EXPERIENCES OF INPATIENT REHABILITATION FROM THE PERSPECTIVE OF PERSONS WITH ACQUIRED BRAIN INJURY – AN INTERPRETIVE DESCRIPTION STUDY

By:

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Abstract

Background & Purpose: Sustaining an acquired brain injury (ABI) can often lead to admission to an inpatient rehabilitation program. The purpose of inpatient rehabilitation is to provide individualized, patient-centered therapy in order to facilitate community re-integration. Considering the patient perspective is beneficial for informing patient-centered care because clinicians and program administrators may develop greater awareness and understanding of patient needs and preferences. There is a lack of qualitative research investigating patient experiences and perspectives of ABI inpatient rehabilitation, and the majority of existing research was conducted in non-Canadian contexts. The present study was thus designed to describe and interpret patient experiences of an ABI inpatient rehabilitation program in urban Ontario. The purpose was to contribute to a patient lens that inpatient rehabilitation staff could consider in their work.

Methods: An interpretive description approach was adopted for this qualitative study. Twelve participants were purposively sampled from a regional ABI rehabilitation program. They completed semi-structured interviews about their experiences. Interviews were transcribed, coded, and analyzed to identify major themes.

Results: Three major themes were identified from the analysis and arranged around three time points. At the time point prior to admission to inpatient rehabilitation, the theme was “Life Rerouted,” where participants described their lives being diverted from what was “normal” after sustaining an ABI. Inpatient rehabilitation was seen as a way to return to their pre-injury life. The second theme described experiences within inpatient rehabilitation and was entitled, “Autonomy within Rehab.” Under this theme, participants emphasized the importance of personal autonomy over their choices and abilities while in rehabilitation, with three related sub-themes: interactions with clinicians, perceptions of institutional policy, and the involvement of family members. Under a minor theme, not directly related to aspects of autonomy, entitled “social comparisons,” participants also made comparisons of their recovery progress to other patients. The third and final theme reflected participants experiences just after discharge and was entitled, “Life (and Recovery) Go On.” Under this theme, participants described an ongoing recovery process leading to sentiments of both frustration and hope for the future.

Discussion: An overarching key message was developed from these themes: “re-establishing personal identity is important to the recovery process.” Two theories (biographical disruption and relational autonomy) are used to interpret this message and describe the strategies and perspectives adopted by patients during inpatient rehabilitation as they attempted to cope with the psychosocial impacts of ABI on their lives.

Conclusions: The findings of this study provide knowledge and a theoretical lens in which program staff can view and understand patients’ experiences, needs and preferences. These findings may enhance patient-centered care within the context of ABI inpatient rehabilitation.

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Table of Contents

List of Figures and Tables

List of Appendices

List of Abbreviations

ABI	Acquired Brain Injury
ADL	Activities of Daily Living
FIM	Functional Independence Measure
GCS	Glasgow Coma Scale
IADL	Instrumental Activities of Daily Living
ICF	International Classification of Functioning, Disability & Health
INESSS	Institut national d’excellence en santé et en services sociaux
LOC	Loss of Consciousness
LOS	Length of Stay
nTBI	non-Traumatic Brain Injury
ONF	Ontario Neurotrauma Foundation
PTA	Post-Traumatic Amnesia
TBI	Traumatic Brain Injury

Declaration of Academic Achievement

The following is a declaration that the content of the research in this document was completed by Janelle Panday and recognizes the contributions of Dr. Jocelyn E. Harris, Dr. Sandra Moll, and Dr. Diana Velikonja in both the research process and the completion of this thesis. Janelle Panday contributed to the study conceptualization and design, completed and submitted the ethics application, and was responsible for data collection, data analysis and writing the contents of this thesis. Dr. Harris contributed to the study design and conceptualization and assisted with data collection, analysis, writing and editing. Drs. Moll and Velikonja contributed to the study design, conceptualization and analysis, and provided critiques and comments on the chapters of this thesis.

Chapter 1: Introduction & Literature Review

1.1 Acquired Brain Injury

Acquired brain injury (ABI) is a leading cause of injury and impairment in Canada, with over 100,000 cases reported annually (Brain Injury Association of Canada, 2014). The rate of occurrence of ABI in Canada surpasses the rates of multiple sclerosis, spinal cord injuries, HIV/AIDS and breast cancer combined (Brain Injury Association of Canada, 2014). In Ontario alone, more than 18,000 new cases of ABI occur each year (Ontario Brain Injury Association, 2012). Furthermore, over half a million Ontarians currently live with the residual effects of ABI-induced impairments (such as physical and cognitive deficits); impacting their ability to complete daily activities and to participate fully in their communities (Ontario Brain Injury Association, 2012).

ABI is defined as any non-progressive brain damage that occurs after birth (Chen, Chan, Zagorski, Parsons, & Colantonio, 2014) and may be categorized as either a traumatic brain injury (TBI) or a non-traumatic brain injury (nTBI). TBI is defined as any brain damage that is due to a jolt or a blow to the head (Rao, McFaull, Thompson, & Jayaraman, 2017). The most common sources of TBIs are falls, motor vehicle accidents, and being struck by or against objects (Jinadasa & Boone, 2016; Langlois, Rutland-Brown, & Wald, 2006). Comparatively, nTBI results from brain damage caused by health condition or infection, such as anoxia, encephalitis, brain tumour, or spontaneous hemorrhage (Cullen, Park, & Bayley, 2008).

Persons with nTBI and TBI have been found to experience a similar course of recovery: brain damage, followed by a period of brain reorganization and recovery until g a stabilized plateau of brain function is reached (Cullen et al., 2008). Past research indicates that approximately the same proportion of persons with nTBIs and persons with TBIs are admitted to ABI inpatient rehabilitation in Ontario (Colantonio et al., 2011; Cullen, 2007). Additionally, persons with TBI and persons with nTBI are shown to achieve similar gains in motor and cognitive function in inpatient rehabilitation (Shah, Al-Adawi, Dorvlo, & Burke, 2004; Shah, Carayannopoulos, Burke, & Al-Adawi, 2007). Given these similarities, both persons with nTBI and persons with TBI were included in the present study. It should be noted that the majority of existing studies focus on TBI; however, where possible, differential (TBI, nTBI) statistics and findings are presented in this literature review.

After sustaining an ABI, persons may be admitted to an inpatient rehabilitation program. These programs can impose significant financial costs on the Ontario healthcare system. In a retrospective study by Chen et al. (2012), first-year medical costs related to participating in ABI inpatient rehabilitation in Ontario (between 2004 and 2007) amounted to $93,340 per person with TBI and $82,241 per person with nTBI. These costs were significantly higher than the yearly inpatient costs incurred by persons with cardiac arrhythmia ($22,000), stroke ($34,000) or hip fracture ($35,000) (Chen et al., 2012, p.10).

With respect to demographics of the ABI inpatient rehabilitation population, Colantonio and colleagues (2011) found that between the years 2001 and 2006, 60.4% (n = 3282) of persons sustaining an ABI in Canada received treatment from inpatient facilities in Ontario. Significantly more males (61.6%) than females (38.4%) were admitted to inpatient rehabilitation, although for persons aged 70 and over, the ratios of men to women were similar. Also, significantly more females sustained a nTBI (n = 1348) as compared to a TBI (n = 737). 59.7% of persons were found to be between the ages of 30 and 70 years (age range = 16 to 100), and the average ages for TBI and nTBI were 47.0 and 58.8 years, respectively. Additionally, 80% of persons were noted to live in urban areas as compared to rural areas.

ABI is prevalent, is a costly public health concern and results in numerous admissions to inpatient rehabilitation each year. The section that follows provides descriptions of common impairments, activity limitations and participation restrictions that can impact a person's life within the first year of sustaining an ABI, and that are often addressed within inpatient rehabilitation programs.

1.2 The Impact of ABI

The International Classification of Functioning, Disability and Health (ICF) was chosen to provide a common language for describing typical outcomes experienced by persons with ABI under the domains of "body functions and structures," "activities" and "participation" (World Health Organization, 2002):

1. **Body functions and structures** refer to the physiological workings of the body or organs. **Impairments** include any deficits or deviations of these, as a result of injury or health conditions. Persons with ABI may present with a myriad of physical, cognitive, behavioural and emotional impairments within the first-year post-injury (Levine & Flanagan, 2010). Table 1 (below) highlights the most common impairments or impaired physiological functions that are typically seen within ABI inpatient rehabilitation; and were identified using the Evidence-Based Review of Moderate-to-Severe Acquired Brain

Injury (ABIEBR, n.d.). These impairments can negatively impact a person's daily life by causing difficulties or challenges related to routine activities such as eating, walking, self-care and communication with others (Rabinowitz & Levin, 2014).

Table 1: Common impairments or impaired physiological functions within the first year of ABI

Physical[1]	Cognitive[2]	Behavioural & Emotional[3]
balance, coordination & gait	memory & new learning	agitation & irritability
fine motor coordination	reasoning & insight	aggression
spasticity	visuospatial processing	reduced motivation
hemiparesis	concentration & attention	mood changes
fatigue & sleep disturbances	verbal expression	impulsivity
	sequencing & planning	

2. Activity refers to any task a person can complete within his or her environment, and **activity limitations** refer to any challenges experienced when attempting to complete such tasks. As a result of ABI-induced impairments, limitations in activities of daily living (ADL) and instrumental activities of daily living (IADL) are common. These limitations can inhibit independent fulfillment of activities that are usually required in the home, at work, school or in other areas of the community. Activity limitations can include difficulties in completing self-care tasks, eating, medication management, shopping, cooking, budgeting and money management, and care of one's home (Duong et al., 2004). Persons with ABI may also experience difficulties with driving, taking part in leisure activities, and using common technology (Bottari, Dassa, Rainville, & Dutil, 2010;

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[1] (Janzen, Anderson, MacKenzie, Marshall, & Teasell, 2016; Marshall, Janzen, Aubut, Janssen, & Teasell, 2016)

[2] (Marshall, Rees, Aubut, Willems, & Teasell, 2013; Welch-West, Ferri, Aubut, Togher, & Teasell, 2013)

[3] (Rees et al., 2016)

Johansson, Högberg, & Bernspång, 2007; Lindén, Lexell, & Lund, 2010; Rosario et al., 2017; Wise et al., 2010). Greater number of activity limitations are associated with lower levels of life satisfaction (Whiteneck, Cuthbert, Corrigan, & Bogner, 2016) and poorer quality of physical and mental health one year after ABI (Andelic et al., 2010).

3. Participation refers to involvement in life roles and situations and any challenges to participation are termed **restrictions**. A person's participation in their home and community is often restricted as a result of ABI-induced activity limitations. For example, persons with ABI who report issues with the use of everyday technology are less likely to be working in paid employment and more likely also to report problems related to involvement in their home and community (Lindén et al., 2010). Within the first year post-ABI, common participation restrictions include problems fulfilling roles such as worker, student, volunteer, friend, spouse and parent provider (Andelic et al., 2010; Edwards, Daisley, & Newby, 2014; Sloan et al., 2009). Persons with TBI are also less likely to return to pre-injury levels of active leisure participation and are more likely to engage in sedentary activities (Wise et al., 2010). An inability to actively engage in and fulfill these roles can lead to social isolation, decreased life satisfaction (Sloan et al., 2009) and lower quality of life within one-year post-ABI (Andelic et al., 2010).

As a result, participation restrictions, along with impairments and activity limitations, can negatively impact community integration after ABI (Sander, Clark, & Pappadis, 2010; Sloan et al., 2009). Community integration is defined as being actively involved or engaged in a wide range of activities, duties and social roles within one's home and extended environment (Willer & Corrigan, 1994). As described above, a person’s ability to complete activities, duties and social roles can be inhibited by the effects of ABI. These issues can, therefore, impede a person’s ability to fully integrate into their community, a notably important goal for persons with ABI (McColl et al., 1998; Nalder, Fleming, Cornwell, Shields, & Foster, 2013). Facilitation of community integration, with the remediation and compensation of impairments and activity limitations, is, therefore, the main goal targeted within ABI inpatient rehabilitation programs (Janzen, Lippert, Weiser, Wiener, & Teasell, 2015; Sander et al., 2010).

In summary, a number of impairments, activity limitations and participation restrictions can impact a person’s ability to re-integrate into their community within the first year after ABI. The purpose of ABI inpatient rehabilitation programs is to help persons regain abilities and develop compensatory strategies in order to facilitate community re-integration. To illustrate how inpatient rehabilitation is designed to accomplish this, the following section outlines the common structure and service delivery model of ABI inpatient rehabilitation programs in Ontario.

1.3 ABI Rehabilitation in Ontario

ABI treatment and rehabilitation programs across the world are diverse. Many developed countries utilize evidence-based clinical practice guidelines which are adapted to their specific healthcare systems (Cullen et al., 2016). In Ontario, the structure and implementation of ABI inpatient rehabilitation programs follow clinical practice guidelines established by a partnership between the Ontario Neurotrauma Foundation (ONF) and Quebec’s *Institut national d’excellence en santé et en services sociaux* (INESSS), primarily based on level B and C evidence. These guidelines provide detailed recommendations regarding the elements needed to create an optimal, patient-centered, ABI rehabilitation program, and for assessing and treating ABI-induced impairments (INESSS-ONF, 2015).

ABI inpatient rehabilitation generally falls into a continuum that begins with acute care (after initial medical treatment), followed by either discharge to a community setting (such as the person's home, assisted living programmes or residential ABI programmes), or referral to an inpatient rehabilitation unit or program (Cullen et al., 2016). Since the present study is focused on patient experiences in an interdisciplinary ABI inpatient rehabilitation program in southern Ontario, this last stage of rehabilitation will be the focus of this literature review.

The primary goals of ABI inpatient rehabilitation are to (1) help persons as much as possible to restore their physical, cognitive, behavioural and emotional functioning, and (2) teach compensatory strategies and skills for non-remediable impairments, so that persons can integrate into their planned discharge setting (ABIKUS, 2007). The composition of ABI inpatient rehabilitation is interdisciplinary, in that staff members from a variety of disciplines coordinate and work as a team to provide care (Choi & Pak, 2006; INESSS-ONF, 2015). According to the INESSS-ONF (2015) clinical practice guidelines, a typical ABI inpatient rehabilitation team consists of one or more occupational therapists, physical therapists, speech-language pathologists, social workers, neuropsychologists, behaviour therapists (or psychologists), nurses, physicians (or physiatrists), nutritionists/dieticians, as well as persons holding support roles (such as a clinical coordinator), therapeutic recreationists and pharmacists.

Referral to ABI inpatient rehabilitation is dependent on the specific admission criteria of each program; however, persons will typically be admitted once they are diagnosed with ABI, are deemed medically stable, and are determined by a clinician, such as an occupational therapist, to benefit from inpatient rehabilitation (INESSS-ONF, 2015). That is, they should be able to participate, engage, learn and experience progress from inpatient rehabilitation. Within the first week of admission to inpatient rehabilitation, a clinical coordinator from the inpatient rehabilitation program will typically consult with the person with ABI, their family/carer and their attending clinicians, to set goals and determine a preliminary discharge plan (Cullen, 2007; INESSS-ONF, 2015).

Once admitted, patients undergo detailed assessments of their functional, activity, and participation domains, which lead to recommendations for altering or confirming individualized goals and discharge plans (INESSS-ONF, 2015). These recommendations are often communicated through a meeting facilitated by the clinical coordinator and program clinicians (such as the occupational therapist, physical therapist and neuropsychologist). In these meetings, patients and their family members are provided with the plan of care and given an opportunity to raise concerns and ask questions (INESSS-ONF, 2015). The team of clinicians, particularly the occupational, physical and speech-language therapists, will then work with the patient towards their goals, in order to improve impairments and reduce activity limitations and participation restrictions. Patients typically participate in therapy for a minimum of three hours per day, five days a week, (Cullen, 2007; INESSS-ONF, 2015). Day, overnight and weekend visits to intended discharge settings are also facilitated to begin the community integration process for both patients and their caregivers (INESSS-ONF, 2015).

Overall, these details about the structure and service delivery of inpatient rehabilitation demonstrate how it is designed to be patient-centered. The following section considers the importance of patient-centered care and how it may be enhanced by considering patient perspectives.

Patient-centered care. Patient-centeredness is a principle that entails clinicians recognizing each patient as a unique individual with consideration of their knowledge, goals, values, preferences and capabilities (Cott, 2004). Clinicians typically try to empower patients to make decisions or share in decision-making about their care (Sandman & Munthe, 2010) and support patient autonomy (Hammell, 2013) where possible. To accomplish this, clinicians make efforts to understand patients holistically (Constand, MacDermid, Dal Bello-Haas, & Law, 2014), and gain knowledge of a patient's experiences with illness and disease, and their perspectives on recovery (Cott, 2004). These aspects of patient-centeredness emphasize the importance of considering patient voices in the provision of rehabilitation and other healthcare contexts. Efforts to include the patient voice in the research evidence-base utilized to guide clinical practice can consequently enhance patient-centeredness, by providing clinicians and program administrators with a greater understanding of patient needs and preferences. Patient voices may also help clinicians and administrators to recognize or confirm barriers or gaps in health care services that should be addressed.

One Ontario hospital system has reported efforts to engage the voices of multiple stakeholders (individuals, community organizations, healthcare professionals and more) in informing changes to their service delivery models (Hamilton Health Sciences, 2016). This included efforts to inform and improve service delivery within their ABI rehabilitation program, resulting in recommendations related to program access, medical risks faced by persons waiting for admission to rehabilitation, and various complexities related to patient care, such as co-morbidities and age-related factors (Hamilton Health Sciences, 2016). This endeavour reflects the importance of including patient voices in informing patient-centered care, as well as a perspective that healthcare can be continuously improved through the engagement of relevant stakeholders. However, the methods and analysis utilized to garner this information were not clearly delineated, which makes it difficult to determine the contributions that were made by persons with ABI. Qualitative research that specifically focuses on patient experiences of ABI inpatient rehabilitation could provide an enhanced understanding of their needs and preferences within this context. Considering patients' perspectives about their ABI inpatient rehabilitation experiences can help to inform and enhance patient-centered care.

1.4 Enhancing Patient-Centered Care with Patient Perspectives

Qualitative research methodology can provide a useful lens to describe and interpret lived experiences through expressed opinions, thoughts, feelings and attitudes (Fossey, Harvey, McDermott, & Davidson, 2002). A person's perspective of his or her experiences as a "patient" in the context of inpatient programs can reflect behaviours and attitudes towards, and engagement in, the rehabilitation process (Öhman, 2005). These behaviours and attitudes can consequently impact functional outcomes at discharge (Öhman, 2005). The patient perspective of rehabilitation is thus important to consider, as persons who were patients can provide descriptions of their experiences and journeys (Cott, 2004). Qualitative research efforts that consider patient voices and experiences can make valuable contributions to the research base by providing healthcare professionals with more awareness and a deeper understanding of patient needs (Kneafsey & Gawthorpe, 2004). This knowledge may, in turn, help to enhance patient-centeredness and lead to more positive experiences for persons who participate in inpatient rehabilitation.

Most qualitative research related to ABI rehabilitation has focused on experiences of (1) the transition from hospital to home within the first six months post-discharge (Abrahamson, Jensen, Springett, & Sakel, 2016; Nalder et al., 2013; Piccenna, Lannin, Gruen, Pattuwage, & Bragge, 2016; Turner, Fleming, Ownsworth, & Cornwell, 2008, 2011; Turner, Ownsworth, Cornwell, & Fleming, 2009), (2) outpatient programs (Couchman, McMahon, Kelly, & Ponsford, 2014; Doig, Fleming, Cornwell, & Kuipers, 2009), or (3) long-term experiences related to ABI-induced life changes (Levack, Kayes, & Fadyl, 2010). A qualitative review of the transition literature indicated that a common concern discussed by persons with ABI is whether inpatient rehabilitation staff provided adequate discharge planning support to them and their carers (Piccenna et al., 2016). These qualitative studies highlighted patient-perceived gaps in inpatient staff support and informed recommendations for improving discharge planning, such as: (1) providing enough guidance and information about the potential challenges of the transition experience, (2) helping in coordinating post-discharge outpatient services and (3) being available to answer questions around the time of discharge. These studies, however, primarily took place in Australia, Europe and the United States, and may not be transferable to ABI rehabilitation in Ontario, given that rehabilitation contexts may differ based on the clinical guidelines of each region or country. The one Canadian study noted in this review focused on the transition barriers faced by Indigenous persons with ABI within northwestern Ontario (Keightley et al., 2011), highlighting issues that would be unique to this subset of the patient population.

There is even less qualitative research that explores patient experiences during their stay in ABI inpatient rehabilitation (Oyesanya, 2017), with just one related qualitative research project conducted in Canada. This project was unique in that it utilized focus groups with TBI survivors, informal carers and healthcare professionals to contribute to the production of theatrical play describing various experiences of living with TBI (Colantonio et al., 2008). This play was then used as a form of educational intervention to teach rehabilitation staff about patient-centered principles (Kontos et al., 2012). The details of these focus groups, however, were not provided in the literature; making it difficult to discern the themes that were developed about this stage of care.

The current state of the qualitative ABI literature based in urban Ontario thus reflects a need for more studies that seek patient voices to describe their experiences within and after ABI inpatient rehabilitation. The first step to contributing to this literature base should be conducting research studies that explore patient experiences of ABI inpatient rehabilitation. Findings from this research are anticipated to improve clinician and program administrator awareness of patient needs, and consequently to improve patient-centered care. The following section reviews how one relevant study described and interpreted patient perspectives of an Australian inpatient rehabilitation program.

1.5 Literature Exploring Perspectives of ABI Inpatient Rehabilitation

A recent systematic review by Oyesanya (2017) demonstrated that only one qualitative study from Australia has explicitly described experiences of inpatient rehabilitation from the perspective of persons with TBI. In this study, researchers utilized a phenomenological approach and conducted semi-structured interviews with persons with TBI (n = 16) and stroke (n = 4) regarding their perceptions of inpatient rehabilitation (Fleming, Sampson, Cornwell, Turner, & Griffin, 2012). Participants were interviewed just prior to discharge as part of a larger longitudinal study exploring perspectives of the transition from hospital to home after brain injury. The questions posed about their inpatient experiences were designed to build rapport with participants, prior to the discussion of their perspectives on the transition experience. Responses to these initial questions were analyzed and led to the identification of three key themes: (1) rehabilitation context/environment, (2) activity/occupation, and (3) support and adjustment. First, under rehabilitation context/environment, participants discussed their views of the physical environment of the rehabilitation unit, as well as the organizational and attitudinal environment of the hospital setting and the staff. The second theme, activity/occupation, referred to discussions about feelings of boredom, frustration and a perceived lack of progress during unstructured time outside of therapy. Finally, the theme of support and adjustment encapsulated participants' interactions with both family carers and rehabilitation program staff, and the support these parties provided to them in a challenging period of their lives.

Overall, Fleming and colleagues (2012) found that participants were able to identify areas of concern and potential avenues for improvement within this inpatient rehabilitation program; however, these findings were not without limitations. As mentioned, the questions posed to participants about inpatient rehabilitation were designed to build rapport. This limited exploration of the inpatient rehabilitation experience as a comprehensive whole, with a lack of discussion around participants' admission experiences, their daily routines and their perceptions about therapeutic activities, outside of the importance of structured time.

The setting of this study was limited to a single multidisciplinary inpatient rehabilitation unit in Australia. This reduces the transferability of these findings outside of similar settings since guidelines ABI inpatient rehabilitation programs can differ significantly between countries or regions. The findings of this Australian study are therefore not representative of experiences of ABI inpatient rehabilitation programs in other regions, like Ontario, and further research is necessary to explore these in order to potentially identify themes unique to the Ontario setting.

Additionally, this study did not include persons with nTBI but did include persons with stroke. In Ontario, ABI inpatient rehabilitation programs include both persons with TBI and nTBI. Moreover, stroke is also not categorized under ABI in Canada, and stroke rehabilitation follows unique clinical practice guidelines (Hebert et al., 2016). Thus, while this study adds significant knowledge about the patient perspective of inpatient rehabilitation after brain injury, it has only captured part of the ABI inpatient rehabilitation experience within the specific context of one program in Australia. Further research is required to expand these findings and to investigate programs in other settings.

1.6 Study Rationale

ABI has high prevalence rates across Canada and within the province of Ontario. ABI also affects a diverse group of people and can ultimately lead to significant personal and healthcare costs. Many persons are admitted to an inpatient rehabilitation program to mitigate the impact of ABI. ABI inpatient rehabilitation programs in Ontario are designed to be patient-centered, with the target of helping persons to meet individualized goals that will prepare them to re-integrate into a community setting. Considering patient perspectives and experiences using qualitative research methods can help clinicians and program administrators to increase their understanding of patients' needs and preferences. The inclusion of patient voices to increase this understanding can consequently enhance patient-centered care. Past studies exploring the patient perspective have highlighted issues related to discharge planning and transition back into the community. There is a lack of research, however, exploring the ABI inpatient rehabilitation experience from admission to discharge. The majority of these studies have also taken place outside of Ontario or Canadian settings, where inpatient rehabilitation services may significantly differ from those provided in other countries. In the study by Fleming and colleagues (2012), persons with TBI (and stroke) provided a unique perspective of an inpatient rehabilitation program in Australia. Participants' insights highlighted potential facilitators and barriers to their rehabilitation experiences that may not have been otherwise recognized by program staff. This study, however, was limited by a lack of investigation of inpatient rehabilitation as a comprehensive whole (that is, experiences from admission to discharge), and more significantly, a lack of transferability to other inpatient settings with different ABI patient populations – such as in Ontario-based programs. The current study was thus designed to address this gap in the literature.

Research Question. The present study was designed to answer the question, "What should clinicians and program administrators know about patients' experiences in an ABI inpatient rehabilitation program in urban Ontario, in order to improve understandings of patient needs and preferences?" Participants experiences of ABI inpatient rehabilitation from admission to discharge were explored using in-depth interviews. The purpose of this study was to provide a patient lens for clinicians and program administrators to better understand patient experiences within an ABI inpatient rehabilitation program in urban Ontario. This study contributes to the sparse qualitative literature base investigating the experiences and perspectives of persons with ABI in Ontario. The findings may provide a patient perspective for ABI inpatient rehabilitation clinicians and program administrators to consider in their work. This might lead to an enhanced understanding of patient needs and may, therefore, enhance patient-centered care in this clinical context.

Chapter 2: Methodology

The methods of this study were guided by interpretive description, which is an applied approach to qualitative inquiry (Thorne, Reimer-Kirkham, & MacDonald-Emes, 1997). With this approach, clinical phenomena are explored in-depth to develop greater understanding and to provide useful recommendations for clinical practice and programming (Thorne, Reimer-Kirkham, & O'Flynn-Magee, 2004). Interpretive description follows a constructivist and naturalistic orientation to inquiry, with the assumption that realities are multiple, complex, subjective and based on past experiences and interactions with others (Hunt, 2009). Exploring patterns and themes in persons' experiences allows an opportunity to develop an understanding and language around what may be encountered in clinical practice (Thorne, 2016). The researcher enters the field with recognition of prior knowledge and biases of the clinical phenomenon under study and, with research participants, co-constructs understandings of the phenomenon to generate new knowledge. Findings are then considered in relation to previous research in order to challenge or add to previous assumptions and to inform clinical practice (Thorne et al., 2004).

Interpretive description was thus chosen to address the current research question: *"What should clinicians and program administrators know about patients' experiences in an ABI inpatient rehabilitation program in urban Ontario, in order to improve understandings of patient needs and preferences?"*

Interpretive description literature informed the methods used to describe and interpret patient experiences of ABI inpatient rehabilitation and to develop useful suggestions to inform programs in this clinical context (Thorne, 2016). The following chapter outlines these methods. First, in order to provide context for participants' experiences, the setting of the ABI inpatient rehabilitation program is described. Next, strategies employed for the sampling and recruitment of participants are explained. The data collection and analysis processes are then outlined in detail, including a description of the principal researcher's positionality in the research process. Finally, a discussion of the strategies implemented to improve the transparency of the research process, and to thus enhance trustworthiness and rigour, is provided. Ethics approval for this study was received from the Hamilton Integrated Research Ethics Board (Appendix I) and all participants provided written, informed consent (Appendix II).

2.1 Setting

The participants of this study completed an interdisciplinary regional ABI inpatient rehabilitation program located in southern Ontario. Typically, referrals to this program originate from the city of Hamilton, the regions of Halton, Waterloo, Niagara, and several surrounding counties. The focus of this program is to facilitate recovery by remediation or compensation of skills and functional abilities with the aim of discharge to the most independent living situation possible. The service delivery model of the program is designed to be patient-centered, with a focus on each person's individualized and mutually agreed upon rehabilitation goals.

A person's length of stay within this program may range from two weeks to three months. During this stay, admitted persons (from here on referred to as "patients") live on the ABI inpatient unit where the program is situated. The unit is electronically secured for safety and includes private and shared patient rooms, as well as communal spaces for meals, therapy and leisure. Each patient's daily routine is designed by therapists with reference to their individual goals and can target, for example, improving ADL performance, mobility, cognition, recreation and leisure. A patient's day will typically begin with self-care activities, such as bathing and dressing, with help from a rehabilitation assistant as necessary. Patients are provided with therapy five days a week, and this can include both group sessions as well as individualized sessions. Therapists (e.g. physical/occupational/speech therapists) conduct these sessions, or they may be delegated to a rehabilitation assistant. In addition, patients will participate in other activities, such as relaxation therapy, aquatic fitness, supervised group outings, community-based opportunities for skill-building, and various support groups. Patients also have free-time after meals and in the evenings. Throughout the day, patients may interact with various clinicians, other patients and their visiting family members and friends. Weekends consist of free time and recreational activities, or patients may go on a trial home visit (or another discharge setting as a trial) to assess their abilities and safety within their community environment.

A patient's readiness for discharge is discussed within the clinical team during weekly meetings and progress towards discharge is based on a patient's ability to meet the functional demands of their discharge location. Recommendations for discharge are then conveyed to the person with ABI and their family members in a “family meeting.” In this meeting, clinicians, family members and the person with ABI discuss the person’s progress and set a potential discharge date. When a person is discharged, they receive a discharge binder, which includes progress reports and recommendations for future care and outpatient services.

2.2 Participant Sampling & Recruitment

A purposive sampling strategy was adopted for this study. Purposive sampling is a non-probability method in which researchers select participants that have experience with the phenomenon of interest, and thus may be considered to be “information-rich” (Palinkas et al., 2015; Patton, 1999). There are a number of purposive sampling techniques, and in this study, a criterion sampling method (Palinkas et al., 2015) was utilized to recruit participants who had completed the inpatient rehabilitation program and thus would be able to provide detailed accounts of their experiences of that specific program. Clinicians from the ABI inpatient and two outpatient programs (located at the same site) referred potential participants based on the following inclusion criteria: age 18 or older; had completed the ABI inpatient rehabilitation program; English-speaking; within 13 months of sustaining an ABI, and able to participate in a 30-45-minute interview (as determined by clinicians). Participants were excluded if they had dementia, receptive aphasia, severe memory deficits, and significant cognitive, communication or behavioural impairments.

During the recruitment process, clinicians identified potential participants using the inclusion criteria mentioned above and briefly described the study to them. When an individual expressed interest in participating in the study, the principal researcher (JP) met with them to describe the study in detail and obtained written consent to conduct the interview. Once consent was obtained, an in-person (at hospital site or home) or telephone interview was scheduled. Participants who were referred from the inpatient program were not interviewed until three to four weeks post-discharge. This interview timeframe was chosen to ensure that the participant could provide a comprehensive description of their experience, including their discharge transition. As a token of appreciation for their time, participants received a $10 gift card.

Sample size considerations. Theorizing an adequate sample size is a contested issue within writings on qualitative methodology. Achieving “saturation” is a common goal for many qualitative researchers and is often defined as the point at which no new themes are emerging from data analysis, and data collection becomes redundant (Morse, 1995). This would imply that the researcher has reached sufficient depth in data collection and analysis, and meeting an adequate sample size is believed to support achieving saturation (Fusch & Ness, 2015). There is, however, a lack of agreement in qualitative methodology literature around what an “adequate” sample size comprises (Bowen, 2008) as well as clear explanations of how to determine if saturation is actually achieved. Additionally, it is noted that less experienced qualitative researchers (such as graduate students) might have difficulties ascertaining whether saturation was obtained (Fusch & Ness, 2015). On consideration of these points, as well as on discussion with a colleague who also utilized interpretive description methods in their graduate work, the principal researcher (JP) chose not to use the concept of saturation to guide sample size projections and assessment of the quality of the findings of this study.

Writings on interpretive description also suggest that the researcher should attempt to achieve sufficient depth to answer the research question or explore a clinical phenomenon (Thorne, 2016). Samples sizes ranging from five to 30 participants are theorized to be suitable for meeting the research objective of conducting an in-depth exploration of a common phenomenon (Thorne, 2016). Sample sizes can initially be based on existing literature about the topic and may change based on the information-rich cases or interactions required to achieve depth during processes of data collection and analysis (Thorne, 2016).

This study explored the common phenomenon of participating in ABI inpatient rehabilitation using in-depth semi-structured interviews. Given the relative lack of interpretive description studies (along with other qualitative research methods) exploring the ABI inpatient experience, the findings of two previous studies were considered when estimating the initial sample size. The first was a previous interpretive description study exploring perceptions of motivation after ABI from the perspective of community-dwelling adults (Kusec, Froese, Albright, Panday, & Harris, 2017). In this ~~previous~~ study, depth was deemed to be achieved with 20 participants. The second, while not an interpretive description study, was the Australian phenomenological study (described in the introduction) which focused on perspectives of inpatient rehabilitation (Fleming et al., 2012). These authors also had a sample size of 20 (although four persons of the sample had a stroke diagnosis) and stated that they had achieved saturation. Thus, the initial sample size projected for this study was 20 participants. Due to time constraints, however, a final number of 12 was achieved with three follow-up interviews (described within the Data Analysis, section 2.4 below). Although the sample size goal was not met, the principal researcher believes that there was enough depth of major themes to answer the research question adequately. The limitations related to the lack of depth in some sub-themes are considered in the Discussion chapter of this thesis.

2.3 Data Collection

In-depth, audio-recorded, semi-structured interviews, comprised of open-ended questions (described below), were conducted with participants ~~in order to pose open-ended questions~~ about their experiences and perspectives of the ABI inpatient rehabilitation program. Interviews ranged from 30 to 60 minutes in length, with the interviewer (JP) asking these questions, as well as probing and additional questions based on the participant's responses. Descriptive data were also collected in order to provide a detailed depiction of the participant group. Demographic and ABI-related data were obtained during interviews and through the review of participants' medical charts. Furthermore, data were collected to describe and understand the inpatient program with the goal of situating the experiences and perspectives shared by participants during the interview process. Information about the inpatient program was obtained from JP's observations of the rehabilitation unit, discussions with a clinical coordinator and a physical therapist from the unit, a review of available documents about the inpatient program, and information garnered during committee meetings (where committee member DV is also a clinician with the inpatient program).

Interview question development. The interview script was designed to address and be consistent with the research purpose of exploring patient experiences from admission to discharge of ABI inpatient rehabilitation. Interview questions were developed through a review of qualitative studies exploring ABI rehabilitation, including topics discussed in the previously-described Australian study on perspectives of ABI inpatient rehabilitation (Fleming et al., 2012) and consultation with committee members (JH, SM and DV). Committee member JH is an occupational therapist and researcher with expertise and knowledge of the ABI population and rehabilitation setting. SM is also an occupational therapist and researcher, with extensive knowledge of qualitative methods. DV is a psychologist and researcher with extensive knowledge of the ABI population and rehabilitation settings, and as previously mentioned, a clinician from the ABI inpatient program examined in this study.

Interview questions focused on (1) participants’ perspectives of the activities in which they participated during rehabilitation, (2) the people with whom they interacted during rehabilitation, (3) their opinions regarding what was helpful or challenging about rehabilitation, and (4) how participants had changed after completing inpatient rehabilitation. JP developed the interview script and refined it based on discussion with committee members JH and SM. Questions were piloted during the first three participant interviews, which were also included in the final analysis. Pilot interviews identified that participants often described: (1) their lives and routines prior to their injury, (2) their experiences in acute hospital care prior to admission to the inpatient rehabilitation program, and (3) their experiences after discharge. Thus, in discussion with all committee members, interview questions were added and modified to capture participants’ experiences from the time of sustaining an ABI to just after discharge. For example, in the initial interview script participants were asked, “Can you tell me a little about yourself and how you ended up in rehab?” On revision, secondary questions were added to this question, including how participant goals and routines had changed since sustaining an ABI and what were their experiences in other hospitals. The original and revised interview guides are presented in Appendices III and IV.

Researcher positionality. Interpretive description methods follow a constructivist paradigm (Thorne et al., 1997) in which the researcher adopts the ontological stance that realities are multiple, “local and specific in nature,” and based on subjective experiences and understandings (Guba & Lincoln, 1994, p. 110). In this study, it was thus recognized that participants might have had different experiences and perspectives of the same ABI inpatient rehabilitation program. These experiences and perspectives would be impacted by contextual factors, such as personal differences, past experiences and knowledge, and the time point in their lives when they sustained an ABI. Use of a constructivist paradigm also implies that findings are created by interactions between the researcher and the participants (Guba & Lincoln, 1994); thus interviews and analysis are co-constructed as both parties bring their subjective perspectives and biases to the research process. The knowledge generated from the research process is shaped and impacted by the researcher and the context within which the research was conducted (Guba & Lincoln, 1994). Therefore, it is necessary for the principal researcher (JP) to acknowledge and state her positionality (Bourke, 2014) in the research process, including her background, prior knowledge, beliefs and her potential position of authority, in order to recognize how these may contribute to data collection and analysis.

JP entered the research environment as a 26-year-old female master's student in rehabilitation science. She had no prior relationship with the participants in the study. JP's knowledge of ABI stems from her academic and personal background, readings on the topic area, as well as discussions with other experts in the field throughout the process of this study. She previously completed an undergraduate degree in psychology and biology, conducted past research requiring participant interviews, and volunteered with persons with various conditions undergoing physical therapy in a complex continuing care program. JP's knowledge and opinions on the research methods, as well as the purpose, importance and benefits of rehabilitation, were thus influenced by these experiences. She believed that (1) interviews would provide a means for developing an in-depth understanding of persons' experiences in rehabilitation, (2) that inpatient rehabilitation was beneficial for helping persons to recover after ABI, and (3) that each person's account of their experiences might be impacted by personal contextual factors, as well as in response to her position as an interviewer.

JP introduced herself to all participants as a student conducting research towards the completion of a degree, with a distinctly stated purpose of adding to the existing knowledge about ABI inpatient rehabilitation. Therefore, participants may have related to her as a "student researcher" as opposed to a clinician or other person in a potentially perceived position of authority. The possibility that participants viewed JP as a "student researcher" may have affected the type of answers and explanations provided, and the degree of candidness in their opinions of their experiences. For example, participants may have been more likely to share negative experiences about the ABI inpatient rehabilitation program, given that JP was not a member of staff. Alternatively, some participants might have been less candid than others, based on their level of comfort to share personal information with a student researcher. For example, some may not have wanted to express all of their experiences or perspectives to a person they had recently met. They may have also been less inclined to share personal details with someone who was not associated with their rehabilitation or other services.

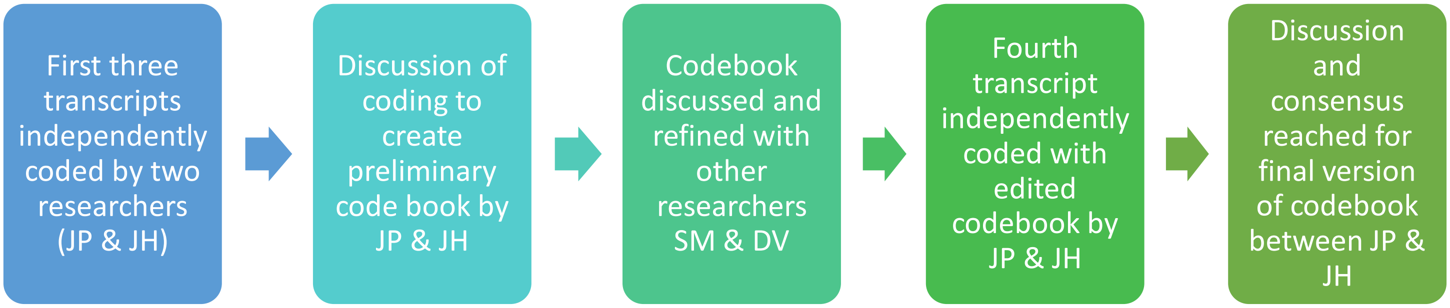
All of these considerations informed JP’s interpretations of the participant interviews. Additionally, by holding the position of “student researcher,” JP recognized that her interpretations of participants’ described experiences might have differed compared to someone with the viewpoint and past experiences of being a staff member of that clinical environment. JP also underwent regular peer debriefing (Hsieh & Shannon, 2005) with her supervisor and committee members, as they provided viewpoints about the data collected, stemming from their clinical experiences and research expertise. These ideas, experiences and potential conflicts of opinion during the research process were noted, and reflected on, within a reflexive journal that JP maintained throughout this study. Maintaining and returning to this journal during data collection and analysis helped JP to consider how these viewpoints impacted her descriptions and interpretations of the findings.

2.4 Data Analysis

Data analysis was guided by interpretive description methods (Thorne, 2016; Thorne et al., 2004), and was an iterative process concurrent with data collection. Prior to and during data collection and analysis, JP kept regular field notes and reflected on ideas, theories and personal biases, in order to enhance transparency and reflexivity. All interviews were transcribed by a transcriptionist and read by JP, who made notes of any important quotes or ideas.

Coding and theme development. JP and JH independently hand-coded the first three transcripts. Coding consisted of selecting and labelling phrases or segments of text that captured similar ideas and perspectives which were then organized into preliminary categories. The codes were then compared across three transcripts in order to ensure consensus regarding coding strategy, key points and recurrent ideas. Initial coding with the three transcripts resulted in the development of a preliminary coding structure. Deeper reflection on coded transcripts and early interpretations were recorded in field notes, with JP seeking to answer questions, such as, "What is going on here?" and "What am I learning from this?" (Thorne et al., 2004). Preliminary coding and interpretations were then discussed in supervisory and committee meetings, in order to examine steps taken in the analytic process and to obtain further guidance on this process. The coding structure was then edited to remove any premature interpretations – such as categories that reflected JP's early interpretations (which were moved to field notes) as opposed to participants' descriptions. JP and JH then independently coded another transcript with this new structure and discussed this process, in order to reach consensus on an agreed-upon codebook (Appendix V). Figure 1 (below) outlines this process.

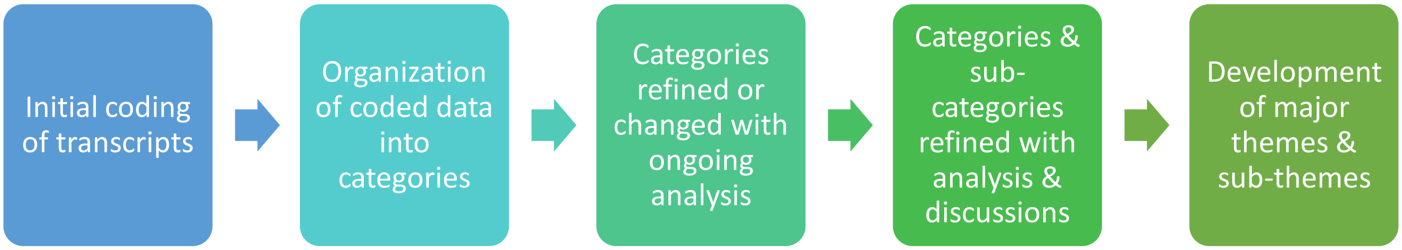
Figure 1: Development of codebook



Transcripts were then loaded into Dedoose qualitative analysis software (SocioCultural Research Consultants LLC, 2018) for coding by JP. A constant comparative approach was utilized (Hunt, 2009; Thorne, 2016), where new information was compared to categories developed from earlier interviews, in order to improve understanding and better refine these categories. Multiple reviews of the data organized under each category allowed for a macroscopic view of potential common themes and unique cases across participants (Thorne et al., 2004). After an initial round of coding by JP, the excerpts under each theme were examined to develop a preliminary report of findings, which was discussed with JH to gather her opinion on the organization of this data. This report entailed describing each theme, based on commonalities and unique cases amongst participants' responses. For example, under an initial theme describing participants' lives prior to sustaining an ABI, responses included descriptions of pre-injury activities, employment and patients' views of their skills and abilities prior to injury.

A second round of coding was completed to ensure excerpts were classified into consistent categories and further sub-categories were added to provide better organization of the data under each category. The report of the findings was then refined and used to further develop interpretations with guidance and probing questions from all committee members, as well as JP's reflection on field notes, memos, personal perspectives and previous qualitative research on ABI inpatient rehabilitation. A strategy to envision, organize and understand these categories also included JP creating concept diagrams individually, and with SM. From these strategies, the categories and sub-categories were developed into major themes and sub-themes, with descriptions and notable quotes for each. Figure 2 (below) illustrates this process.

Figure 2: Coding and development of themes and sub-themes



Member checking. Once interviews and analyses were completed, JP conducted member checking. The goal of member checking is to garner whether the themes and sub-themes developed during analysis depict the messages and meaning that participants meant to convey during the interview process (Carlson, 2010). For this study, JP contacted the last six participants interviewed. These persons were chosen as they completed interviews within the last two months and were thought to more likely respond compared to persons who participated earlier in the study. JP believed that contacting half of the participants would provide sufficient feedback on findings. Three persons ultimately responded and agreed to participate. Participants were presented (via email) with summaries of the major themes and sub-themes, and initial interpretations of the meaning of these themes that had been developed through analysis. JP then telephoned each participant, at a mutually agreed-upon date and time, and asked them to comment as to whether or not the interpretations were reflective of their own experiences and to expand further on the themes if possible (Thorne, 2016). The summary of themes and sub-themes presented to participants during member checking and the questions posed are presented in Appendix VI. Participant responses from member checking helped JP to consider the conclusions she formulated in her analysis. This helped her to determine if she was accurately accounting for the complexities and nuances of a person's experiences. For example, an initial interpretation was that participants viewed institutional rules negatively, and this led to an assumption that participants may not have understood their purpose. Through member checking, JP was able to recognize that participants did understand the purpose of rules, and while they may have found them to be prohibitive, they did not necessarily view them negatively.

Interpretation. When analyses and member checking were completed, a final report of the findings was developed and organized under the refined themes and sub-themes. Examination of content under each theme was done to identify what aspects of participants' accounts seemed informative and important for clinicians and program administrators to know (Thorne, 2016). Knowledge recognized as important was organized under an overarching key message which was considered in light of current literature and theories, in order to develop suggestions for clinical implications and further research.

2.5 Trustworthiness & Rigour

As previously mentioned, efforts were made in this study to support the explicitness of the data analysis and interpretation processes, and to consequently enhance trustworthiness and rigour in the methods applied. In qualitative research, trustworthiness and rigour are commonly demonstrated using four quality criteria: credibility, confirmability, transferability and dependability (Guba & Lincoln, 1982).

Credibility. Credibility refers to the degree to which the participants' experiences and perspectives reflect their subjective perspectives of reality (Krefting, 1991). In this study, strategies to improve credibility included the maintenance of a reflexive journal and field memos during interviews and analysis. This allowed JP's perspective and experiences to be considered throughout the research process, with reflection on how these may affect data collection and analysis (Shenton, 2004). Reflexive journaling and memos were also used to record developing ideas and ways of organizing and thinking about the meaning of the data collected. Furthermore, following up with participants through member checking allowed participants to provide their opinions on whether the themes presented were reflective of their experiences and opinions (Thorne et al., 2004).

Confirmability. Confirmability refers to the degree that the study's interpretations are based on participants' descriptions as opposed to pre-conceived viewpoints and biases of the researcher (Shenton, 2004). The maintenance of a reflexive journal and memos, with consideration of how JP’s perspectives and knowledge may have contributed to the data collection and analyses processes, helped to support this criterion. Committee members aided this process by questioning and commenting on JP’s reports of the findings, as she developed them. These efforts allowed JP to consider whether the descriptions of the findings that she created were representative of the information that participants had shared with her or were potentially skewed by her interpretations of what the findings might mean. Member checking, once again, also served as a means to provide support that the themes developed were reflective of participants’ experiences and perspectives.

Transferability. Transferability is defined as the extent to which a reader or user of a qualitative study may apply the findings to similar settings (Shenton, 2004). For example, in this study, a reader may consider these findings in the context of another ABI inpatient rehabilitation program targeting persons that will re-integrate into a community setting after discharge. A strategy to enhance transferability is the inclusion of “thick description” of the research setting and population (Geertz, 1973). In this study, efforts were made to develop thick description through the collection of various types of participant data in order to generate a detailed description of the participant group. A detailed description of the inpatient setting was also developed, and efforts were made to gather more information about the inpatient program in order to situate participants’ descriptions of their experiences. This information was collected through observations, document reviews, and discussions with program staff.

Dependability. Dependability refers to the confidence in the consistency of the logical decisions made to move the collected data from description to interpretation (Shenton, 2004). In this study, dependability was aided by the maintenance of a field journal to document data collection and analysis decisions. A detailed description of the data analysis process was also developed to make this decision process transparent. The double-coding of transcripts and then discussion of this process by JP and JH also improved dependability by providing another perspective for understanding and organizing the data (Shenton, 2004).

Furthermore, a strategy of re-coding previous transcripts as new data was collected allowed all data to be considered and re-considered with ongoing analysis and the emergence of new understandings and ideas about the data (Shenton, 2004). ‘Peer’ debriefing through regular discussions between JP and JH, as well as during committee meetings, also allowed for the consideration of the findings from multiple viewpoints and expert professional backgrounds. These meetings also allowed committee members to probe and test the decisions JP made during the organization, analysis and interpretation of the findings (Shenton, 2004).

Chapter 3: Findings

The following chapter presents the major findings of this study. First, demographic and descriptive data are presented to provide a depiction of the participants. This information includes pertinent injury details, level of disability and a description of the reported main cognitive impairments that persons presented with during inpatient rehabilitation. The findings that emerged from the analysis of participant interviews are then described under three major themes with supporting quotes. These themes are, “Life Rerouted,” “Autonomy within Rehab,” and “Life (and Recovery) Go On.”

3.1 Participant Characteristics

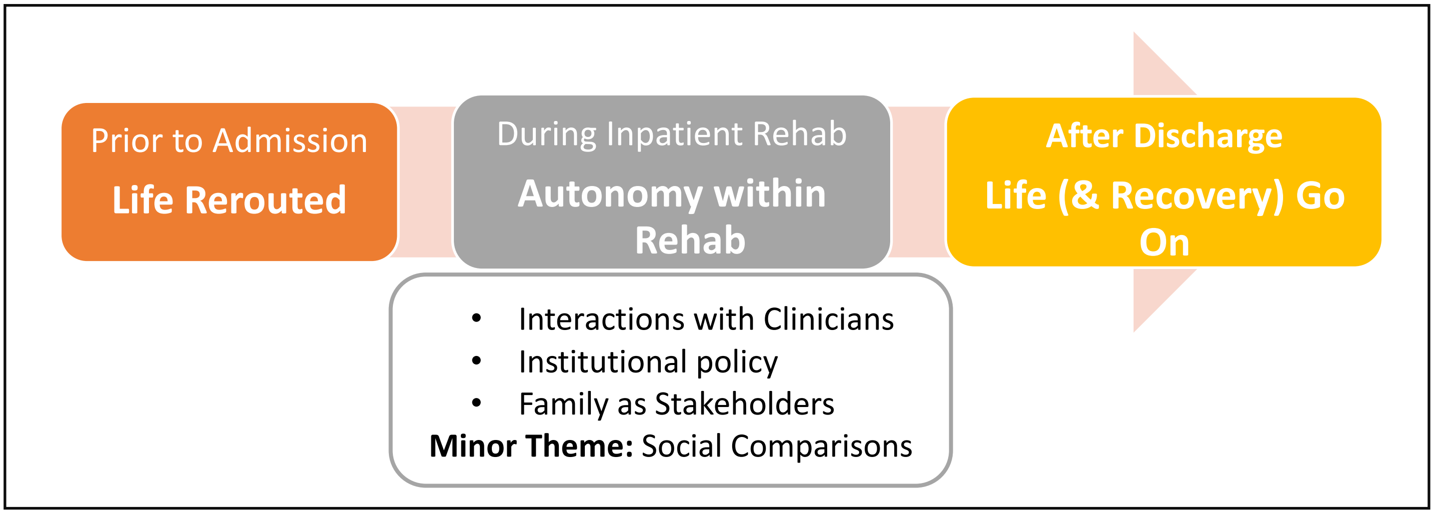
In total, there were 12 participants (eight males and four females) with a mean age of 52.1 years (range = 21-82). Participants’ demographic, ABI and functional information, as well as length of stay in inpatient rehabilitation, are detailed in Table 1.0 (p. 52). A total of 11 participants completed the ABI inpatient rehabilitation program at the regional rehabilitation centre, while one participant completed rehabilitation at a similar program located within the same health region. Eight participants were working at the point of sustaining an ABI, three were retired, and one was attending a post-secondary institution. Nine participants sustained a TBI, and the main source of TBIs were falls. The median length of stay in inpatient rehabilitation was 38 days (range = 15 - 119). Most participants were interviewed within two weeks to two months post-discharge (n = 9), with three participants interviewed up to 12 months post-discharge. Eleven participants were discharged home, and one participant was discharged to an assisted living setting.

With respect to level of disability, the median pre-admission total Functional Independence Measure (FIM) score was 84 (range = 44-120) which indicates that participants demonstrated a moderate level of disability (e.g. requiring assistance with most ADL's), given that median scores fell within the middle third of the FIM score range (18-126). The median FIM score at discharge was 115 (range = 104-122), which indicates that participants required little to no assistance with ADL's, given that scores fell in the top third of the FIM score range. Based on the medical charts, participants' main ABI-induced cognitive issues were related to "attention," "memory" and "reasoning." With respect to attention, clinical notes reported reduced ability to sustain attention and a high level of distractibility. Difficulties with working memory included impairments in the consolidation and retrieval of memories, such as remembering a conversation or rehabilitation goals. Additionally, while it was reported that participants had "relatively good insight" about their impairments, they had challenges related to abstract reasoning. Clinical notes also indicated difficulties with understanding complex concepts, as well as problem-solving. No participants were noted to demonstrate significant behavioural issues.

3.2 Overview of Major Themes & Sub-themes

During interviews, participants described: 1) their lives and routines prior to injury; 2) their experiences of sustaining their ABI; 3) experiences within emergency and acute care prior to admission to inpatient rehabilitation; 4) the inpatient environment (social, physical and institutional), including the clinicians and other staff members with whom they interacted, and activities in which they participated; 5) the involvement of family members in their rehabilitation; 6) opinions and comments about the inpatient program; 7) their perceived quality of recovery since discharge; and 8) their personal goals and feelings about recovery. This content was organized into major themes and sub-themes that were generated from the analysis and were informed by member checking. These themes were arranged along a series of three time periods. First, "Life Rerouted" encapsulates participants discussions about the time from sustaining an ABI to prior to admission to inpatient rehabilitation. Next, " Autonomy within Rehab" includes participants' experiences within inpatient rehabilitation with related sub-themes, as well as the minor theme of "Social Comparisons" which was distinct from the major theme of autonomy. Finally, " Life (and Recovery) Go On" includes the period just after discharge. Figure 3 presents these themes, with the direct sub-themes of major themes indicated by bullet points.

Figure 3: Major Themes and Sub-Themes



3.3 Theme 1: Life Rerouted

Based on interview questions, participants described their lives, routines and activities prior to injury and discussed involvement in activities of daily living, work, leisure, school and volunteering. They also described their social participation, including time and activities spent with significant others, family and friends. Activities included gardening, various forms of exercise (walking, swimming, and other sports), outings with friends and family, and travelling abroad. These activities and routines were part of what participants described as their "normal lives." As a result of sustaining an ABI, participants described inabilities to participate fully in regular roles and activities and consequently were unable to participate fully in their normal lives. Based on these descriptions, sustaining an ABI seemed to lead to a *re-routing* of, or diversion from, participants' normal lives. For example, one participant described how regular activities, independence, and quality of life were diminished after sustaining an ABI.

> "We used to have a better life…My [spouse] and I go to Florida every year…now we're missing it for me…we do really miss it. My license was [also] taken away from me, which took away a lot of my independence at the same time." [Participant 7]

This "rerouting" of normal life also led participants to place a new focus on recovery and rehabilitation. All participants described inpatient rehabilitation as a way to "get back to normal." The term "normal" was defined by participants in multiple ways and included: regaining strength and abilities; feeling like themselves again and resuming work and (or) other activities. Participant 1, for example, viewed rehabilitation as a way of preparing a person "to go back into the community" by "getting you into a better position to be released." Similarly, another participant, who intended to continue working in the future, described the purpose of rehabilitation as a way: "to help you actually rehabilitate…so you can either live a useful life or get back into the workplace" [Participant 11].

The time period prior to starting inpatient rehabilitation encapsulated participants' experiences of sustaining an ABI and how this had diverted them from their regular abilities, activities, routines and goals. Inpatient rehabilitation was consequently described as a way to achieve recovery and to return to their intended life trajectories.

3.4 Theme 2: Autonomy within Inpatient Rehab

Regarding their experiences within inpatient rehabilitation, participants expressed both positive and negative opinions about their freedom of choice or control over themselves and their rehabilitation. The term "autonomy" was chosen to describe these concepts. Key aspects of patients' experiences that affected (enabled or interfered with) perceived autonomy during this stage included: interactions with clinicians, understandings and opinions of institutional policies, and the involvement of family members as stakeholders in their recovery. A minor theme of "social comparisons" (not directly related to the major theme of "autonomy") was also identified as significant to participants' descriptions of their inpatient experiences. Participants compared themselves to other patients with respect to severity of injury and perceived recovery progress.

Interactions with clinicians. Clinicians and staff members that were specifically mentioned by participants included physicians, occupational therapists, physical therapists, rehabilitation assistants, the neuropsychologist and nurses. All participants made positive statements regarding the clinicians they encountered. Terms or phrases used to describe clinicians included: “kind,” “caring,” “hard-working,” “generous,” having “good attitudes,” and “friendly.” Participants often described daily interactions with members of the clinical team which included social pleasantries, receiving help for self-care activities, therapy sessions and guided activities, and communication about questions and concerns. Elements of participants’ discussions of these interactions seemed to reflect a perception of altered autonomy while occupying the “patient” role and their efforts to retain their autonomy. These included: (1) the viewpoint that clinicians held the authority or control to determine a patient’s discharge readiness, (2) descriptions of the ways that participants exerted their control over their recovery by participating in clinician-recommended activities in order to demonstrate discharge readiness, and (3) the quality of communication with clinicians that impacted participants’ choices and control over their rehabilitation and health.

Participants described clinicians as persons who could determine and recommend if a patient was ready to be discharged based on level of recovery. As one participant stated, “I remember asking [name] “How do I get [out of the program]?” She said, “Once you become better, we’ll release you” [Participant 2]. This explanation was perceived by the participant as having to gain permission from clinicians to be discharged from the unit. Following instructions and partaking in rehabilitation activities provided by clinicians were consequently seen as ways to achieve recovery and to return to one’s community. For example, another participant said: “You do whatever [the clinicians] are expecting you to do [and] you get back to normal as fast as possible” [Participant 3].

Participants also described actions they took in order to demonstrate to clinicians both their motivation to participate in rehabilitation activities, as well as progress towards discharge. Participation in these activities was viewed as vital to achieving the independence required for discharge and included rising early, bathing, dressing or being ready to be helped by clinicians, participating in as many activities as possible that were available to them, and going for walks during free time to get more exercise and regain strength. For example, one participant described her morning routine while in inpatient rehabilitation.

> Whenever my therapist came, I was ready. She would come at 7:30 and I would already have my clothes ready [from the night before] ...She had to help me in the shower. But I could sit down and look after myself. I think I needed [to do it myself because] you could see other patients improving too and doing little by little, more themselves. [Participant 5]

These actions were viewed by participants as ones which they held some control over and were ways to show clinicians they were recovering and becoming more independent. As one participant explained, “I do [laundry] by myself. I need to show them that I can” [Participant 9].

Being able to communicate concerns and inquiries to clinicians, and clinicians’ receptiveness and responsiveness, were also identified as critical aspects related to participants’ descriptions of autonomy. There were positive comments from almost all the participants regarding responsiveness to their concerns and questions. For example, participant 3 recalled being able to talk to his doctor: “I was just talking normally to the doctor and…I told them about the stuff [medication] that they were giving me, and they cancelled everything… I noticed the change immediately…because I started coming back to normal.” This experience gave the participant the sense that his voice was being heard by clinicians. Another participant described a situation where she disagreed with staff about priorities for her therapy, but through discussion, they came to an agreement:

> At the beginning sometimes, I would do group activities, and because I was in there, I would miss out on my physio. And the whole point [of being] there was to do physio and get better. We talked to [a clinician] about that, and after that, it got a little better. [Participant 6]

These interactions seemed to give participants some control over their rehabilitation and healthcare. However, not all participants felt that their voices were heard. One participant, for example, had a negative experience shortly after being admitted:

> …they put me in the chair, and I sat there for probably 20 minutes and … I said, “Can I get some help?” And [a clinician] said “Yes. Go into this room … and sit on the bed.” So, I went in there, and I sat there for well over an hour, and no one came in. So finally, I went back to the reception area again, and I said, “No one has contacted me.” And with that, they said, “Sit in this wheelchair.” And so, I said “Okay.” I sat in the wheelchair, and they strapped me in. I couldn’t get out…I felt like an animal caged and I couldn’t get out of it. So finally, the one lady came, and she helped me and got me out into the bedroom [and put] my clothes away. But it was the first impression which I don’t like…It’s lasting, and that’s the one that I don’t want to remember. [Participant 2]

This participant’s account indicated the level of distress that he felt at the lack of two-way communication, as well as the feeling that his voice was disregarded, and that his autonomy was compromised.

In summary, many participants indicated that clinicians controlled discharge from the program. As a result, participants often tried to show clinicians they were progressing and ready for discharge by being motivated and active participants. Most participants felt supported by clinicians, and clear, two-way communication with clinicians appeared to provide a sense of control and decision-making power over their health and rehabilitation.

Institutional policy. When asked to describe the inpatient environment, the majority of participants mentioned the physical boundaries and institutional rules they encountered, mainly because they affected control over their movements within and outside of the unit. Institutional policies that seemed to affect participants' perceived autonomy included: (1) rules regarding off-unit access e.g., the ability (or inability) to go for short walks, for coffee or to smoke a cigarette, as well as the ability to be able to go the gym outside of scheduled therapy sessions; and (2) rules around safety within the inpatient unit that were enforced by staff members of the inpatient unit, such as walking with or without gait aids and getting in and out of bed.

Many participants mentioned rules regarding permission to leave the inpatient unit. While mall walks and other outings were often part of participants' therapeutic activities, not all participants were allowed to leave the unit unaccompanied during their free time due to safety issues. Individuals with off-unit access described feeling less restricted than those without this access. For example, one participant (without off-unit access) stated: "I couldn't get out, but I wanted to get out, and I wanted to get out and walk, but you couldn't leave the premises. I couldn't leave the floor!" [Participant 2]. In contrast, another participant (with off-unit access) stated; "The environment didn't feel restrictive whatsoever because I could go where I needed to go to or wanted to go to. I had the privilege to go grab a coffee or do whatever I wanted" [Participant 3]. Being able to go where one wished appeared to provide participants with a sense of control. Another participant explained, “It gives me something to do instead of sitting in here and looking at [the room] …Picture yourself in here for five days in a row. What are you going to do?” [Participant 10]. The feeling of freedom and normalcy reportedly had a positive impact on participants’ well-being or state of mind. Access to the therapy gym was another point of tension for some participants. Although this area was seen by participants as important to their recovery, a few participants noted the use of the gym was limited to certain hours of the day. As one participant notes; “…someone had to be there when you were “rehab-ing” so, or else I probably would’ve gone more.” [Participant 12]. Another participant made a similar comment explaining that he compensated by walking laps around the inpatient unit.

Many participants explained that staff members of the unit enforced the institutional rules and policies, particularly as they related to safety in the rehabilitation environment. For example, participant 5 recalled making sure that her roommate had her walker because “you don’t want to get caught by the nurses without your walker.” She also described being “glad to get rid of [her own] walker and extra help” because initially, she could not get out of bed on her own, “I figured I could get out and do this all myself but not safely according to them.” Another participant explained that he was a fall risk and that there were cautionary signs in his room to warn others, “I’ve got a sign on the bed for falling. It’s a wonder they don’t have one for me to wear around my neck.” He also understood that “your first fall is bad enough but [a] second fall, if I hit my head again, [the problems] go up exponentially.” [Participant 11] These accounts seemed to reflect participants' recognition of the reasoning and importance of safety rules, but also some angst about the lack of freedom and control when rules were enforced.

Overall, institutional policies of the unit were seen, at times, as restricting patients' freedom and control. Although this was a source of tension for some participants, most understood why these policies were in place. For those who experienced more freedom, the institutional rules were not considered to be an imposition. Participants' sense of autonomy, therefore, appeared to be complicated by their understanding and acceptance of institutional policies that were in place to ensure safety and optimize recovery.

Family as stakeholders. Participants' family members also seemed to impact their perceived autonomy as a patient, by acting as stakeholders with a vested interest in their loved one's recovery. Participants often described their spouses and (or) family members visiting daily or staying nearby and most stated that their immediate family often took control of their care, from the initial point sustaining an ABI, during their inpatient stay and after discharge. This involvement included communicating with clinicians, providing hands-on help with toileting and bathing, and providing other sources of support, such as escorting them on trips both within and outside of the hospital. Most participants described being appreciative of relinquishing control to their family and explained their presence was comforting. As one participant stated: "My daughter, she was wonderful, she just took over. She just became my caregiver completely," [Participant 7].

Some participants, however, made comments that seemed to reflect drawbacks to the role of family members in their recovery. Their accounts implied that there was pressure to recover in order to resume roles held prior to their ABI (e.g. parent or family provider) and to not become a burden. These tensions appeared to reflect competing priorities between rehabilitation demands and family demands. Several participants described feeling the need to return to work in order to earn money for their family. For example: “My son needs a hand doing things…The [spouse] doesn’t have a job… My job is to be able to walk again [and] my job is to start a business again, collect money again,” [Participant 8]. These conflicts appeared to cause persons to split their focus between their need to progress in rehabilitation while also being an active member of their family. As another example, participant 7 explained that while family members were supportive and helpful, they expressed their need for her to be independent after discharge:

> Well [my daughter] doesn’t want to have to look after me, she’s got enough to do, she very busy. She’s the one who wanted me to get up on my own and get doing things faster…and my husband - both of them; they’re in it together – they’re in cahoots. [Participant 7]

She also later noted, “I’m just trying to get myself better right now. But the kids lose patience with you.” For these participants, there may have been an underlying pressure or a sense of responsibility to one’s family that conflicted with their ability to focus on the goal of recovery and being a “patient” as opposed to a “parent” or “provider,” or not being a burden. Thus, while family members often assumed welcome control of a participant’s care, some participants perceived an expectation that they were supposed to recover quickly and take back that control as soon as possible.

Social comparisons. When asked about their interactions with other patients, participants talked about communication with roommates as well as seeing others in the dining room and other common areas, and in group rehabilitation activities. Almost all participants stated they did not have many friendships with other patients, other than their roommates. Participants explained that their priority was to focus on themselves and their family members, so they did not feel the need to make further friendships. As participant 11 explained,

> I’ve talked to other patients here, but I would say it’s a gradual thing. You’re still looking after yourself. I wouldn’t say everyone is concerned about their own, but they do tend to focus on it. I mean I’ll admit, I do too because the first thing I want…even though all the care is great, you want to get home. [Participant 11]

Social comparisons were often made to other patients with respect to the level of recovery and severity of injuries. For example, some participants referred to themselves as being ‘better off’ or ‘doing better’ than others. Other participants made comments like: “They were sicker than me. I was ahead of most of them.” [Participant 7], or “I take care of myself, I go wash myself. Other people need care…they need more than I do” [Participant 8]. Two participants also mentioned wanting to help their roommates, including efforts such as making sure a roommate was walking with their walker or trying to help another patient to get into bed. Thus, participants seemed to view other patients as persons with more severe injuries and as persons needing more assistance than they did.

Overall, the theme of autonomy within inpatient rehabilitation reflects the perspective that participants’ experiences were framed by tensions over their autonomy as a patient. Comments made by participants encapsulated how they perceived and exerted freedom of choice and control in the context of their interactions with program clinicians, institutional rules and policies, and family members. Participants also notably discussed other patients being a basis with which to measure their progress and level of "normalcy."

3.5 Theme 3: Life (and Recovery) Go On

The final theme of "Life (and Recovery) Go On" focuses on participants' experiences after being discharged from inpatient care. Under this theme, participants discussed how inpatient rehabilitation prepared them for discharge, their perceived progress since completing the program, their feelings about having to adjust to altered abilities and having to wait for further progress, and their expectations for the future. Most described the positive changes they experienced from inpatient admission to discharge such as improvements in balance, strength and walking, a calmer demeanour, and regaining the ability to participate in activities like driving, sports and socializing. Participant 3 described this change, "I play tennis now. I play. I ride my bike. I don't need to have someone behind me saying "You've got to this!" Participant 1 also described himself as starting to return to the person he was prior to his ABI, "I was in a bad position when I first went in [to inpatient rehab]. I was almost like a grown child. [Later] I felt a lot more like the old me."

Most participants stated that inpatient rehabilitation had prepared them well for discharge into the community. A few participants mentioned that the inpatient program had been tailored to their needs at home and targeted activities that they normally liked to do, such as walking, swimming and gardening. One participant also noted that the clinicians had made an effort to ensure she could continue swimming at a community pool, given she had started frequently swimming during inpatient rehabilitation. Discharge from inpatient rehabilitation, however, was notably regarded by all participants as one stage in an ongoing recovery process. Participants often discussed having to adjust to (and accept) altered lifestyles and abilities as a result of their ABI, a concept which was described by one participant as “a new normal.” Some participants also expressed a desire to return to work, usual ADLs and leisure activities but faced barriers in achieving these goals and had to modify their performance. Frustrations with the ongoing recovery process were captured in the following quote:

> I still can’t walk properly. I still need work on my hands, and emotionally, I get frustrated a lot easier because of this – there are simple things that I used to be able to do that I can see my parents or sister do and I get frustrated because I’m not up there yet. I know I’m going to be there, but it gets frustrating when you need help to do stuff. And I always say I’m like a little child because I need more help doing things. It’s like I’ve gone back in time. [Participant 6]

Participant 5 noted that she was advised by inpatient clinicians to “slow down” and found that she could not be as active as she was previously. When discussing the challenge of returning to life after discharge, she stated, “[Rehab] is preparing you to continue on with your life, and you do need to be prepared because it’s overwhelming.” A few participants also noted frustrations by not being able to return to driving as yet, with one person noting it was a requirement for their work. Despite their frustrations, most participants expressed hope for the future regarding being able to regain their abilities and to return to their normal lives. Recognizing that full recovery would take time, one participant described needing to be patient about the recovery process.

> "Yesterday…was the first time that I thought "Oh, this is actually getting better." So, I don't know how long it's been since it's happened exactly, but it was a long road and…I still have a long way to go. It's just hard to deal with having to wait for everything. I know it's going to take time and it is getting better." [Participant 4]

The period just after discharge from inpatient rehabilitation was thus recognized as part of a longer period of ongoing recovery. All participants perceived that inpatient rehabilitation had helped them, but they had to adjust to a "new normal" due to impaired abilities. This process was slow and frustrating for some, but most continued to be hopeful and positive about the recovery process and their futures.

3.6 Summary of Findings

This chapter has provided a detailed description of the findings under major themes and sub-themes, arranged as the time periods leading up to, during and after inpatient rehabilitation. Under the theme of "Life Rerouted," participants' lives were diverted due to their injuries, and their main goal was to return to normal roles, activities and routines. Inpatient rehabilitation was seen as a way to achieve this goal. When reflecting on their time within the inpatient rehabilitation program, under the theme of "Autonomy within Rehab," participants emphasized the importance of personal autonomy over their choices and abilities, and how this was enacted under sub-themes related to interactions with clinicians, perceptions of institutional policy, and the involvement of family members. Participants also viewed other patients they encountered as a source of comparison for rehabilitation progress. Despite their varied experiences, under the theme of “Life (and Recovery) Go On,” all participants described inpatient rehabilitation as helpful to them and viewed it as an important step in recovery. Most participants faced an ongoing recovery process after discharge, leading to sentiments of both frustration and hope for the future.

Table 2.0: Participant Demographic Information, Injury Details & Functional Scores

ABI	Sex	Age	Education	Marital Status	Cause	Injury Severity	FIM- Pre[5]	FIM-Post	LOS[6]
TBI	M	25	High School	Single	MVA[1]	7 (GCS[2])	72	111	35
TBI	M	79	High School	Married	Fall		81	121	31
TBI	M	47	High School	Married w/Children	Fall	13 (GCS)	120	122	40
TBI	F	82	Post-Secondary	Married w/Children	Fall		93	113	46
TBI	F	79	Post-Secondary	Married	Fall				15
TBI	M	56	Post-Secondary	Married	Fall		44	112	56
TBI	F	39	Post-Secondary	Married	MVA	12 (GCS)	85	120	34
TBI	M	69	Post-Secondary	Married w/Children	Fall	1.5(PTA[3]); 30 (LOC[4])	67	104	35
TBI	M	38	Post-Secondary	Single	MVA	3 (GCS)	90	125	40
nTBI	M	43	High School	Single	Aneurysm	3 (GCS)	84	104	43
nTBI	F	21	Post-Secondary	Single	Hydrocephalus		83	115	119
nTBI	M	47	High School	Unmarried w/Children	Encephalitis		105	118	28

Abbreviations: 1 = Motor vehicle accident; 2 = Glasgow Coma Scale reported at initial hospital admission; 3 = Post-Traumatic Amnesia score; 4 = length of Loss of Consciousness (mins); 5 = Functional Independence Measure score (motor + cognitive subscales) at rehabilitation admission and discharge; 6 = Length of stay in inpatient rehabilitation

Chapter 4: Discussion

This study was designed to address the question, “What should clinicians and program administrators know about patients’ experiences in an ABI inpatient rehabilitation program in urban Ontario, in order to improve understandings of patient needs and preferences?” The following chapter presents an in-depth synthesis and reflection on the study findings, organized under the following overarching key message: “re-establishing personal identity is important to the recovery process.” This key message was developed based on analysis of each theme, where the purpose was to identify what concepts and ideas were significant in answering the research question (Thorne, 2016). This key message is interpreted using two related theoretical viewpoints, biographical disruption and relational autonomy (described further on), positioning the findings within the context of existing literature on ABI rehabilitation. The knowledge generated from the findings is then used to explore potential clinical implications. Next, the limitations of these findings and recommendations for future research are outlined, followed by strategies for knowledge dissemination and overall conclusions.

4.1 Re-establishing personal identity is important to the recovery process

When discussing their experiences prior to inpatient rehabilitation, participants often described that, as a result of their ABI, they were no longer able to participate in activities, roles and goals that encompassed what they termed as their “normal” lives. Their “normal life” seemed to constitute their personal identity because participants noted that ABI had caused a disconnect from the person they were prior to sustaining an ABI. Inpatient rehabilitation was viewed as a means to return to normal and to re-establish personal identity by facilitating recovery. Within inpatient rehabilitation, participants often experienced tensions related to autonomy as they simultaneously occupied the patient role while attempting to return to the person they were prior to ABI//. These tensions were reflected in their discussions about clinicians, institutional policies and family involvement. Participants also described comparing themselves to other patients in order to assess their own severity of injury and degree of progress towards recovery. Even after discharge, however, participants described themselves as still being in the process of recovery. They were often trying to adjust to life changes and altered abilities; this experience was described as a “new normal.” Overall, disruptions to normal life and sense of self that were experienced by participants were evident in their descriptions of how life had changed due to ABI, and in their efforts to return to their normal life prior to ABI during and after inpatient rehabilitation.

Biographical disruption & repair after ABI. Developed initially within chronic illness research (Bury, 1982), the theory of biographical disruption purports that an injury or illness resulting in lasting impairment can be considered a critical or disruptive event. In such an event, persons can experience significant changes to the structure of daily living, including his or her sense of self, abilities, life trajectory and relationships with others (Bury, 1982). Similar experiences are commonly noted across qualitative literature exploring long-term recovery after TBI (Levack et al., 2010), where studies have reported disconnection from the pre-injury self, as well as feelings of loss, lack of competence and lowered self-worth. Social relationships notably change with increased dependence on family members and loved ones (Levack et al., 2010). Previous ABI research has also used biographical disruption theory in order to interpret and address these experiences (Cutler, Nelson, Nikoloski, & Kuluski, 2016; Lorenz, 2010; Sveen, Ostensjo, Laxe, & Soberg, 2012). This theory thus provides a lens for considering the experiences of participants in the present study. These include (1) the biographical disruption encountered due to ABI, and (2) the strategies adopted in order to manage or adjust to ABI-induced changes in their sense of self and social relationships (known as "biographical repair" (Bury, 1982)) within and beyond the context of the inpatient environment.

Sense of self or personal identity for persons with ABI is often ascribed to the roles and activities in which they regularly participate (Conneeley, 2012; Cutler et al., 2016; Levack et al., 2010; Sveen, Søberg, & Østensjø, 2016) and biographical disruption, as noted above, results in a departure from one's pre-injury sense of self or identity. In the present study, persons with ABI reported inabilities to participate in desired social roles (such as being a parent, employee or volunteer) and leisure activities, and to independently complete tasks of daily living that comprised their normal lives prior to injury. Similar to other research with individuals who have experienced a TBI (Levack et al., 2010; Nalder et al., 2013), participants in our study described their post-injury self as different from their pre-injury self and expressed desires to return to the person they were prior to ABI. This disruption of self can also lead to changes in perceived life trajectory, where persons with ABI often need to reassess their goals and plans due to the impact of their impairments (Sveen et al., 2016). This was also noted in the present study when participants described having to put goals and activities on hold to focus on recovery.

Inpatient rehabilitation was viewed as a means to achieve recovery and to return to living in the community, which in turn gave participants some intrinsic motivation to participate in therapy activities. Participants' efforts to re-establish their pre-injury identities were also reflected in descriptions of other patients encountered during inpatient rehabilitation. Participants commonly described other patients as worse, different, and in need of more help than them. This implied that other patients served as personal markers of recovery progress, perhaps as part of the identity struggle post-injury. Past research notes that persons with TBI commonly utilize social comparisons to consider their own circumstances (Arenth, Corrigan, & Schmidt, 2006; Arigo & Haggerty, 2016). Social comparisons might be upward (comparisons with persons seen as better off than themselves) or downward (comparisons with persons seen as worse off) (Arigo & Haggerty, 2016). The downward social comparisons made in the current study might shed light on how these adjustment issues impact a person's perspective of themselves or self-identity within the context of inpatient rehabilitation. Patients may not be ready to accept that they are people who also require support, as this identity does not reflect the persons that they were prior to sustaining an ABI.

Congruent with biographical disruption theory, the dynamics of participants' relationships with family members were also noted to change as a result of the ABI. Similar to previous research (Fleming et al., 2012), family members became many participants' informal caregivers from injury onset to community living after discharge from inpatient care. Family support is referred to as a "mobilization of resources" that may arise as a response to a person's biographical disruption (Bury, 1982 p.175). Similar to Fleming et al. (2012), participants noted that the involvement of family members in inpatient rehabilitation provided a connection to home and participants' lives prior to injury, which in turn provided a sense of normalcy. An added complexity to these relationships were participants who noted occupying parental or provider roles or being more active and independent, before their ABI. They described perceived pressure from family members or internal pressures to recover and return to these roles. This led to some personal conflict over prioritizing personal recovery needs over family needs, with some understanding that in order to support family members, they needed to go through the recovery process.

Family members consequently seemed to be stakeholders in their loved one's recovery, suggesting that biographical repair is a collective experience as opposed to an individual one. This dynamic may have reflected a level of interdependence common in family structures, and that a sudden critical event such as an ABI can shift and put stress on the established organization of families (Larøi, 2003). Milbourn and colleagues (2014) note that one's sense of self is rooted in the experiences and connections shared with others. Sustaining an ABI may not only disrupt the life of the person who experiences it, but also the lives of family members who often adopt new roles to support their loved one. To address the stressors that ABI can put on the family unit, researchers have found value in family therapy (Couchman et al., 2014; Larøi, 2003), which gives persons with ABI and their loved ones the opportunity to raise thoughts/concerns and assists them in adjusting to the changes experienced.

After discharge, most participants recognized that life was still significantly different as most had not returned to work or all pre-injury activities. Some felt they were eventually going to achieve the “normalcy” they knew from their life pre-ABI. Others recognized they might need to adjust to a “new normal” as they continued recovery, which included using compensatory strategies, having less independence and the inability to return to certain pre-injury activities. Adjustment to and acceptance of a “new normal” is noted to assist persons in dealing with the disruption caused by ABI (Couchman et al., 2014; Jumisko, Lexell, & Söderberg, 2005; Nalder et al., 2013). In the present study, participants seemed to be at the beginning of this adjustment period, as they came to realize that the recovery they desired may take longer than expected or may not occur at all. This realization was met with reported feelings of both frustration and optimism. Past findings demonstrated that persons with ABI often face difficulties adjusting to life after injury, as they might be fixating on the past or future and face difficulties in accepting the life changes (Cutler et al., 2016; Sveen et al., 2016). The construction of a personal narrative is noted to help persons with ABI connect their pre-injury and post-injury selves (D’Cruz, Douglas, & Serry, 2017; Lorenz, 2010; Nochi, 2000), allowing them to accept changes and move forward with a more positive self-concept.

In summary, inpatient rehabilitation is evidently a crucial stage within which persons expect to recover and hope to return to the lives they occupied prior to ABI. Biographical disruption provides a theoretical viewpoint for considering the impact of ABI on a person’s sense of self. The current findings highlight this impact and the coping styles persons may adopt to contend with this disruption during and after inpatient rehabilitation.

Relational autonomy. Another major finding of this study was that participants experienced struggles related to their autonomy within inpatient rehabilitation. It is important to consider participants' perceptions of their autonomy as inter-related to the concept of biographical disruption, as one's perceived autonomy over their choices and actions are significant parts of personal identity (Knox, Douglas, & Bigby, 2017). That is, participation in roles, activities and relationships that comprise one's self-concept include the ability to exert some autonomy in order to achieve goals and desired outcomes. In this study, participants described struggles related to exerting their autonomy (decisional control and freedom of choice) in the recovery process. Struggles arose from the tensions around study participants occupying a patient role while also working towards a level of independence that would allow them to return to the community, and consequently to their desired personal identity. Participants' described their struggles for autonomy in interactions with clinicians, in their perspectives of institutional policies and the involvement of family members in rehabilitation. This implies that participants experienced influences on their autonomy in relation to other persons and the inpatient environment, which is consistent with the theoretical concept of relational autonomy.

Initially developed within feminist (Mackenzie & Stoljar, 2000) and critical disability (Ells, 2001) studies, the concept of relational autonomy acknowledges that individuals exist within interpersonal relationships and broader social environments; these can affect perceived self-identity, decisional control and freedom of choice (Ells, Hunt, &

Chambers-Evans, 2011; Entwistle, Carter, Cribb, & McCaffery, 2010). A relational perspective of autonomy also recognizes that “autonomy, self-identity and decisional capacities, are dynamic…changing with the meanings and structures of people’s relationships and their world” (Ells et al., 2011, p. 86). In clinical practice literature, respect for patient autonomy is considered a fundamental bioethical principle (Entwistle et al., 2010) and another vital aspect to facilitating patient-centered care (Cardol, De Jong, & Ward, 2002; Hammell, 2013). As previously defined, patient-centeredness entails clinicians recognizing each patient as a unique individual with goals, values, preferences and capabilities, and enabling patients to make decisions or share in decision-making about their care (Cott, 2004). Relational autonomy recognizes that, within rehabilitation, a person’s choices and experiences can be directly or indirectly influenced by the clinicians with whom they interact; the institutional policies that affect rehabilitation care; the rehabilitation environment; relationships with others; and, the impact of their condition or disability (Hunt & Ells, 2011).

Consequently, considering autonomy as relational is theorized to facilitate patient-centeredness because it recognizes the many contributing factors that can influence a person’s sense of identity, control and freedom (Ells et al., 2011; Entwistle et al., 2010). Consistent with the present study, relational autonomy also reflects the reality that persons are in a more interdependent state within the inpatient context (Ells et al., 2011), often relying on clinician and family member support when they are faced with disability or impairment. Past research exploring relational autonomy within ABI rehabilitation has focused on the balance of responsibility over safety and risk-taking by clinicians, persons with ABI and their family during transitions of care (Andreoli, 2010), as well as perceptions of autonomy within residential rehabilitation settings (Martin, Levack, & Sinnott, 2014; Schipper, Widdershoven, & Abma, 2011). Relational autonomy thus provides a suitable theoretical lens to consider the current findings.

Interactions with clinicians. A prominent sub-theme was the perception that clinicians alone controlled discharge. Clinicians were viewed as persons with the knowledge to assess whether patients had achieved a level of recovery to return to normal life and who could permit this return. In response to this perception, participants seemed externally motivated to participate in therapy activities and to complete various tasks independently, in order to demonstrate their progress to clinicians. By completing tasks independently, participants felt a sense of control over their recovery, which may have provided a source of internal motivation to continue participating in rehabilitation. For example, some described themselves as feeling like they were returning to the person they were before ABI.

The perceived clinician control of discharge might also reflect a participant viewpoint that clinicians hold more power within the patient-clinician relationship; a relationship quality recognized as inherent in rehabilitation and one that is challenging to overcome (Clapton & Kendall, 2002; Eisenberg, 2012; Sim, 1998). The ideal patient-centered model of care places the patient as an equal partner to clinicians where possible (Lund, Tamm, & Bränholm, 2001), reflecting a balance of control and shared-decision making (D'Cruz, Howie, & Lentin, 2016). Persons with ABI can, however, experience physical, cognitive and behavioural impairments that require clinicians to adopt more protective roles, particularly earlier within inpatient rehabilitation in order to ensure safety within the recovery progress (Sandman & Munthe, 2010; Sim, 1998). The participants of the current study seemed to recognize that clinicians possessed the knowledge to guide their rehabilitation and felt following their instructions would result in recovery. Most participants described understanding the level of control exerted by clinicians over their rehabilitation and felt able to depend on them for guidance. This was further enhanced when clinicians listened to their input and responded to their concerns. As a contrasting example, when one participant experienced feeling disregarded and unheard by staff, he expressed negative sentiments; likening it to inhumane treatment. Quality of communication can significantly impact the patient-clinician relationship (Ruiz-Moral, 2010). For example, past research notes that a lack of communication about the discharge process and potential challenges after discharge from clinicians can leave patients and their family members feeling uninformed and abandoned during their transition from rehabilitation to community living (Abrahamson et al., 2016; Fleming et al., 2012; Turner et al., 2008). In the present study, quality of communication between clinicians and patients had the effect of enhancing or detracting from patient autonomy.

As mentioned, a relational perspective of autonomy acknowledges the dynamic nature of patient autonomy - priorities and the nature of relationships can change. Thus, within inpatient rehabilitation and in the face of a significant injury, participants regarded clinicians positively for guiding them through the process. They seemed comfortable with the perceived control and power that clinicians held, but also valued opportunities to exert their own control over their health and rehabilitation when they raised important concerns or questions.

Institutional policies. Institutional policies were another source of influence on participants' perceived autonomy and these included rules about off-unit access and safety precautions. Inpatient ABI units, as previously noted, are secured for patient safety; an aspect mentioned by most participants. Persons who were permitted to leave the unit unaccompanied felt less confined and controlled, as compared to persons without such permission. The contrast was evident as one person stated that off-unit access provided a sense of normalcy, while another person expressed strong negative opinions about not being able to leave the floor. Fleming et al. (2012) found that persons with TBI likened the secured inpatient unit to a "prison" when they were unable to leave without permission from clinicians. Fleming and colleagues (2012) noted that some persons did not understand the purpose of the secured ward, while others did, but all found it to be restrictive. In the present study, the majority of participants seemed to understand the purpose of the secured ward, but also valued when they had permission to leave unaccompanied. This might have contributed to a sense of enhanced autonomy and some assurance that they were recovering or were not as significantly impaired as other patients.

Participants also commented on certain safety rules and precautions that controlled their movements and actions, such as staff members needing to be present to assist with transfers in and out of bed or if they wished to access the therapy gym outside of scheduled therapy time. These were instances when participants believed they could perform certain actions independently but required permission or supervision from clinicians - once again reflecting a power imbalance. Nevertheless, while rules and precautions were restricting and viewed to be excessive, participants understood their purpose.

Before sustaining an ABI, participants were independent adults with control over their movements and decisions. Within the patient role, participants recognized they had to follow the rules of the inpatient setting. The tensions they seemed to experience might have reflected their struggle to adjust to the role of a patient in rehabilitation – an unexpected role in their life trajectory. Thus, while they were not necessarily happy with the limitations imposed on their autonomy by the environment and institutional policies, they still abided by them.

Family involvement. Through the lens of relational autonomy, family members were also a source of influence. Similar to Fleming et al.'s (2012) findings, participants noted that family members were welcome sources of support during their time in inpatient rehabilitation. Family members often assumed much responsibility for their loved one's care from the point that they sustained an ABI and acted as sources of support. Participants seemed comfortable being dependent on and vulnerable with family members, likely because family members were persons whom participants knew well and trusted. Within the theory of relational autonomy, Ells and colleagues (2011) note that, during rehabilitation, a supportive family can facilitate a person's exertion of autonomy, while it may be hindered with an oppressive family situation. In the present study, family members acted as advocates for participants by helping to navigate the hospital system, seeking information and raising concerns. However, as noted previously, some participants needed to recover in order to support their family, while others described still being dependent on family members after discharge. Thus, participants might have welcomed the control assumed by family members in the earlier stages of ABI, particularly when they were in more vulnerable positions during the early period of sustaining an ABI. They also, however, experienced tensions related to reducing this control after discharge.

The findings of this thesis highlight and stress the importance of contextual factors in contributing to participants' perceived autonomy within the patient role and the related struggles they might experience as a result of the biographical disruption. Participants faced difficulties adjusting to being 'a person with a brain injury,' an identity notably different from their pre-injury selves. This was reflected in their desires to return to "normal" and the difficulties faced as they coped with the impact of ABI on their identity and independence. Relational autonomy accounted for some of the tensions that arose when participants experienced a loss of decisional control and an increased level of dependence on others. A major source of tension experienced by participants was the complexity of occupying a patient role (which seemed to require some level of interdependence with clinicians and family members) while simultaneously attempting to become more independent in order to return to life prior to ABI. The findings of this study have shed light on perspectives and strategies that patients may adopt within inpatient rehabilitation, as they attempt to re-establish their personal identity after sustaining an ABI.

4.2 Implications for Clinical Practice

Based on the current findings, persons with ABI experience a complex recovery journey within ABI inpatient rehabilitation. This journey not only encompasses the regaining of functional abilities and the development of compensatory strategies but also includes challenges to re-establish personal identity and sense of autonomy. As in our study, a growing body of evidence recognizes that ABI may significantly threaten one’s sense of self (Levack et al., 2010; Roger, Wetzel, Hutchinson, Packer, & Versnel, 2014) and that the biographical disruption caused by ABI should be recognized and addressed in clinical contexts (Ownsworth & Haslam, 2014). Participants seemed to experience tensions between dependency on clinicians and family members, and the desire to increase their independence in an effort to return to their pre-injury selves.

The findings of this study provide descriptions and interpretations of patient experiences of ABI inpatient rehabilitation that clinicians and program administrators can consider in their work. Patient-centered care principles encourage clinicians to know their patients holistically, by developing an understanding of their experiences, needs, preferences, abilities and goals (Kitson, Marshall, Bassett, & Zeitz, 2013). The current findings provide evidence that clinicians and program administrators may utilize to better understand and describe patients’ needs. By better addressing patient needs, patient-centeredness is enhanced, and patients may experience more positive outcomes in rehabilitation (Doyle, Lennox, & Bell, 2013). Based on the current findings, it is suggested that when considering the rehabilitation needs of persons with ABI, psychosocial services are included as core therapy along with occupational, physical, and speech-language therapies. Patients need support as they face changes in their physical and cognitive abilities and, our study highlighted, to their self-identity.

Additionally, on discussion with staff from the ABI inpatient rehabilitation program in this study, it is recognized that psychosocial needs are often addressed within the existing core therapies, as well as with neuropsychologists, psychologists and social workers. With that in mind, it may be beneficial for these clinicians to directly address the biographical disruption experienced by patients and utilize strategies to assist them through this adjustment process. For example, a systematic review by D'Cruz and colleagues (2017) noted that activities where persons with ABI have the opportunity to develop their personal narratives (e.g. through song, writing and visual arts), are effective for helping them to acknowledge and grieve the changes to the sense of self that are experienced as a result of ABI.

Psychosocial therapy efforts, such as psychological counselling, need to include patients' family members. Family therapy is beneficial because the injury impacts the family as a unit and results in changes in family dynamics, structures and roles (Larøi, 2003). Therapy of this nature may provide an opportunity for everyone to express potential stressors and establish realistic expectations for recovery and return to previously-held familial roles.

A relational perspective of autonomy recognizes that clinician support for patients during this period of identity adjustment promotes their sense of autonomy (Ells et al., 2011). When developing ABI programs, clinicians need to consider the many factors that contribute to patient autonomy in order to ascertain how decisional control may be enhanced while still ensuring patient safety. For example, persons with ABI often express a need for clinicians to provide them with more information about discharge, and the realities of transitioning to the community after inpatient rehabilitation so they may feel more prepared to face potential challenges (Piccenna et al., 2016). Similarly, participants in our study seemed to be seeking information about their recovery progress, often making comparisons to other patients in order to gauge their own progress. This may reflect a need for program staff to provide more regular updates to patients about their progress during their inpatient stay. These might take the form of written updates, where clinicians may have patients write goals and activities down and keep them in a personalized binder; this may serve as a memory aid and point of discussion with family. Additionally, further efforts to maximize patient autonomy, where possible, may give patients a greater sense of control over their rehabilitation and care. For example, providing a forum for discussion, staff asking questions during therapy interactions, having a weekly 10-minute meeting with core staff to discuss progress and make decisions for next steps, and an exit interview may be beneficial. These efforts could enhance a patient-centered approach to improving care.

4.3 Limitations

This study has limitations. The credibility of this study is limited by the use of one source of data collection. Triangulation of different data sources (such as the patient and the service provider) is a suggested qualitative method for forming thick description of the issue of interest, and consequently improving study credibility (Shenton, 2004). The use of focus groups to investigate inpatient clinicians' and administrators' perspectives of the findings of this study could have helped provide more context to patient descriptions, such as those relating to patient interactions with clinicians and perceptions of institutional policies. Additionally, member checking was only conducted with three participants. Member checking with more participants might have provided further context or clarifications to the findings that were reported; further enhancing credibility.

This study was also limited by low recruitment (n = 12, rather than the desired sample size of 20 participants). A larger number of participants may have provided an opportunity for negative case analysis, thereby enhancing the credibility of the findings. Negative-case analysis allows researchers to explore emerging patterns by considering viewpoints that contradict them (Shenton, 2004). For example, participants who discussed family involvement in their care regarded this as a mainly positive aspect of their rehabilitation. Given that sustaining an ABI is stressful for both the person with ABI and their family (Oyesanya & Bowers, 2017), there may be possible incidents of family conflict that can negatively affect inpatient experiences. This strategy might have contributed to the depth of the finding by forming a richer picture of patient experiences.

Finally, this study focused on participants who were able to return to community living and who attended a specific inpatient program in southern Ontario. As such, the findings reflect a specific practice context, and may not be transferable to other settings (Shenton, 2004). Thick descriptions of the service delivery model, participant group and the inpatient program were provided to enable readers to determine the transferability of these findings to other ABI inpatient contexts.

4.4 Future Research Directions

This study contributes to an area of research that is under-explored within the ABI inpatient context. Future qualitative research endeavours should be designed, however, to expand on these findings. The current study reflects a sample of persons who completed inpatient rehabilitation, were able to return to community living, and other distinguishing demographic and clinical variables (See Table 1.0). They were recruited from one program of an ABI inpatient rehabilitation unit. This unit also comprises two other programs: (1) a slow-to-recover program for persons with more severe ABI, and (2) a neurobehavioural program for persons displaying challenging behaviour or mental health issues. Given that patients from these programs will have more severe impairments or comorbidities, as well as potentially longer inpatient stays, their experiences will likely differ compared to the experiences described by participants in the current study. Future research projects should be designed to explore the inpatient experiences of persons from these programs in order to enrich the knowledge around the patient perspective of this stage of care.

4.5 Knowledge Dissemination

Knowledge dissemination is an important step for moving research evidence into practice and entails sharing the main messages of research findings with key stakeholders within the context under focus (Straus, Tetroe, & Graham, 2009). Key stakeholders in the present study include clinicians and administrators working within the field of ABI inpatient rehabilitation, as well as persons with ABI. The main message of these findings stresses the importance of considering patient voices in informing ABI inpatient rehabilitation care. It also emphasizes that psychosocial needs might require greater consideration, along with functional needs. Efforts to disseminate the findings of this study have thus included the presentation of these findings to the clinicians and staff of the ABI program under investigation. This gave attendees the opportunity to reflect on the findings and to discuss strategies they could employ. For example, attendees suggested that patients might need to receive more frequent progress updates, have rehab goals and activities in written format, or be included more frequently in team meetings to discuss their progress and contribute to decisions about their care. Additionally, study findings were presented in poster-format at an ABI rehabilitation-focused conference, which was attended by persons with ABI, clinicians, researchers and other professionals in the field. In the future, this study will also be submitted for publication in a relevant academic journal in order to make the findings more widely available to research users.

4.6 Conclusions

This is one of the first known studies to utilize in-depth interviews to explore experiences of ABI inpatient rehabilitation from the perspective of persons with ABI, within the context of urban Ontario. Interpretive description methods guided the description and interpretation of participants' experiences in relation to relevant theories and past research. The patient lens provided by these findings underscores the biographical disruption that persons with ABI may face, and how tensions in relational autonomy reflect their struggle to reclaim their sense of identity within and beyond the context of the inpatient rehabilitation unit. These are issues that need to be considered by inpatient clinicians and administrators in order to create the conditions by which patients can have the opportunity to work through these tensions. The knowledge generated and interpreted from participants' experiences in this study also provide both a theoretical language and connections to previous ABI literature that clinicians and program administrators can utilize to increase their sensitivity around the perspectives, needs and preferences of patients at this stage of care (Thorne, 2016). Increased understanding of patients' perspectives can contribute to improving patient-centered care in the ABI inpatient context. As a way to achieve this, the current thesis has suggested that addressing both the functional and psychosocial needs of persons with ABI may better prepare them for the difficulties they face moving forward after discharge.

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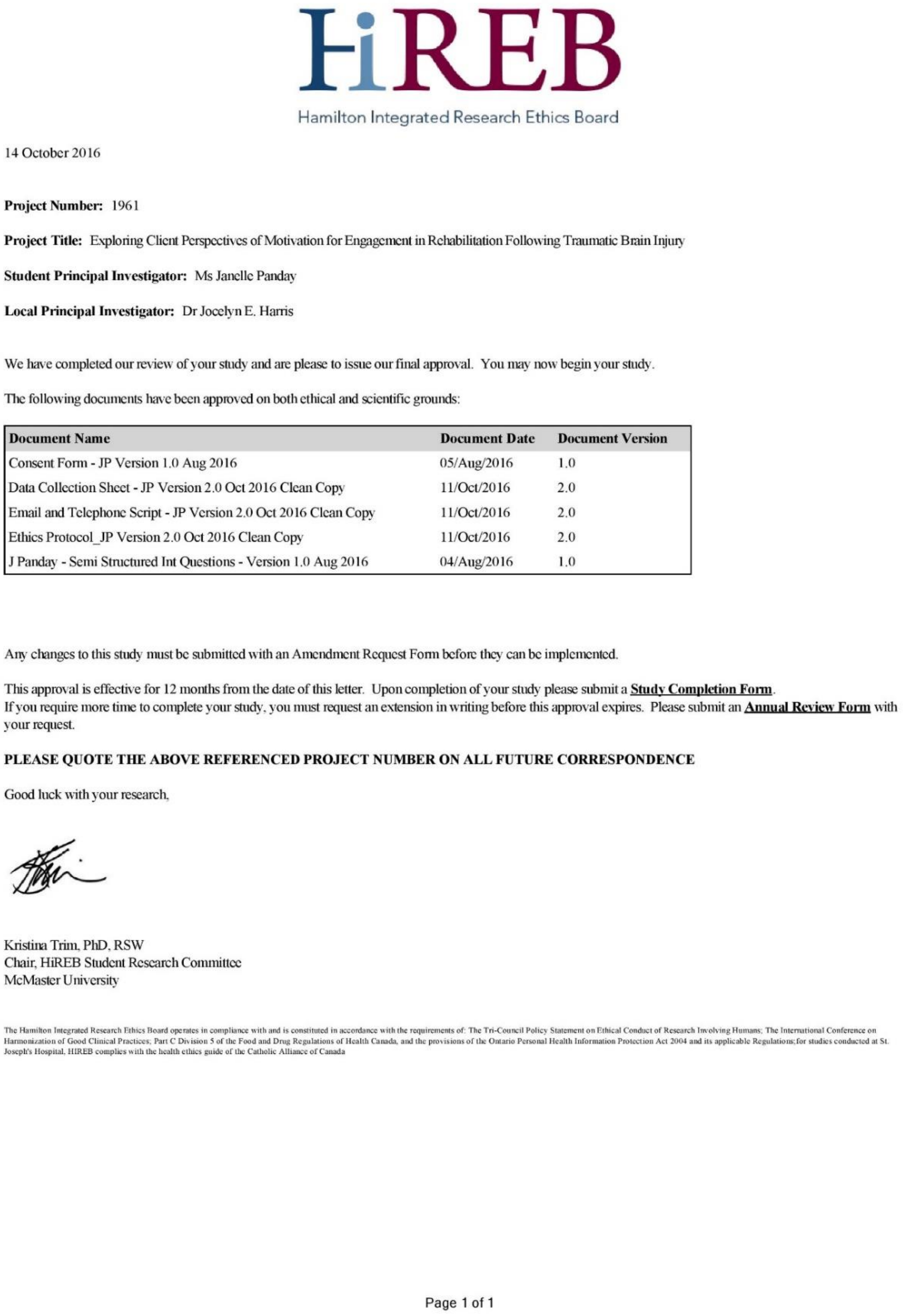
Appendix I: Ethics Approval and Amendment Approval Letters



HiREB
Hamilton Integrated Research Ethics Board

14 October 2016

Project Number: 1961

Project Title: Exploring Client Perspectives of Motivation for Engagement in Rehabilitation Following Traumatic Brain Injury

Student Principal Investigator: Ms Janelle Panday

Local Principal Investigator: Dr Jocelyn E. Harris

We have completed our review of your study and are please to issue our final approval. You may now begin your study.

The following documents have been approved on both ethical and scientific grounds:

Document Name	Document Date	Document Version
Consent Form - JP Version 1.0 Aug 2016	05/Aug/2016	1.0
Data Collection Sheet - JP Version 2.0 Oct 2016 Clean Copy	11/Oct/2016	2.0
Email and Telephone Script - JP Version 2.0 Oct 2016 Clean Copy	11/Oct/2016	2.0
Ethics Protocol_JP Version 2.0 Oct 2016 Clean Copy	11/Oct/2016	2.0
J Panday - Semi Structured Int Questions - Version 1.0 Aug 2016	04/Aug/2016	1.0

Any changes to this study must be submitted with an Amendment Request Form before they can be implemented.

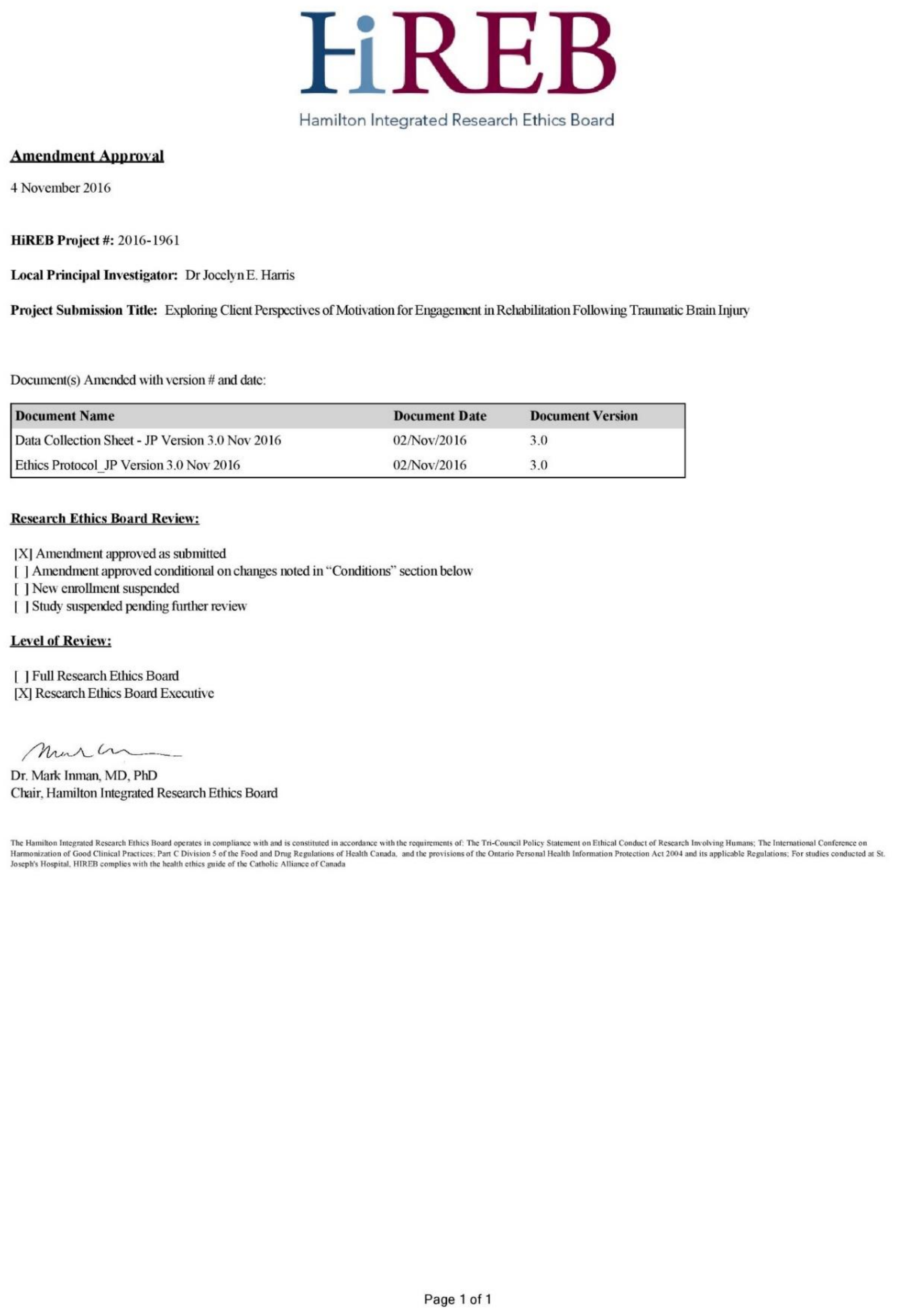
This approval is effective for 12 months from the date of this letter. Upon completion of your study please submit a **Study Completion Form**.
If you require more time to complete your study, you must request an extension in writing before this approval expires. Please submit an **Annual Review Form** with your request.

PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

Good luck with your research,

Kristina Trim, PhD, RSW
Chair, HiREB Student Research Committee
McMaster University

The Hamilton Integrated Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations;for studies conducted at St. Joseph's Hospital, HIREB complies with the health ethics guide of the Catholic Alliance of Canada



HiREB

Hamilton Integrated Research Ethics Board

Amendment Approval

4 November 2016

HiREB Project #: 2016-1961

Local Principal Investigator: Dr Jocelyn E. Harris

Project Submission Title: Exploring Client Perspectives of Motivation for Engagement in Rehabilitation Following Traumatic Brain Injury

Document(s) Amended with version # and date:

Document Name	Document Date	Document Version
Data Collection Sheet - JP Version 3.0 Nov 2016	02/Nov/2016	3.0
Ethics Protocol_JP Version 3.0 Nov 2016	02/Nov/2016	3.0

Research Ethics Board Review:

[X] Amendment approved as submitted
[ ] Amendment approved conditional on changes noted in "Conditions" section below
[ ] New enrollment suspended
[ ] Study suspended pending further review

Level of Review:

[ ] Full Research Ethics Board
[X] Research Ethics Board Executive

Dr. Mark Inman, MD, PhD
Chair, Hamilton Integrated Research Ethics Board

The Hamilton Integrated Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations; For studies conducted at St. Joseph's Hospital, HIREB complies with the health ethics guide of the Catholic Alliance of Canada

Appendix II: Participant Consent Form

PARTICIPANT CONSENT FORM

Study Title: Exploring Client Perspectives of Motivation for Engagement in Rehabilitation Following Traumatic Brain Injury

Investigators:

Local Principal Investigator:	**Student Investigator:**
Dr. Jocelyn E. Harris, PhD, OT	Janelle Panday, BSc
School of Rehabilitation Science	School of Rehabilitation Science
McMaster University	McMaster University
Hamilton, ON, Canada	Hamilton, ON, Canada
(905) 525-9140 ext. 27813	**(416)-871-5797**
E-mail: jharris@mcmaster.ca	E-mail: pandayj@mcmaster.ca

For study information and questions, contact Janelle Panday at pandayj@mcmaster.ca

What are we trying to discover?

You are invited to take part in a study that will explore your perspectives of rehabilitation and what motivates you to participate in rehabilitation after a Traumatic Brain Injury (TBI). This research is conducted as a master's thesis project. The aim is to learn about your experiences in therapy after your injury including what you did and did not like; how you think your therapy could be improved; and what you found motivating or demotivating about the process. This form is designed to provide you with detailed information about this study. If you would like to participate, you will be asked to sign the last page of this document.

What will happen during the study?

You will be asked questions about your experiences in therapy and also asked for some personal information such as your age, educational background and injury information. The interview will take 30-45 minutes to complete and will be done at Hamilton Health Sciences Regional Rehabilitation Centre or over the telephone. The interview will also be audio-recorded and handwritten notes will be taken.

Here are some sample questions that you may be asked:

- For you, what was the purpose of rehabilitation?
- What did you find challenging about rehabilitation?
- What parts of rehab did you like? What parts did you not like?

Are there any risks to doing this study?

It is not likely that there will be any harms or discomforts from taking part in this study. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. You also may stop at any time and ask for a break, and you can stop taking part in the study at any time. The steps taken to ensure privacy of your information are outlined below.

Are there any benefits to doing this study?

It is hoped that what is learned as a result of this study will help us to better understand the rehabilitation experience after brain injury. This could help therapists to improve therapy and rehabilitation programs in general. There are no direct benefits from participating in this study.

Reimbursement

For your participation in this study, you will receive a Tim Horton's gift card (valued $10.00) as a token of appreciation for your time as well as reimbursement for your parking or use of public transportation or HandyDART if you attend an in-person interview

.

Confidentiality

You are participating in this study confidentially. Your name will not be used nor any information that would allow you to be identified. Instead, you will choose a false name or pseudonym to be used during the interview. No one but the interviewer will know whether you participated unless you choose to tell them. The information/data you provide will be kept in a locked cabinet at McMaster University where only the Local Principal Investigator and myself (the Student Investigator) will have access to it. Information kept on a computer will be protected by a password. Once the study has been completed, the data will be destroyed after 10 years as per McMaster regulations.

What if I change my mind about being in the study?

Your participation in this study is completely voluntary. If you decide to be part of the study, you are free to stop (withdraw) from it at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you.

The information that you provided up to the point where you withdraw will be kept unless you request that it be removed. Also, if you do not want to answer some of the questions, you do not have to, but you can still be in the study. Finally, your decision of whether or not to be part of the study will not affect your continuing access to services at Hamilton Health Sciences.

How do I find out what was learned in this study?

We expect to have this study completed by approximately August 2017. You can receive a summary of the results if you are so interested. You can provide your contact information below.

Questions about the Study

If you have questions or need more information about the study itself, please contact the interviewer (Janelle Panday) at **(416) 871-5797** or **pandayj@mcmaster.ca** OR Dr. Jocelyn Harris at **(905) 525-9140 ext. 27813** or **jharris@mcmaster.ca**.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

SIGNATURE OF PARTICIPANT/LEGALLY-AUTHORIZED REPRESENTATIVE

Title of Study	Exploring Client Perspectives of Motivation for Engagement in Rehabilitation Following Traumatic Brain Injury
Primary Investigator	Jocelyn Harris, Ph.D., O.T., School of Rehabilitation Science, McMaster University
Student Investigator	Janelle Panday, BSc, School of Rehabilitation Science, McMaster University

Signature of Participant

I have read the preceding information thoroughly. I have had the opportunity to ask questions, and all of my questions have been answered to my satisfaction. I agree to participate in this study involving the procedures described above, with an understanding of the known possible risks that might occur. I understand that I will receive a signed copy of this form.

____

Participant Name Participant Signature Date

Signature of Person Obtaining Informed Consent

I confirm that I have explained the nature and purpose of the study to the participant name above. I have answered all questions. I believe the participant has the legal capacity to give informed consent to participate in this research study.

____

Name and title Signature Date

Signature of Principal Investigator

Primary Investigator Name Primary Investigator Signature Date

Future research: Are you willing to be contacted about future studies in our laboratory? (Circle one)

Yes **No**

Consent to be contacted: Would you like to receive a summary of the study results? (Circle One)

Yes **No**

Contact for study results and future research (circle which one or both)
Email:
Phone number:
Address:

Appendix III: Semi-Structured Interview Questions – Initial

Traumatic Brain Injury & Motivation to Engage in Therapy
Semi-Structured Interview Questions

1. Can you tell me a little about yourself and how you ended up in rehab?

2. Can you tell me about your experience doing rehab while in the hospital?
    a. What kind of things do you do in rehab/therapy?
    b. Who do you work with in rehab/therapy? Or who helps you?
    c. Did anyone besides the therapist help you?
    d. Can you describe the room(s)/space where you did your therapy? What was it like?
    e. What there a time or experience that stood out for you in rehab?

3. What do you think is the purpose of rehab/therapy?

4. What are your personal reasons for coming to rehab?

5. What do/did you like about rehab/therapy?
    a. Can you give me some examples of that?

6. What did you find hard/challenging about rehab?

7. What do you think has changed about you since you have started rehab? / What has changed over time?

8. Is there anything else about your rehab experience that you'd like to talk about that we haven't discussed yet?

9. Do you have any suggestions for making rehab better?

Appendix IV: Semi-Structured Interview Questions – Revised

Traumatic Brain Injury & Motivation to Engage in Therapy
Semi-Structured Interview Questions

Revised: March 3rd, 2017

1. Can you tell me a little about yourself and how you ended up in rehab?
    a. Can you tell me about the hospitals you stayed at before coming to Hamilton General?
    b. How have your goals or plans changed since your injury? (How has your life been disrupted?)
    c. Can you tell me about when you first arrived at the unit?
        i. What were your first impressions?
2. Can you tell me about your experience doing rehab while in the hospital?
    a. What kind of things do you do in rehab/therapy? (Prompt using list of activities)
    b. Who do you work with in rehab/therapy? Or who helps you?
    c. Did anyone besides the therapist help you?
        i. Family?
        ii. Friends?
    d. Can you describe the room(s)/space where you did your therapy? What was it like?
    e. What there a time or experience that stood out for you in rehab?
3. What do you think is the purpose of rehab/therapy?
    a. Why did you go to rehab?
4. What do/did you like about rehab/therapy?
    a. Can you give me some examples of that?
5. What did you find hard/challenging about rehab?
6. What do you think rehab did for you?
    a. Did rehab help you?

10. Do you have any suggestions for making rehab better?

11. Is there anything else about your rehab experience that you'd like to talk about that we haven't discussed yet?

Appendix V: Codebook for Analysis

1. Getting Back to Normal

Description: Participant describes the purpose of rehab as getting back to normal (their routines and activities prior to their ABI) and/or mentions that they wanted or worked towards getting back to normal.

a. The Purpose of Rehab

Description: Participant describes the purpose of rehabilitation as helping one returning to normal and/or the community.

b. Impact on Activities and Life Roles

Description: Participant describes how the injury has affected their abilities to participate in routine activities; how the injury has impacted important roles in their life (work/leisure/family).

c. Self-Motivations

Description: Participant describes perceptions of being self-motivated for rehab and the reasons behind this.

2. Personal Journey

Description: Participant describes their injury experiences – how the sustained their ABI; the hospitals prior to inpatient rehabilitation & how the ABI has affected them and their loved ones.

a. Personal Identity & Changes Since Injury

Description: Participant describes who they are and how they want to be perceived. Participant may also describe changes they have seen in themselves since experiencing injury.

b. Injury Experience & Hospital Pathways

Description: Participant describes how the injury was sustained. Also, may describe hospital and rehab programs admitted to prior to and after inpatient rehab

c. Family & Friend Dynamics

Description: Participant describes roles and actions of family members and loved ones in the initial onset of injury and during rehabilitation.

3. Rehabilitation Experiences

Description: Participant describes various aspects and experiences of the rehab program (activities, environment, persons with whom they interacted).

a. Standout Experiences

Description: Participant describes any standout experiences that occurred.

b. Clinician Relationships with Inpatients

Description: Participant provides opinions, descriptions and comments about clinicians.

c. Comparisons & Relationships with Other Inpatients

Description: Participant describes how they perceived their status of health and wellness as compared to other patients; and also describes their relationships with other patients.

d. Autonomy, Communication & Trust

Description: Participant describes whether or not (and how) concerns and questions during rehab were heard and addressed; discusses trust of clinicians and healthcare system; discusses the quality of communication received from healthcare providers; and/or discusses having control of actions and decisions.

e. Activities & Physical Features of the Environment

Description: Participant describes activities that they took part in within rehab; provides descriptions and opinions of the physical environment.

Appendix VI: Participant Follow-up Summary Sheet & Questions

Exploring Person-Perspectives of Facilitators & Barriers to Engagement in Rehabilitation following Acquired Brain Injury

Summary of Findings

Persons with Acquired Brain Injury often show lower levels of engagement in participation during inpatient rehabilitation. But, there is little known about the inpatient experience from the view of the patient. The purpose of this study was to explore the views of persons with Acquired Brain Injury who completed inpatient rehabilitation. The knowledge gained from this study will be used to make suggestions for improving rehabilitation. Below is a summary of the key themes developed from reviewing the interviews of 12 participants:

1) **Life, Interrupted**
   We found that brain injury often interrupts people's normal lives and routines. They might be in at least one other hospital before entering inpatient rehabilitation. Also, people often have to wait several weeks to get into the inpatient program, and this can be difficult. It can also be especially frustrating if the hospital in which they are waiting does not provide very good care.

2) **Struggles for Freedom & Control within Inpatient Rehabilitation**
   We found that person's often have issues retaining their person freedoms and control over themselves while in inpatient rehab. This includes being able to make your own decisions and move freely around while in rehab. Areas that affected personal freedoms included: hospital rules, interacting with therapists and other employees, and having family take some control of a person's care.

a) Hospital Rules

Most persons had to deal with hospital rules that may not have allowed them to leave the inpatient area unattended or even get out of bed without help. Persons who were able to leave the inpatient area did not feel as restricted but could not go everywhere they wanted to, such as the gym, without someone with them.

b) Interacting with Therapists and Other Employees

Persons also had very positive opinions about their therapists, nurses and doctors. But they also saw them as the gatekeeps of rehabilitation – that is the persons who decided whether they could leave the hospital to go home. Persons often felt they had to prove to their therapists that they were able to take care of themselves in order to go home. Being able to talk to and feel listened to by therapists and other employees lead to positive experiences. But if one did not feel they were being listened to, it was a less positive experience.

c) Family Control

Persons' family members were often present during the stay in inpatient rehab. Family members also would take control by asking questions and making decisions for the patient. This was viewed positively by most patients, possibly because they trusted their family members and we comfortable with them taking this control. Family also acted as a welcome connection to a person's home and normal life.

3) Comparisons with other Patients

Most persons in this study did not try to make many friends while in inpatient rehab. They were more focused on their own recovery and having family there may have lessened the need to make other friends. Also, most persons often compared themselves to other patients. They felt that other patients had worse injuries or problems and also felt that they were doing better in comparison.

4) Life Goes On – Returning to Regular Life

Being discharged from rehabilitation meant that the majority of persons in this study could return to their normal lives and communities. However, most were also not fully recovered but expected to see progress with time. Participants realized they would have to be patient and wait to fully recover all their abilities. This was frustrating for most persons, but they were also generally positive about their life going forward.

Questions:

1. Did you feel that the theme "Life, interrupted" reflected some of your experiences?
    a. What did you find common/uncommon?

2. Did you feel that the theme about "Struggles for Autonomy" reflected some of your experiences?
    a. How did you feel about the role of institutional rules?
    b. How did you feel about the role of clinicians/therapists?
    c. How did you feel about the role of your family?

3. Did you feel the sub-theme about "Comparisons with Other Patients" reflected some of your experiences?
    a. What did you find common/uncommon?

4. Did you feel that the theme about "Life Goes On" reflected some of your experiences?
    a. What did you find common/uncommon?

5. Did you have any comments (questions/opinions) about the study findings in general?
    a. Did you have anything you wanted to add that you feel is important?

Appendix VII: Recruitment & Data Collection Flow Diagram