional skills required by the client. The information provided by this study’s participants, along with the information from the literature, underscores the importance of both the community agency representatives and

physicians' awareness regarding their client/patient's goals, as this affects access to programs and services.

Participants identified the importance of *adaptive strategies* as essential in the community reintegration process and for resuming regular activities. Adaptive strategies were required by participants with BI in all areas of life; from general household tasks, to making and keeping doctors appointments. Although each participant described employing different strategies; the commonality was the need for these strategies to be based on their unique needs and personal goals. Examples of adaptive strategies included memory aids, and compensatory strategies such as shared responsibility for decision making.

Helping people with BI develop adaptive and compensatory strategies before they leave the rehabilitation program could be addressed by a community reintegration program. Lisa indicated in her interview, that she and her husband had to work together, without community support to develop the adaptive and compensatory strategies that allowed her to function independently at home. The literature indicates that a gradual return to community enables people with BIs to overcome the fears, depression, and dependency that are often experienced during this process. This gradual return also provides time for the person with a BI, family, and others in the social network to make the psychological adjustment from injury related roles (patient) to more conventional community roles such as spouse, parent, neighbor (Goggins et al., 1990). With this literature in mind, the lack of community reintegration programs for people with BI in Manitoba may be a contributing factor to the depression of interviewed participants with BI, and further research regarding this topic is required.

Community reintegration was perceived by many participants in this study to be an *individualized process* where services should be designed for the needs and goals of the individual with a BI. The literature provides support for this individualized approach to community reintegration by indicating that the needs of people with BI are so diverse and the consequences of the process so varied that it is difficult to create a program for a heterogeneous group (Seaman et al., 1993; Venzie et al., 1996).

Many of the key characteristics and barriers identified by participants of both the case study and key informant interview phases of this study indicate the need for further work examining potential need and utility of formal community reintegration programs that follow people with brain injuries from hospital to community.

#### *Examining the Results within a Systems Theory Context*

During conceptualization of this study, it was anticipated that systems theory may be useful as a theoretical framework. Systems theory suggested that the participant groups may interact as part of a connected group that operates within the confines of a larger health care/social system. Using the definition of a system as put forth by Ackoff (1981) is a set of at least two interrelated participant groups with the following properties:

- 1) Each participant group has an effect on the functioning of the whole;
- 2) Each participant group is affected by at least one other participant group in the system; and
- 3) All possible subgroups of participants also have the first two properties.

Interpreting the collected data suggested that this theory was inconsistent with the relationship between the participants of this study. The basis for this contention is illustrated using Ackoff's (1981) defining principles.

The first criterion states that “each participant group has an effect on the functioning of the whole”. It was determined through the course of this study that decisions and actions undertaken at any individual level did not affect the functioning of the whole group. The professional activities of the physician and community agency participant groups could, and did, occur in isolation, not affecting the process of community reintegration for the person with a brain injury. For example, a person with BI could return to the community after hospitalization, and the primary care physician may receive no information about their BI and/or rehabilitation until a primary health concern arose.

Ackoff’s second criterion stated that “each participant group is affected by at least one other participant group in the system”. Although decisions made at a participant group level may have had an impact on one of the other participants, it was often a unidirectional affect. For example, decisions made by the physician or the community agency, would potentially affect the person with a BI, but rarely had an affect on the other service provider. Decisions made by the person with a BI, however, had little affect on the professional roles of the primary care physician and community agency. This suggests a power differential in the system. If one participant group does not have the power to affect the actions of the other participant groups, are they truly equal members of the system?

The third criterion for a system: “possible subgroups of participants also have the first two properties,” was therefore not applicable for the participants of this study. It was determined that not all “potential subgroups”, using Ackoff’s definition, actually participated as subgroups. The physician and the community agency rarely, if ever, had

any contact, and operated virtually in isolation from each other. This may be contrary to what people with BI believe happens when they are returning to the community. As one physician indicated: “they (people with BI) probably do expect more communication between physician and wherever they’ve been involved; because in my experience, they’re often surprised that I haven’t heard about their admission and/or discharge for instance”.

The lack of “system” was particularly apparent in the integrated case study. By being linked together through a single person’s experience (Bill) it would have been evident if any of the properties attributed to systems theory were present. Both the community agency representative and the physician had a significant lack of information about Bill’s experience, and admitted that there was no contact between them. This was supported by the information collected from key informants, with the exception of one new community program that anticipated having regular contact with the primary care physicians of their clients. The communication that the representative suggested however, would still be unidirectional, with the agency sending the physician updates and progress notes.

This physician disconnect in the process of community reintegration is supported by the literature. With the exception of the self directed learning module in the physical medicine and rehabilitation journal (Miller et al., 2003), the researcher found limited mention of physician (physiatrists or primary care physicians) involvement in the process of community reintegration. One study mentioned health care professionals as members of the community reintegration process, but no articles discussing community reintegration as it relates to primary care were found. This is further supported by the

anecdotal evidence that the term “community reintegration”, and its theoretical underpinnings was unfamiliar to physicians; as one primary care physician participant, when asked, “are you familiar with the term “community reintegration”, responded “only through you” (referring to the researcher).

The lack of awareness of participant groups regarding the community reintegration process conceptually may represent a paradox for research in this area. Are researchers studying the community reintegration process to determine “best practices” and create an understanding of an experience which may be in contrast to the beliefs of the participants? Bill stated he did not see the process of leaving hospital and returning home as “reintegration” – it was just another challenge in his life. Further work exploring the perspectives of participants regarding terminology and context in which they view the experience would be beneficial.

An additional aspect of systems theory suggests that participants and their perspectives should be considered equal to each other and the system as a whole. From the data collected it was noted that a hierarchical relationships existed between participants. Terms such as “doctor/patient” and “service user/provider” do not suggest collaborative relationships between the participants. Furthermore, the use of titles for physician members of the system (Dr. Brown) and first name usage for the other participants by the participants themselves, contribute to the perception of power differential between participants.

This power differential is supported by information collected regarding interactions between participant groups. Some physician participants indicated that their focus was on the physical aspects of health status, with limited knowledge or focus on

their patients' goals and priorities. This is supported by the data; physicians indicated that an absence of physical health concerns, and a reduction in the amount of services required could/would indicate successful reintegration, and subsequently good health. What becomes apparent is the concept of contrasting goals. If the priorities of a person with a BI is social and emotional health, and the physicians' focus is on physical function, are the health needs of the person with a BI being met?

### *Community Reintegration and Subjective Well Being*

Three overarching and related concepts were identified in the literature as part of subjective well being: quality of life, life satisfaction, and health related quality of life (Diener et al., 1985). The term quality of life has been conceptualized in many different ways, although the majority of these conceptualizations centre on "how good life is" for people (Raeburn & Rootman, 1996; p.16). Schumaker et al. (1990) define quality of life as "an individual's overall satisfaction with life and general sense of personal well being" (as cited in Smith et al., 1998). Renwick and Brown (1996) define quality of life as "the degree to which a person enjoys the important possibilities of his or her life" (p. 80); providing the link between the presented research and the conceptual grounding.

When quality of life is assessed in clinical and rehabilitation settings, it is typically viewed as a component of functional status which is assumed to increase as the individual's level of functional performance improves. This concept was reinforced by the research participants' focus and emphasis on maximizing physical functioning, and was particularly salient when reflecting on the reintegration situation of people with BI; if functional abilities and performance plateau, what are the indicators of quality of life?



What other measures could be used to determine if quality of life improves post discharge?

The literature regarding life satisfaction, notes that the experiences of persons with BI are sufficiently different to warrant separate consideration. This concept should be considered from the individual's perspective as there may be disability specific factors that have a determining role (Corrigan et al., 2001). Data from the presented study suggest that the concept of an "invisible disability", and the unique experiences of people with BI, seem to support the need for additional research around measures of life satisfaction and community reintegration specific to people with BI.

Health related quality of life is the subjective perceptions of well being after taking into account the impact of disease and treatment. This is in contrast to literature that suggests life satisfaction is not related to the extent of impairment and disability, but related to dimensions of societal participation. Further work which examines the concepts of health related quality of life, specific to people reintegrating to the community would be beneficial.

#### *Implications for Practice and Recommendations*

The results of this study supports the need for additional work examining the utility and benefits of formal community reintegration programs for people with BI, regardless of the severity of the injury. All of the study participants identified a need for more information regarding the process of returning to the community; and increased knowledge of and access to community services and future research could further explore the participants' perspectives on a potential reintegration program.

Based on the information collected from participants, a community reintegration program implemented at the time of active rehabilitation, should:

- 1) Actively involve all stakeholders to develop a process that meets the needs of the client, and service providers. Much of the information presented in this study suggested that types of programs and services were variable; services received were based on hospital, service provider and personal resources of the person with BI.
- 2) Take into account the unique needs and priorities of the person with a BI. Much of the information presented suggested that some participants in the process were very client centred, while others were focused on improving functional abilities, regardless of participant goals
- 3) Be developed with a holistic health perspective. All participants identified a variety of bio-psycho-social aspects of health that should be included in a community reintegration program.
- 4) Provide opportunities for people with BI to practice community reintegration skills in the context of their home and community. Study findings and literature suggest this is essential in the community reintegration process.
- 5) Provide opportunities for continual communication between all the process participants.
- 6) Provide educational resource materials to participants. All participants with BI suggested that would have like more information regarding the experience of reintegrating to the community. Community representatives suggested that awareness of their programs was based on health practitioner awareness and

referral processes. Secondly, community agency representatives suggested that primary care physicians could benefit from updated educational materials regarding resources and services available.

- 7) The process should be continuous – initiating in hospital and rehabilitation, and extending into the transition to a community setting.
- 8) Take into account the “time constrained” perceptions of the primary care physician.

#### *Contributions and Limitations of the Study*

This study makes some important and interesting contributions to the literature regarding community reintegration and people with BI. As exemplified in the literature review, there is a paucity of research to date that has attempted to present a holistic understanding of the community reintegration process. The community reintegration experience of one individual with a BI, from multiple perspectives, is presented in the study results.

Examining a single experience from multiple perspectives provided greater depth and breadth to the discussions regarding key characteristics, barriers and determinations of success than would have been possible from a single perspective representation.

This study has shown that it is possible to collect trustworthy and credible data from people with BI. Historically, the perspectives of people with BI have been viewed with skepticism (Racino & Williams, 1994, p. 39). The information collected from participants with BI is often viewed as unreliable on the assumption that impaired cognitive functioning precludes the ability to comprehend the questions and provide accurate information (DiDonato & Schaffer, 1994). This researcher demonstrated that with appropriate data collection techniques it was possible to collect valuable and

meaningful information regarding the community reintegration experience. These first person accounts provided the researcher with many areas for further study and exploration, as the participants were able to talk about facets of the experience of which the other participants were unaware.

An additional contribution of this study was the presentation of physician perspectives regarding their patients' community reintegration experiences. As noted in the literature review, with the exception of one journal article, the researcher was unable to locate work that indicated or reflected primary care physicians' involvement in community reintegration. This was supported in the findings of this study, whereby physician participants indicated that they were both unaware of the term "community reintegration"; many facets of the experience fell outside the scope of their primary mandate: physical health and functioning. Information regarding primary care physicians' perspectives, as well as the potential for greater involvement in the community reintegration process are presented in the study results. By exploring primary care physicians' perspectives, the researcher was able to determine areas of future work that may be explored, with greater involvement and representation from physicians.

One of the limitations of this study relates to data collection techniques and procedures. Integrated case studies, the original data collection approach, were not feasible. Increased legislation regarding protection of personal and health information seemed to make many of the community agencies approached hesitant to agree to participate. Secondly, community groups that did agree to participate did not have clientele that met the original inclusion and exclusion criteria. Additionally, in depth interviews, although very appropriate for collecting a large amount of data from an

individual, required a significant amount of time on the part of the research participant. The participants with BI were eager to meet with the researcher and discuss their community reintegration experiences; this was not the case for the community agency representatives and physicians. Participants from these groups expressed concern regarding the amount of time the interview would consume from their busy schedules. Most were only willing to commit approximately 30 to 45 minutes for the interview. Anecdotal evidence collected from these participants suggested that an alternate method of data collection would have been preferred. One alternate approach suggested by physician participants was an open ended survey, which would allow the participant to provide data as time permitted during their day.

A limitation of this study, related to the time constraints of participants, was the lack of member checking. Although transcriptions of the interviews were offered to participants, only two indicated that they would be interested or able to review the materials and provide feedback on the accuracy of the information collected. This opportunity would have allowed the researcher to seek additional information or clarification that would have enhanced the data collected, ensuring that data presented accurately reflected to perspectives of the participants.

A final limitation may be researcher/interviewer inexperience. Over the course of conducting interviews, the researcher continually engaged in personal reflection, reviewing transcribed materials in an attempt to identify and capture any preconceptions and assumptions that she may have had. This activity also allowed her to determine what interviewing techniques needed improvement.

### *Future Research*

During the analysis and interpretation of the data, the researcher realized that all of the case study participants talked about Bill's wife and the role she played in Bill's reintegration. As well, participant in the key informant interviews identified having a caregiver as a key characteristic of community reintegration. The consistent mention of caregiver involvement indicates that perhaps caregivers are a participant group in community reintegration, not included in the presented research, but potentially the link between the participants. Future work regarding the experience of community reintegration from a systems theory perspective should identify all the stakeholders that act as a member of the "system".

Future studies in the area of community reintegration and persons with BI could focus on the experiences of informal caregivers and support providers. Questions that may be interesting to explore may include: What is the role of the caregiver? What aspects of the process are they involved in? How do caregivers contribute to "successful" reintegration, and what is the impact of the caregiving on their subjective well being?

An additional concept that arose from the findings of this study is the perception that a discrepancy exists between access to resources and services based on personal financial status, or funding from an external source. Future work could explore this facet of community reintegration, as all participants of this study identified information and access to resources as being both an essential characteristic of the process; as well as a barrier experienced by people with BI.

In regards to the concept of an "invisible disability", there is support in the literature for the development of a unique program and service delivery approach for

people with BI. Future work should determine the similarities and differences between needs of people with cognitive and physical disabilities, and how they relate to the stated requirements of people with BI when reintegrating to the community? What specifications would be required from a community reintegration program to meet the needs of a population with cognitive impairments?

All of the participants with BI in the presented study identified depression as an aspect of their experiences; two participants identified this as a barrier in community reintegration. The literature indicates that there is a high level of association between depression and brain injury (Berg et al., 2003); however, additional research exploring all of the risk factors, association to functional status and implications for people with BI is needed.

### *Summary and Conclusions*

This study has contributed to a limited body of knowledge regarding community reintegration. By comparing multiple perspectives on the key characteristics, meanings associated “successful” reintegration, and constraining factors of the experience, the researcher was able to generate a holistic representation of the process.

The themes identified from both phases of this study indicate the importance of information and access to resources during rehabilitation and upon return to the community. This must be a process of continual communication; it is not enough to assume that people will access resources and information independently. This may require additional training and education for all service providers, as it may be assumed that people with BIs ultimately return to “status quo”, as one participant suggested. It is

noteworthy that the absence of information and access to resources were identified as barriers for people with BI during community reintegration.

All of the participants with BI reported receiving no formal community reintegration program as part of their rehabilitation. When comparing their stated needs with the information presented by other participant groups, it became apparent that there may be a need for a formal, well developed community reintegration program that involves all potential stakeholders, and the concept should be explored in future research. This future research should include rehabilitation professionals, physicians, community agencies and most importantly, the person with a BI. For programming and best practices to meet the unique and diverse needs of this population, the goals and priorities of the individual must be included at all levels of program planning and development.

One of the most significant contributions of this study is the demonstration that it is possible to collect trustworthy, credible data from people with BI regarding their experiences. Not only is it possible to include the perspectives of people with brain injuries, but it is essential if striving to honour an individually derived definition of “successful reintegration.”



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APPENDIX A

Integrated Case Study: Person with a Brain Injury Study Materials

## Michelle Nelson

◆ ◆ ◆  
 Xx xxxxx xxxxxx ◆ Winnipeg, MB XXX XXX  
 Phone xxx-xxxx ◆ Email: mnelson@sbrc.ca

<DATE>

Dear Potential Participant;

I am a Masters of Arts student at the University of Manitoba, conducting a study “Community Reintegration by People with Brain Injuries: Comparing Perspectives” as my thesis research. The <INSERT ASSOCIATION> has agreed to participate; and I asked them to send these letters to clients that may be interested in taking part.

In this study, I will compare your opinions about community reintegration with your primary care physician’s and with the community groups from which you receive services. By better understanding and comparing these opinions, I will identify similarities/differences in opinion, with the ultimate aim of improving community reintegration for people in the future.

If you decide to participate in this study, you will (please see that attached materials for a detailed description):

- i) Complete the information form attached to this letter.
- ii) Allow the researcher to contact your physician to invite them to take part in the study
- iii) Provide consent to the researcher, indicating your willingness to take part in the research.
- iv) Take part in an interview that will take about one hour, at a location agreed upon by you and the researcher. Please remember that you can choose to withdraw from the study or refuse to answer any questions at any time.
- v) Allow the researcher to interview your family doctor and a representative of the <INSERT ASSOCIATION>
- vi) Review transcribed interview materials, providing feedback on the accuracy of the information and themes developed from the materials.

If you have any questions about this research please contact the researcher **Michelle Nelson (xxx-xxxx)** or **Dr. Jennifer Mactavish (474-8627)**, the researcher’s academic advisor.

Thank you for your time and anticipated interest.

Yours truly,

Michelle Nelson BRS, BA

## Participant Information Form

**If after reviewing all the attached information** you are interested in taking part, please fill in the information below, put this paper in the envelope provided and give them to your contact at the <INSERT ASSOCIATION>, or you can call Michelle Nelson at xxx – xxxx.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Telephone Number: \_\_\_\_\_

The information collected from each of the groups will be based on your experiences, so it is necessary to invite the community service agency and your doctor to participate before starting any interviews.

Do you have a family doctor?    Yes \_\_\_\_\_    No \_\_\_\_\_

If “yes”, what your Doctor’s name? \_\_\_\_\_

What clinic do they work at? \_\_\_\_\_

Can the researcher call your physician and invite them to participate?

Yes \_\_\_\_\_    No \_\_\_\_\_

Your doctor will be told that they were identified as having a client that recently had a brain injury. They will be told about the study and asked if they would like to participate. **No personal health information** will be requested from the physician and your privacy will be protected and respected at all times. Only after you, the community group, and your doctor have agreed to participate, will you take part in the interview.

Please note that that all three people (you, the agency that provides services for you, and your doctor) must want to participate. If anyone declines to participate, you will not be able to take part in the study and I thank you for your time and interest.

If you have any questions about this research, please contact the researcher (Ms. Michelle Nelson at xxx – xxxx).

## **Research Study Participant Information and Informed Consent Form**

### **People with Brain Injuries**

**Title of the Study:** Community Reintegration by People with Brain Injuries:

Comparing Perspectives

**Researcher:** Michelle Nelson BRS, BA

**Contact Information:** XXXXXX – xxx xxxxx xxxxxx  
Winnipeg, MB XXX XXX  
(204) xxx –xxxx

#### **What is the Purpose of this Study?**

You are being asked to take part in a research study looking at different groups of people's opinions on community reintegration. This study is most interested in the experiences of people that have had brain injuries and needed rehabilitation.

In this research, community reintegration will be discussed with three groups: people with acquired brain injuries, the community based groups that support these people, and their family doctors.

This study wants to understand:

- the meaning of community reintegration;
- key characteristics of community reintegration for people with brain injuries;
- what “successful” reintegration; and,
- the barriers people with acquired brain injuries experience when reintegrating to the community.

One of the interesting and most important aspects of this study is the different perspectives of the participants. This means that your doctor and the service agencies from which you receive support and services will provide information about the topic of community reintegration while thinking of your experiences.

#### **Why am I getting this information?**

You are receiving this information from the community service agency, (Insert Association) that you receive services from. The researcher provided this information to the (Insert Association) asking them to give this package to people that may be interested in taking part.

#### **Is My Taking Part in this Study Voluntary?**

Your decision to take part in this study is voluntary. You may refuse to take part, or if you do choose to take part, you can still:

- refuse to answer any questions you want
- stop being in the study at any time

**What if I don't want to take part in the study?**

If you do not want to take part in the study,

- tell the researcher that you no longer wish to take part in the study
- All the information collected from you or your physician will be deleted from the study

**What happens if I agree to take part in this study?**

If you decide to take part in this research study, you will be asked to:

- vii) Provide consent to the researcher, indicating your willingness to take part in the research study.
- viii) Completed an information form that asks for your name, address and/or telephone number. This form will also ask you questions about your family doctor.
- ix) Allow the researcher to contact your physician to invite them to take part in the study. Please be aware that this conversation will only tell them that you said they were your family doctor, and ask them if they would be willing to take part in the study. Unfortunately if your physician indicates that he/she can't take part, you will not be able to take part either; and we thank you for your interest in this study.
- x) Take part in an interview with the researcher.
  - This interview will last for approximately 1 hour
  - This interview will be tape recorded so the researcher can listen to them again
  - These tapes will be transcribed and stored in a locked location for a minimum of 7 years.
- xi) Allow the researcher to interview your family doctor and the community group (insert name of association) that you belong to. The researcher will not ask for private information, but will ask these people to answer the same interview questions you did, while thinking about your experiences.
- xii) You will be asked to review the transcribed interview materials and provide feedback on the accuracy of the information and themes developed from the materials. Reviewing the materials may take anywhere from 1 to 2 hours; and the follow up conversation may occur in another short interview (in person or telephone), or by other electronic methods (email or fax). This interview may take approximately 30 minutes.

**Are there any risks to me if I agree to take part in the study?**

It has been determined that the risks of this study to you are considered minimal.

- Some of the discussion topics or specific interview questions may make you feel uncomfortable.
- You do not have to take part in any discussions, or answer any questions that make you feel uncomfortable.

**Will my identity be kept private?**

- The information gathered will be kept in a locked filing cabinet in the researcher's office.
- No governing bodies will receive any raw data from this research, and
- Only the researcher will see personal information about you (name, address, or telephone number).
- During your involvement in the study, the researcher cannot guarantee your confidentiality and anonymity from the other study participants, as the community agency, and your physician will be providing their thoughts about your experiences returning to the community from rehabilitation.
- Personal information may be disclosed if required by law.
- The University of Manitoba Education and Nursing Ethics Board may review records related to the study for ethical compliance purposes.

**Will it cost me anything to take part in the study?**

Taking part in this study will not cost you anything.

**Will I be paid for taking part in the study?**

You will not receive pay for taking part in this study; however, the researcher will cover any expenses (parking, bus tickets, etc.) for your involvement.

**Who do I call if I have questions about being in this study?**

You can call the researcher (**Michelle Nelson at 204-xxx-xxxx**).

**Who do I call if I have questions about my rights as a research subject?**

You can call the University of Manitoba, Education and Nursing Research Ethics Board at **204-474-7122**.

**Please do not sign this consent form if you have not had a chance to ask questions and received answers to your questions.**

**Statement of Consent**

I:

- have read this form or it was read to me
- have been able to ask questions
- got answers to my questions
- got an explanation for anything that was not clear
- understand what will happen in this study
- understand the benefits and risks of this study
- willingly choose to take part in this study

It is clear to me that:

- taking part in this study is voluntary
- I can stop taking part any time
- I will get a copy of this consent form
- The research ethics board can review all the study information for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

Participant Signature \_\_\_\_\_ Date \_\_\_\_\_

Participant Printed Name \_\_\_\_\_

**Please provide your mailing address if you would like to receive a summary of the study results.**

Name: \_\_\_\_\_

Street: \_\_\_\_\_

Postal Code: \_\_\_\_\_

**APPENDIX B**

**Integrated Case Study: Community Service Agency Study Materials**



## Michelle Nelson



Xx xxxxxxxx xxxx ◆ Winnipeg, MB XXX XXX  
Phone xxx-xxxx ◆ Email: mnelson@sbrc.ca

<DATE>

Dear <AGENCY> Representative;

I am a graduate student at the University of Manitoba, conducting a study entitled, ‘*Community Reintegration by People with Brain Injuries: Comparing Perspectives*’ as my thesis research. Your organization was identified as a community service agency that provides services for individuals with brain injuries; therefore, I would invite you to participate in this study.

This research offers the potential for unique insights into community reintegration as it incorporates the perspectives of three key groups in this process: people with brain injuries, support agencies and family physicians. While there is literature that addresses the community reintegration of people with brain injuries, the perspectives of these individuals has received limited attention, and no research has examined similarities and differences from multiple viewpoints. Your support and assistance is important and would be greatly appreciated.

If you decide to participate in this study, you will (please see that attached materials for a detailed description):

- i) Provide introductory materials to individuals with brain injuries (i.e., your clients) based on the attached inclusion and exclusion criteria.
- ii) Provide consent to the researcher, indicating your willingness to participate. Please note that participants form a triad (individual with brain injury, a support agency and a physician); all three must be able and willing to participate in order to proceed.
- iii) Participate in an interview that will take approximately one hour at a mutually agreed upon location. Please be assured that your participation is voluntary and you may withdraw or refuse to answer any questions at any time.
- iv) Review interview materials and provide feedback on the accuracy of the information and themes developed from the materials.
- v) Review sections of the final report, providing feedback on the accuracy of the information and results presented.

If you have any questions about this research please contact the researcher **Michelle Nelson (xxx-xxxx)** or **Dr. Jennifer Mactavish (474-8627)**, the researcher’s academic advisor.

Thank you for your time and anticipated interest.

Yours truly,  
Michelle Nelson BRS, BA

## **Community Reintegration by People with Brain Injuries: Comparing Perspectives**

### **Participant Groups Inclusion and Exclusion Criteria**

#### *People with Brain Injuries*

The individual with an acquired brain injury is the consumer of community and health care services.

Inclusion criteria: Individuals who had a non-traumatically acquired brain injury (e.g. caused by tumours, strokes) in the past five years, and have been discharged to the community from acute/inpatient rehabilitation will be invited to participate. Participants must be over the age of 18 years, and able to communicate fluently in English. Included participants must be able to express their thoughts and feelings about their experiences easily without relying on communication aids.

Exclusion criteria: Individuals not considered medically stable (as per their primary care physician), or having any behavioural issues that may be inhibitive to their participation will be excluded from the study group. In addition, any person deemed/assessed as legally incompetent will not be included.

#### *Community Service Agencies*

Agencies that are currently providing services to people with recently acquired and long-term neurological impairments, have acted as a liaison with governing bodies, and have knowledge of policy development and/or practice guidelines regarding community reintegration for people with ABI will be invited to participate in the study.

#### *Primary Care Physicians*

When people with acquired brain injuries leave an acute/active rehabilitation setting and return to the community, a primary care physician resumes the provision of primary health care. Primary care physicians will be purposely selected for their provision of health services to the people with ABI that are participating in the study. A primary care physician is defined as a physician that is not currently registered as a specialist with the College of Physicians and Surgeons.

**Participant Information and Informed Consent Form**  
**Representative of the Community Service Agency**

**Title of the Study:** Community Reintegration by People with Brain Injuries:  
 Comparing Perspectives

**Researcher:** Michelle Nelson BRS, BA

**Contact Information:** XXXXX XXX XXXXX XXXXXX  
 Winnipeg, MB XXX XXX  
 (204) xxx – xxxx

**Introduction and Purpose of Study**

You are invited to participate in a study designed to examine different groups of people's opinions on community reintegration. For the purpose of this study, the focus will be on the experiences of people with brain injuries that required rehabilitative care.

While there is literature that discusses community reintegration pertaining to people with brain injuries, limited amounts of this work include the perspectives of the people with brain injuries; and no research has compared multiple groups' thoughts and opinions of community reintegration.

In the proposed research, the concept of community reintegration will be discussed with three key groups: individuals with acquired brain injuries, the community based advocacy groups that support these individuals, and their primary care physicians. The purpose of this study is to identify similarities and differences in perspectives between these groups on issues related to community reintegration. Specifically, the research objectives are:

1. To identify and understand the meaning attributed to community reintegration;
2. To identify key characteristics of community reintegration for people with Acquired Brian Injuries;
3. To enhance understanding of what "successful" reintegration means from the perspectives of each of the informant groups; and,
4. To identify and understand the barriers (factors that constrain) people with acquired brain injuries experience when reintegrating to a community setting.

One of the interesting and most important aspects of this study is the interrelated perspectives of the participants. This means that the physician and service agencies from which the person with a brain injury receives support and services will provide information based on their perceptions of the experiences of that individual.

**Study Procedures**

You are receiving this information because your organization provides community services to a people with brain injuries.

If you decide to participate in the research, you will be asked to perform the following activities:

- xiii) Provide consent to the researcher, indicating your willingness to participate in the research. Study activities are explained in this document.
- xiv) Provide recruitment materials to clients of your organization as per the provided inclusion and exclusion criteria. Please note that participants form a triad (physician, patient and community group); all three individuals must be able and willing to participate in order to proceed.
- xv) Participate in an interview with the researcher. This interview will last for approximately 1 hour and will take place at a quiet location of your choosing. In order to ensure the accuracy of the reports from the interviews, the discussions will be audio taped. These tapes will be transcribed and stored in a locked location for a minimum of 7 years.
- xvi) You will be asked to review transcribed interview materials and provide feedback on the accuracy of the information and themes developed from the materials. Reviewing the materials may take anywhere from 1 to 2 hours; and the follow up conversation may occur in another short interview (in person or telephone), or by other electronic methods (email or fax). This interview may take approximately 30 minutes.

**Risks and Discomforts**

It has been determined that the risks of this study to you are considered minimal. It may be possible that some of the discussion topics or specific interview questions may make you feel uncomfortable. Please be aware that you do not have to participate in any discussions, or answer any questions that make you feel uncomfortable.

**Payment for Participation**

You will not receive pay, or reimbursement for any expenses related to taking part in this study.

**Confidentiality**

You will be providing information during an interview. The information gathered will be kept in a secure locked filing cabinet in the researcher's office. No governing bodies will receive any raw data from this research, and only aggregate findings from this study will be presented or published in public forums. Personal information such as your name, address, or telephone number will only be seen by the researcher.

During your involvement in the study, please be aware that the researcher cannot guarantee your confidentiality and anonymity from the other study participants, as the person with a brain injury, the community service agency, and the primary care physician will be providing information about their opinions about one person's experiences returning to the community. Please be aware that personal information may be disclosed if required by law. The University of Manitoba Education and Nursing Ethics Board may review records related to the study for ethical compliance purposes.

### **Voluntary Participation/Withdrawal from the Study**

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time and you will not be penalized if you decide to do so. To withdraw, simply tell the researcher that you no longer wish to participate in the study. All data collected from you will be removed from the study files and disposed of in a confidential manner.

### **Questions**

You are free to ask questions about the study and your rights as a research participant. If you have any questions during or after your participation, please contact the researcher (**Michelle Nelson at 204-xxx-xxxx**). If you have any questions about your rights as a research participant, please contact the University of Manitoba, Education and Nursing Research Ethics Board at **204-474-7122**.

**Please do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers.**

### **Statement of Consent**

I have read this consent form. I have had the opportunity to discuss any questions about the consent form and/or study procedures with the researcher. I understand that I will be provided a copy of this consent form after signing it. I understand that my participation in the study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this study. I authorize the inspection of any of my information that is related to this study by the University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in research.

Participant Signature \_\_\_\_\_ Date \_\_\_\_\_  
Participant Printed Name \_\_\_\_\_

**Please provide your mailing address if you would like to receive a summary of the study results.**

Name: \_\_\_\_\_

Street: \_\_\_\_\_

Postal Code: \_\_\_\_\_

APPENDIX C

Integrated Case Study: Primary Care Physician Study Materials

## Michelle Nelson

◆ ◆ ◆  
 Xx xxxxxxxx xxxxxx ◆ Winnipeg, MB XXX XXX  
 Phone xxx-xxxx ◆◆ Email: mnelson@sbrc.ca

<DATE>

Dear Dr. <Name>;

I am a graduate student in the Masters of Arts – Recreation Studies degree program and am approaching you to participate in my thesis research, “*Community Reintegration by People with Brain Injuries: Comparing Perspectives*”. **You are receiving this information because an interested participant (insert name) has identified you as his/her current primary care physician.**

This research offers the potential for unique insights into the process of community reintegration, as it incorporates the perspectives of the three key groups: people with brain injuries, support agencies and primary care physicians. While there is literature that addresses community reintegration of people with brain injuries, the perspectives of these individuals has received limited attention and no research has examined similarities and differences from multiple viewpoints. This study uses a triad approach, which requires the participation of the three groups that are involved in the reintegration process. Therefore, your support and involvement is important and would be greatly appreciated.

If you decide to participate in this study, you will (please see that attached materials for a detailed description):

- i) Audit the identified patient’s medical chart to determine if the patient is appropriate for inclusion in the study based on the attached inclusion/exclusion criteria. Please note that participants form a triad (physician, patient and community group); all three individuals must be able and willing to participate in order to proceed.
- ii) Provide signed informed consent to the researcher.
- iii) Participate in an interview with the researcher (approximately 1 hour) at a mutually agreed upon location. You will not be asked to divulge any personal health information about your patient, and consent to approach you has been received by your patient. Your participation is voluntary; you may refuse to answer any questions or withdraw at any time.
- iv) Review interview materials and provide feedback on the accuracy of the information and themes developed from the materials.
- v) Review sections of the final report, providing feedback on the accuracy of the information and results presented.

If you have any questions about this research please contact the researcher **Michelle Nelson (xxx-xxxx)** or Dr. Jennifer Mactavish (474-8627), the researcher’s academic advisor. Thank you for your time and anticipated interest.

Yours truly,  
 Michelle Nelson BRS, BA

## **Community Reintegration by People with Brain Injuries: Comparing Perspectives**

### **Participant Groups Inclusion and Exclusion Criteria**

#### *People with Brain Injuries*

The individual with an acquired brain injury is the consumer of community and health care services.

Inclusion criteria: Individuals who had a non-traumatically acquired brain injury (e.g. caused by tumours, strokes) in the past twelve months, and have been discharged to the community from acute/inpatient rehabilitation in the previous six to eight months will be invited to participate. Participants must be over the age of 18 years, and able to communicate fluently in English. Included participants must be able to express their thoughts and feelings about their experiences easily without relying on communication aids.

Exclusion criteria: Individuals not considered medically stable (as per their primary care physician), or having any behavioural issues that may be inhibitive to their participation will be excluded from the study group. In addition, any person deemed/assessed as legally incompetent will not be included.

#### *Community Service Agencies*

Agencies that are currently providing services to people with recently acquired and long-term neurological impairments, have acted as a liaison with governing bodies, and have knowledge of policy development and/or practice guidelines regarding community reintegration for people with ABI will be invited to participate in the study.

#### *Primary Care Physicians*

When people with acquired brain injuries leave an acute/active rehabilitation setting and return to the community, a primary care physician resumes the provision of primary health care. Primary care physicians will be purposely selected for their provision of health services to the people with ABI that are participating in the study. A primary care physician is defined as a physician that is not currently registered as a specialist with the College of Physicians and Surgeons.



**Participant Information and Informed Consent Form**  
**Primary Care Physician**

**Title of the Study:** Community Reintegration by People with Brain Injuries:

Comparing Perspectives

**Researcher:** Michelle Nelson BRS, BA  
**Contact Information:** XXXX - XXXXXXXXXXXXX  
 Winnipeg, MB XXX XXX  
 (204)xxx – xxxx

**Introduction and Purpose of Study**

You are invited to participate in a study designed to examine different groups of people's opinions on community reintegration. For the purpose of this study, the focus will be on the experiences of people with brain injuries that required rehabilitative care.

While there is literature that discusses community reintegration pertaining to people with brain injuries, limited amounts of this work include the perspectives of the people with brain injuries; and no research has compared multiple groups' thoughts and opinions of community reintegration.

In the proposed research, the concept of community reintegration will be discussed with three key groups: individuals with acquired brain injuries, the community based advocacy groups that support these individuals, and their primary care physicians. The purpose of this study is to identify similarities and differences in perspectives between these groups on issues related to community reintegration. Specifically, the research objectives are:

5. To identify and understand the meaning attributed to community reintegration;
6. To identify key characteristics of community reintegration for people with brain injuries;
7. To enhance understanding of what "successful" reintegration means from the perspectives of each of the informant groups; and,
8. To identify and understand the barriers (factors that constrain) people with acquired brain injuries experience when reintegrating to a community setting.

One of the interesting and most important aspects of this study is the interrelated perspectives of the participants. This means that the physician and service agencies from which the person with a brain injury receives support and services, will provide information based on the experiences of that individual.

**Study Procedures**

You are receiving this information because a person with a brain injury has identified you as their current family physician.

If you decide to participate in the research, you will be asked to perform the following activities:

- i) Provide consent to the researcher, indicating your willingness to participate in the research. Study activities are explained in this document.
- ii) Audit the identified patient's medical chart to determine if the patient is appropriate for inclusion in the study based on the inclusion/exclusion criteria provided. Please note that participants form a triad (physician, patient and community group); all three individuals must be able and willing to participate in order to proceed. If you are unable to participate, or the identified patient is not eligible to participate, you are asked to simply decline participation without stating reason, whereby protecting the privacy of the patient.
- iii) Participate in an interview with the researcher. This interview will last for approximately 1 hour and will take place at a quiet location of your choosing. In order to ensure the accuracy of the reports from the interviews, the discussions will be audio taped. These tapes will be transcribed and stored in a locked location for a minimum of 7 years.
- iv) You will be asked to review the transcribed interview materials and provide feedback on the accuracy of the information and themes developed from the materials. Reviewing the materials may take approximately 1 hour; and the follow up conversation may occur in another short interview (in person or telephone), or by other electronic methods (email or fax). This interview may take approximately 30 minutes.

### **Risks and Discomforts**

It has been determined that the risks of this study to you are considered minimal. It may be possible that some of the discussion topics or specific interview questions may make you feel uncomfortable. Please be aware that you do not have to participate in any discussions, or answer any questions that make you feel uncomfortable.

### **Payment for Participation**

You will not receive pay, or reimbursement for any expenses related to taking part in this study.

### **Confidentiality**

You will be providing information during an interview. The information gathered will be kept in a secure locked filing cabinet in the researcher's office. No governing bodies will receive any raw data from this research, and only aggregate findings from this study will be presented or published in public forums. Personal information such as your name, address, or telephone number will only be seen by the researcher.

During your involvement in the study, please be aware that the researcher cannot guarantee your confidentiality and anonymity from the other study participants, as the person with a brain injury, the community service agency, and the primary care physician will be providing information about their opinions about one person's experiences returning to the community. Please be aware that personal information may be disclosed if required by law. The University of Manitoba Education and Nursing Ethics Board may review records related to the study for ethical compliance purposes.

### **Voluntary Participation/Withdrawal from the Study**

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time and you will not be penalized if you decide to do so. To withdraw, simply tell the researcher that you no longer wish to participate in the study. All data collected from you will be removed from the study files and disposed of in a confidential manner.

### **Questions**

You are free to ask questions about the study and your rights as a research participant. If you have any questions during or after your participation, please contact the researcher (**Michelle Nelson at xxx-xxx-xxxx**). If you have any questions about your rights as a research participant, please contact the University of Manitoba, Education and Nursing Research Ethics Board at **204-474-7122**.

**Please do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers.**

### **Statement of Consent**

I have read this consent form. I have had the opportunity to discuss any questions about the consent form and/or study procedures with the researcher. I understand that I will be provided a copy of this consent form after signing it. I understand that my participation in the study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this study. I authorize the inspection of any of my information that is related to this study by the University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in research.

Participant Signature \_\_\_\_\_ Date \_\_\_\_\_  
Participant Printed Name \_\_\_\_\_

**Please provide your mailing address if you would like to receive a summary of the study results.**

Name: \_\_\_\_\_

Street: \_\_\_\_\_

Postal Code: \_\_\_\_\_

APPENDIX D

Key Informant Interview Guide - Primary Care Physician

## **Interview/Question Guide Primary Care Physicians**

*Thank you for taking the time to meet with me to talk about your perceptions about client's experiences in the time after their brain injury. I am conducting this study trying to understand what different groups of people involved in community reintegration think about this process. There are no right or wrong answers, I am simply interested in your thoughts and opinions about what it is like to have a brain injury and to talk to you about your perceptions regarding the experiences of clients as they moved from rehabilitation to the community.*

*In general, I am interested in:*

- 1. To identify key characteristics of community reintegration for people with brain injuries;*
- 2. To enhance understanding of what "successful" reintegration means from the perspectives of each of the informant groups; and,*
- 3. To identify and understand the barriers (factors that constrain) experienced by people with acquired brain injuries when reintegrating to a community setting.*

### **BACKGROUND/CONTEXT QUESTIONS**

#### **How much do Primary Care Physicians know about a client's injury/accident?**

Possible probes:

- Would you know when/where it happened?
- When would you be made aware that your client had this injury/accident? (What are your thoughts on this timing?) When do you think physicians should be made aware of a client's injury?
- Are there any systemic factors that may contribute to how much information a physician would receive about a client's injury and prognosis? (it was suggested that being admitted to a hospital where the staff knew the doctor may change the "typical" communication process – can you comment?)
- Can you comment on any differences that may exist between different reimbursement strategies?
- What do you know about the type of services a client would receive during their rehabilitation?
- Would you know what services your client receives after they were discharged from rehabilitation?
- Did your client express that these services helpful in preparing to move home? Any one more so than others?
- Would you be involved in this client's rehabilitation? If yes - at what point in the rehabilitation process would you become involved? If No – do you think you should be involved: In what capacity?

## **QUESTIONS RELATED TO THE MEANING ATTRIBUTED TO COMMUNITY REINTEGRATION**

**Have you heard the term “community reintegration” before?**

- **If yes, what does it mean to you?**
- **If no, rephrase provide the following: “community reintegration refers to leaving the hospital or rehabilitation and going back to the community”.**

Possible Probes:

- What information would you receive about this return to community? (Was this information provided during your undergraduate work or in independent study?)  
Is this an adequate amount of information?
- From the perspective of primary care – why is community reintegration important?
  - Can it be determined if a person is successfully reintegrated? What would determine success?
- What affect do you think this experience (community reintegration) has on an individual and their daily life?

## **QUESTIONS RELATED TO BARRIERS AND CONSTRAINTS**

**Would you be aware of any problems that your client would have experienced when returning to the community?**

Possible Probes:

- If no – please elaborate.
- Would you be aware of the range of barriers experienced ie. personal (physical & cognitive) or systemic?
  - Would you be involved in helping your client overcome these problems?
- What advice would you give a colleague (physician) who has a client preparing to leave a rehabilitation program?

## **QUESTIONS RELATED TO KEY CHARACTERISTICS OF COMMUNITY REINTEGRATION**

**What aspects of life do you think are the most important for someone reintegrating to the community?**

Possible Probes:

- What aspects of life do you think are most important for someone in rehabilitation?
- What areas of life received the most/least attention during your client’s reintegration process?
- What involvement would you have in a client’s reintegration?
  - What makes it difficult for a primary care physician to be involved in this aspect of their client’s life?
- What should a client be aware of before they reintegrate to the community?

- Based on your experiences, what do you think are the key characteristics of community reintegration for people with brain injuries (e.g. social activities, access to health care, family, etc.)?

**PARTICIPANT GROUP SPECIFIC QUESTION:**

**Based on the perceptions you shared with me today, what additional roles/activities would you recommend primary care physicians become involved in for their patients with brain injuries?**

When would this occur – pre or post reintegration?

One last question that I'm interested in your perspective on relates to the study itself. Originally, my plan was to talk to a person with a brain injury, a representative from a community support organization that person used during recovery, and the person's doctor...this didn't work, I couldn't find people who were connected in this sort of way to talk with me about their experiences. From your point of view, do you have any ideas as to why this is?

APPENDIX E

Key Informant Interview: Community Service Agency



## **Interview/Question Guide Community Service Agencies**

*Thank you for taking the time to talk with me about your perceptions of your organization's clients' experiences post injury. I am conducting this study trying to understand what different groups of people involved in community reintegration think about this process. There are no right or wrong answers, I am simply interested in your thoughts and opinions about what it is like to have a brain injury and to talk to you about the issues that help or don't help as your clients move from rehabilitation to the community.*

*In general, I am interested in:*

- 1. To identify key characteristics of community reintegration for people with brain injuries;*
- 2. To enhance understanding of what "successful" reintegration means from the perspectives of each of the informant groups; and,*
- 3. To identify and understand the barriers (factors that constrain) experienced by people with acquired brain injuries when reintegrating to a community setting.*

### **BACKGROUND/CONTEXT QUESTIONS**

From the perspective of a service/support agency, what would be most important to know in supporting someone following an ABI??

Possible probes:

- Would you know When/where it happened?
- What do you know about the type of services your client received during their rehabilitation?
- Would you be aware of the services your client received after they were discharged from rehabilitation?
- Do your clients express that these services were helpful in preparing to move home? Any one more so than others?
- Is this level of awareness typical of most community service agencies?
- What factors may influence an agencies level of knowledge?

### **QUESTIONS RELATED TO THE MEANING ATTRIBUTED TO COMMUNITY REINTEGRATION**

**Have you heard the term "community reintegration" before?**

- **If yes, what does it mean to you?**
- **If no, rephrase provide the following: "community reintegration refers to leaving the hospital or rehabilitation and going back to the community".**

Possible Probes:

- Can you tell me what this experience (rehab to community) is like for your clients?
- What information would you receive about a client's return to community? How would this information be obtained?
- What is your organization's philosophy about a person with a brain injury's return to community? How is that put into practice?
- From the perspective of your organization– why is community reintegration important?
  - Can it be determined if a person is successfully reintegrated? What would determine success?

### **QUESTIONS RELATED TO BARRIERS AND CONSTRAINTS**

**Would you be aware of problems that a client experienced when returning to the community?**

Possible Probes:

- If no – please elaborate.
- Would you be aware of the range of barriers experienced ie. personal (physical & cognitive) or systemic?
  - How would you or your organization be involved in helping your client overcome these problems?
- What advice would you give a client preparing to leave a rehabilitation program?

### **QUESTIONS RELATED TO KEY CHARACTERISTICS OF COMMUNITY REINTEGRATION**

**What aspects of life do you think are the most important for someone reintegrating to the community?**

Possible Probes:

- What aspects of life do you think are most important for someone in rehabilitation?
- What areas of life do you think receive the most/least attention during a client's reintegration process?
- What role would you play in a client's reintegration?
- What should a client be made aware of before they reintegrated to the community?
- Based on your experiences, what do you think are the key characteristics of community reintegration for people with brain injuries (e.g. social activities, access to health care, family, etc.?)

**PARTICIPANT GROUP SPECIFIC QUESTION:**

**Based on the perceptions you shared with me today: if your organization had the opportunity to design a reintegration program, what would this program look like?**

Possible Probes:

- What would be the focus and emphasis?
- What would make this program different?
- What is missing in the current programs? What would you add to the current process?

One last question that I'm interested in your perspective on relates to the study itself. Originally, my plan was to talk to a person with a brain injury, a representative from a community support organization that person used during recovery, and the person's doctor...this didn't work, I couldn't find people who were connected in this sort of way to talk with me about their experiences. From your point of view, do you have any ideas as to why this is?

APPENDIX F

Key Informant Interview: Person with a Brain Injury

## **Interview/Question Guide People with Brain Injuries**

*Thank you for taking the time to meet with me to talk about your experiences since you had your injury. I am conducting this study trying to understand what different groups of people involved in community reintegration think about this process. There are no right or wrong answers, I am simply interested in you thoughts and opinions about what it is like to have a brain injury and to talk to you about the issues that helped or didn't help as you moved from rehabilitation to the community.*

1. *To identify key characteristics of community reintegration for people with Acquired Brian Injuries;*
2. *To enhance understanding of what “successful” reintegration means from the perspectives of each of the informant groups; and,*
3. *To identify and understand the barriers (factors that constrain) experienced by people with acquired brain injuries when reintegrating to a community setting.*

### **BACKGROUND/CONTEXT QUESTIONS**

#### **Can you tell me about your injury/accident?**

Possible probes:

- When did it happen?
- Where did it happen?

#### **What happened next?**

Possible probes:

- How long were you in the hospital
- When you left the hospital, where did you go (inpatient rehab/outpatient rehab/other)?
  - (a) Rehabilitation specific, possible probes
    - How long were you in rehabilitation?
    - What services did you receive while you were there (physiotherapy, occupational therapy, speech language pathology, therapeutic recreation)?
    - Were these services helpful in preparing you for moving home? Any one more so than others?
    - Any thing else about your experience in rehabilitation that was helpful?
  - (b) Once you left rehabilitation, where did you go (e.g., home, supported living, etc.),
    - Were these services helpful in preparing you for moving home? Any one more so than others?

### **QUESTIONS RELATED TO THE MEANING ATTRIBUTED TO COMMUNITY REINTEGRATION**

### **Have you heard the term “community reintegration” before?**

- **If yes, what does it mean to you?**
- **If no, rephrase “when people working in rehab talked about returning home, did they ever use the term reintegration”?** (If participant is unable to answer – will provide the following: “community reintegration refers to leaving the hospital or rehabilitation and going back to the community”).

#### Possible Probes:

- Can you tell me what this experience (rehab to community) was like for you?
- From your experience, what made moving to <Insert Location> the most difficult (constraints: people, lack of supports, rehab related shortcomings)? How did you deal with these issues? What or who was the most (least) helpful in this process?
- From your perspective – why is community reintegration important?
  - Can it be determined if a person is successfully reintegrated? What would determine success?

### **QUESTIONS RELATED TO BARRIERS AND CONSTRAINTS**

#### **What problems did you experience when you returned to <Insert Location>?**

##### Possible Probes:

- What made it so difficult?
- Were the barriers personal (physical & cognitive) or systemic?
- Do these problems still exist?
  - If yes - What do you do (compensatory strategies) to accommodate or minimize these identified barriers?
  - If no – what happened that helped you get rid of those problems?
- What advice would you give someone who is getting ready to leave rehabilitative care?
- Based on your experience, what are the key characteristics of community reintegration for people with brain injuries?

### **QUESTIONS RELATED TO KEY CHARACTERISTICS OF COMMUNITY REINTEGRATION**

#### **What aspects of life do you think are the most important for someone reintegrating to the community?**

##### Possible Probes:

- What aspects of life do you think are most important for someone in rehabilitation?
  - Did you have an opportunity to tell your therapists (in rehab) what was important to you?
  - If “yes”, did it change your therapy sessions?
  - If “no”, would you have liked to tell them what was important to you? Why did you not tell them?
- What areas of life received the most/least attention during your reintegration process?

- If you were returning to the community again, what, if anything, would you do differently?
- Now that you are in the community, living <INSERT LOCATION>, can you think of anything that you wished you had known before reintegrating to the community?
  - Who should have been responsible for telling/showing you?
  - How did you learn or obtain those things after you were living at <INSERT LOCATION>?

**PARTICIPANT GROUP SPECIFIC QUESTION:**

**Based on the experiences you shared with me today, if you could give the health care administrators some feedback about the rehabilitation program you used, and your experiences of community reintegration, what would you say?**

**"One last question that I'm interested in your perspective on relates to the study itself. Originally, my plan was to talk to a person with a brain injury, a representative from a community support organization that person used during recovery, and the person's doctor...this didn't work, I couldn't find people who were connected in this sort of way to talk with me about their experiences. From your point of view, do you have any ideas as to why this is?"**

APPENDIX G

Researcher Assumptions



### **Researcher's Preconceptions Regarding Community Reintegration**

- I. The process of community reintegration is important for people with brain injuries and rehabilitation programs should address the range of issues potentially experienced during return to community.
- II. Rehabilitation programs are primarily focused on functional recovery, and people with brain injuries are discharged when they have recovered enough functional skills to live independently or with supports from family and home care programs.
- III. People with brain injuries are discharged from rehabilitation programs with little or no skill development regarding instrumental activities of daily living.
- IV. People with brain injuries require support and services in the community in order to resume their activities of daily living.
- V. Primary care physicians are always aware of their patients' brain injury and subsequent admittance to rehabilitation programs, as patients are expected to see their primary care physician upon discharge.
- VI. Primary care physicians do not have time to work on psycho-social issues with their clients with brain injuries.
- VII. Primary care physicians are primarily focused on physical health and functioning.
- VIII. People with brain injuries, community service agencies and primary care physicians believe this to be an important area of study, and one in which there are areas of improvement.
- IX. People with brain injuries, community service agencies and primary care physicians currently interact regarding the wide range of needs people with brain injuries experience during the process of community reintegration.