

Understanding family involvement in adult inpatient traumatic brain injury rehabilitation

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Thesis submitted to the
University of Ottawa
in partial fulfillment of the requirements
for the Doctor of Philosophy degree in Rehabilitation Sciences

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Summary

Traumatic brain injury is a substantial cause of disability worldwide; recovery is a long-term, intensive process. Patients with traumatic brain injury are admitted to inpatient rehabilitation with the goal of preventing disability and the need for long-term care as well as promoting patient independence. Acknowledging that traumatic brain injury also affects the family, much of the literature focuses on the well-being of families and their needs, bringing attention to family functioning, resilience, and psychosocial well-being. Recognizing the important role of families in health care, Canadian healthcare institutions espouse family-centred philosophy. Not to mention, the resulting impairments from traumatic brain injury and the complex nature of inpatient rehabilitation can also lead to the involvement of families in this process. However, we do not yet fully understand how families are involved in adult inpatient traumatic brain injury rehabilitation. Given the adoption of a family-centred philosophy as well as the potential benefits of family-centred care for patient and family outcomes, it is important to understand this involvement to guide the provision of family-centred health and rehabilitation services. This study is the first step in a program of research that is devoted to understanding family involvement in adult inpatient traumatic brain injury rehabilitation.

I used an interpretive qualitative approach with a two-phased sequential design to elucidate how families were involved in the inpatient rehabilitation process. I conducted one-on-one semi-structured interviews with six patients with TBI, four family members, and 10 healthcare professionals followed by observations on the inpatient Acquired Brain Injury ward at a Canadian adult rehabilitation centre. In Phase 1 interviews, both the patients and family members described family involvement as family members being with and supporting the patients, informing other family members as well as the healthcare professionals and keeping

themselves informed, helping the patients to make decisions, and participating in care and therapy. The healthcare professionals similarly described family members being with and supporting the patients; however, they conversely illustrated family members' involvement as providing information to and receiving information from the healthcare professionals as well as making decisions when required or deemed necessary by them, and learning care and therapy. While the observation findings supported the patients', family members', and healthcare professionals' perceptions that family members support the patients by being present and spending time with them, they highlighted the healthcare professional-led nature of the rehabilitation process in the inpatient setting in relation to information sharing, decision making, and care and therapy. They also illuminated the potential impact of the ward environment on family involvement.

This study was the first to explore family involvement with this adult patient population in the inpatient rehabilitation setting from the perspectives of patients, family members, and healthcare professionals as well as through direct observation. It revealed that patients and family members had different understandings than healthcare professionals of the ways in which families were involved. Given the adoption of a family-centred philosophy, we need to understand how to operationalize it in this type of adult setting and close the gap between theory and practice.

Keywords: adult, family, inpatients, qualitative research, rehabilitation, traumatic brain injuries

Acknowledgements

I would like to thank my thesis supervisor, Mary Egan, for her guidance and encouragement throughout my doctoral studies. I would also like to thank my committee members, Katherine Moreau and Shawn Marshall, for their time and invaluable assistance with my thesis. Furthermore, I would like to thank Julie Chartrand and Virginia Wright for the time committed to reviewing my thesis and for their thoughtful feedback.

I would like to extend a special thank you to my husband, Christopher, as well as my family for their encouragement and everlasting support. Their support helped make this research possible. Finally, I would like to dedicate this thesis to my brother and cousin who are both brain injury survivors as well as my nephew, a superhero conquering every mountain in his life. They inspired me to be the support that they needed through their health challenges.

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List of Acronyms

In order of first appearance:

IPFCC: Institute for Patient- and Family-Centered Care

CFHI: Canadian Foundation for Healthcare Improvement

TBI: Traumatic Brain Injury

ACCH: Association for the Care of Children's Health

HCQ: Healthcare Consumers Queensland

CIHI: Canadian Institute for Health Information

ABIEBR: Acquired Brain Injury Evidence-Based Review

PTA: Posttraumatic Amnesia

CBT: Cognitive-Behavior Therapy

CHRP: Comprehensive-Holistic Rehabilitation Program

ABI: Acquired Brain Injury

Chapter 1: Introduction

Description of Problem

Family involvement in health care has become more prominent over the years as the participation of families (i.e., relatives, friends, and significant others) in the care and services provided to patients becomes recognized and better understood by healthcare organizations and professionals (Allen & Petr, 1998; DePompei & Williams, 1994; Law et al., 2003a). Families are integral to health care because they are central in the lives of individuals. This perspective of the family within health care stems from the humanistic movement. This movement promotes mutual respect and compassion between patients, family members, and healthcare professionals (Plant, Barone, Serwint, & Butani, 2015). Carl Rogers promoted humanism in health care in the 1940s and 1950s with the emergence of client-centred therapy (see Rogers, 1951). Further support for humanistic perspectives came in the 1970s with Bronfenbrenner's ecological systems theory, which stresses the importance of considering the interaction between an individual and their environments, such as their family, and the impact that this can have on their development (Bronfenbrenner, 1977; 1994). As research increasingly showed that a humanistic approach to health care positively influences patients' adherence to treatment and interventions, health outcomes, and satisfaction (see for example, Hojat et al., 2011; Steinhausen et al., 2014; Sylvia et al., 2013), healthcare organizations and professionals began to change paternalistic views of healthcare delivery in favor of more humanistic ones. Essentially, the humanistic movement placed patients and families at the centre of the healthcare system, instead of healthcare professionals, in an effort to improve the quality of interactions and care (Hughes, Bamford, & May, 2008).

These changes in the views of patients and families and advances in humanistic perspectives led to the implementation of patient- and family-centred philosophies to inform healthcare delivery; philosophies in which the roles of patients and families are formally recognized by healthcare organizations and the professionals working within them. Many argue that these philosophies, operationalized through family-centred care, can improve the quality of care and patient safety (Johnson, 1999; 2004). Research evidence supports the implementation of these philosophies, showing that they positively impact patient and family satisfaction with care as well as health outcomes, including adherence to interventions and treatments, cognitive and physical functioning, and well-being (see for example, Boudreaux, Francis, & Loyacano, 2002; Dunst, Trivette, Davis, & Cornwell, 1988; King, King, Rosenbaum, & Goffin, 1999; King, Teplicky, King, & Rosenbaum, 2004).

This shift within health care and the subsequent emergence of new philosophies to inform healthcare delivery promote an environment where health care is a mutual endeavor inclusive of patients, families, and healthcare professionals. This understanding is shown in the recent integration of patient- and family-centred philosophies as one philosophy by the Institute for Patient- and Family-Centered Care (IPFCC); reflecting the position that both patients and families, and therefore both philosophies, are equally important in the delivery of healthcare services and in all contexts. Support for this position is evident with the adoption and promotion of this integrated philosophy by Canadian healthcare organizations such as Accreditation Canada (2013), the Canadian Foundation for Healthcare Improvement ([CFHI], 2016), and Canadian Patient Safety Institute (2016) as well as adult academic health science centres. The IPFCC (2017a) defines patient- and family centred care as “an approach to the planning, delivery, and

evaluation of health care that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families. It redefines the relationships in health care.”

Patient- and family-centred philosophy and its related concepts, such as involvement, are important for guiding healthcare delivery. As Hughes et al (2008) express, “They are part of the body of ideas through which professionals and others make sense of their work and attribute moral meaning and value to it” (p. 456). The work of Hughes and colleagues (2008) also highlights the importance of considering the nature of the interaction and the context in which it takes place when approaching healthcare delivery, as the desired level of involvement of both the patients and families may vary. Murphy, Lee, Turnbull, and Turbiville (1995) provide further support for this argument by explaining that each healthcare setting and program includes a unique group of patients, families, and staff members, as well as its own unique organizational culture. The setting and its organizational culture are important factors to consider when implementing a philosophy that aims to guide practice as they have shown to influence an organization’s actions, performance, and direction for change (Mitchell & Pattison, 2012). Importantly, years of research efforts have consistently associated organizational culture with healthcare quality and patient safety (Chassin, 2013).

A setting illustrative of this unique makeup and organizational culture is the inpatient rehabilitation setting, interconnecting many programs and disciplines as well as healthcare professionals to work with patients and their families. Adding to this are the unique challenges of an adult inpatient rehabilitation setting, where patient-centred philosophy solely guided healthcare delivery prior to the additional adoption of family-centred philosophy. While families generally play an important role in health care, they can play an especially active role in the rehabilitation process in inpatient rehabilitation settings (Foster et al., 2012). Given this

conception, healthcare professionals may work with patients and families on a day-to-day basis to, for example, make decisions about care and set goals (DePompei & Williams, 1994). In this type of setting, the successful integration of all team members, including family members, and their productive interactions are vital to patient health outcomes (Behm & Gray, 2012; Lefebvre, Pelchat, Swaine, G  linas, & Levert, 2005; McLaughlin & Carey, 1993).

The important role that families play in rehabilitation is highly recognized in the rehabilitation of children with disabilities. Pediatric rehabilitation settings unequivocally embrace family-centred care and family involvement is prominent in these settings, such that researchers have focused their efforts on this area and developed a framework (i.e., CanChild framework) to facilitate the understanding of their family-centred philosophy and approach to care in this type of setting. Within family-centred care, research shows that family involvement in pediatric rehabilitation has a positive impact on patient and family outcomes, including, for example, patients' cognitive and physical functioning and psychological adjustment, as well as parental satisfaction with care and life (Braga, Da Paz Junior, & Ylvisaker, 2005; Rosenbaum, King, Law, King, & Evans, 1998). In light of this, many have called for all contexts to adopt a family-centred philosophy, including adult healthcare settings (Bamm & Rosenbaum, 2008; Clay & Parsh, 2014; Shelton, 1999). However, we (i.e., patients, families, healthcare professionals, researchers, administrators) do not fully understand family involvement in adult rehabilitation. Following in the footsteps of pediatric rehabilitation, healthcare professionals acknowledge the important role that families play in adult rehabilitation and the research literature is now beginning to bring attention to this. For example, healthcare professionals believe that family involvement in adult stroke rehabilitation can help facilitate treatment carryover (e.g., generalize new behaviors and activities to the home) and may increase patient participation in therapeutic

activities (e.g., time spent doing exercises), resulting in greater potential for improvement (Galvin, Cusack, & Stokes, 2009; Harris, Eng, Miller, & Dawson, 2010).

Understanding family involvement in the rehabilitation of adult patients with traumatic brain injury (TBI) is particularly important. Traumatic brain injury affects a person's cognitive, behavioral, psychosocial, and physical functioning, and has enormous implications for the patient, their family, and society. Rehabilitation services may include, depending on individual needs, occupational therapy, physiotherapy, therapeutic recreation, speech-language therapy, and cognitive and/or behavioral rehabilitation. Recovery from all levels of TBI is a long-term, intensive process in which families can often be intimately involved (Fleming, Sampson, Cornwell, Turner, & Griffin, 2012; Foster et al., 2012). It is believed that, during inpatient rehabilitation, families of patients with TBI can play a valuable role by, for example, providing information to the care team and assisting in goal setting and care planning (DePompei & Williams, 1994). However, despite general adoption of a family-centred philosophy on inpatient rehabilitation units and centres, we do not yet fully understand how families are involved in the rehabilitation process, as research in this area is very limited.

Although there is a well-developed body of literature that deals with either the recovery of adult patients with TBI or the well-being of their families (see for example, Barclay, 2013; Schönberger, Humble, Zeeman, & Teasdale, 2006a; 2006b; Simpson & Jones, 2013; Tyerman & Booth, 2001), we know relatively little about family involvement in adult inpatient TBI rehabilitation. So far, we know that the healthy functioning of families and their relationships with healthcare professionals can impact patient outcomes, including patient participation in rehabilitation, program completion, return to productivity, and social integration (Foster et al., 2012; Sander et al., 2002; Sander, Maestas, Sherer, Malec, & Nakase-Richardson, 2012; Sherer

et al., 2007). This research highlights the need to support families of patients with TBI. We also know that families identify involvement in the rehabilitation process as an important need (Keenan & Joseph, 2010; Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007). We have some information regarding how healthcare professionals perceive family involvement (Levack, Siegert, Dean, & McPherson, 2009). However, despite the key role of families in health care, we have minimal insight on how they are involved in the rehabilitation process for adult patients with TBI. Given the adoption of a family-centred philosophy and considering the important research evidence that demonstrates its impact on patient and family outcomes, quality of care, and safety, a greater understanding of how families are actually involved in this type of setting is vital to ensuring that we understand how to operationalize family-centred philosophy and guide the provision of family-centred health and rehabilitation services in adult inpatient TBI rehabilitation.

This knowledge gap highlights the need for the present two-phase qualitative study. This study is the first step in a program of research that is devoted to understanding family involvement in adult inpatient TBI rehabilitation. To begin to understand family involvement in this type of setting, this study aims to elucidate how families are involved in the rehabilitation of adult patients with TBI.

Contributions to the Field

In recent years, we have seen an increasing number of adult healthcare organizations adopt a family-centred philosophy. Recognizing the impact that these philosophies have on patient and family outcomes, the quality of health care, and patient safety, researchers are now interested in exploring these philosophies in relation to healthcare delivery within the adult population. However, research efforts have neglected to explore the ways in which family

members are involved in inpatient rehabilitation processes for adult patients with TBI. This study is the first to explore this concept within the adult population and, as such, with this study, I extend knowledge and understanding of family involvement and contribute to rehabilitation practice in several ways.

First, despite recommendations for increased family involvement in health care, we know little about how families are involved in inpatient rehabilitation for adult patients with TBI. By exploring family involvement in adult inpatient TBI rehabilitation, this study allows for a better understanding of this topic. As such, this study contributes to the growing body of research on family involvement and family-centred care and builds on the very limited body of empirical research on family involvement in adult inpatient TBI rehabilitation. Second, research in this area has neglected the perspectives of adult patients with TBI and their families. Therefore, this study adds to the limited amount of literature looking at family members' perceptions of family involvement in adult inpatient TBI rehabilitation and elucidates for the first time the perceptions of patients. Third, this study informs practice and professional development as the findings can improve healthcare professionals' awareness and understanding of family involvement, and by extension, family-centred care in adult inpatient TBI rehabilitation. Fourth, this study informs the operationalization of a family-centred philosophy in similar adult rehabilitation settings. Finally, with this study, the delivery of care and services can potentially be adapted in future, with the goal of improving the health and well-being of patients with TBI and their families.

The findings from this study also help form the foundation upon which to develop future studies in this area. For example, the findings from this study can inform studies looking at the following: (1) overall perceptions of family involvement and the factors that influence family involvement, (2) the relationship between family involvement and patient and family outcomes;

(3) how healthcare professionals can best support family involvement; and (4) how family involvement in this type of setting might differ from other areas of rehabilitation. The findings from this study can also help further the development of measures of family involvement that researchers developed with little empirical information regarding the family perspective.

Overview of the Study

In addition to this introductory chapter, this thesis includes five other chapters that provide an overview of the study, including: (1) a literature review and conceptual framework; (2) an overview of the study design; (3) Phase 1 of the study; (4) Phase 2 of the study; and (5) a discussion of the key findings, contributions, strengths and limitations, future research, and conclusion. Chapter 2 of this thesis presents a review of the literature and relevant concepts as well as the conceptual framework that guided the study design. Chapter 3 then describes the two-phased sequential design of the study. This chapter describes the context of inquiry, discusses my position as a researcher, and presents an overview of the qualitative approach used as well as the relevant ethical considerations. Chapter 4 presents the findings of the Phase 1 interviews with patients, family members, and healthcare professionals where I explored participants' perceptions of how families are involved. Chapter 5 then presents the findings of the Phase 2 observations of patient, family, and healthcare professional activities and interactions where I obtained a firsthand encounter with family involvement. The sixth and final chapter of this thesis discusses the key findings with reference to the published literature. It also highlights study contributions to knowledge, practice, and methodology, the strengths and limitations of the study, and areas for future research.

Chapter 2: Literature Review and Conceptual Framework

This chapter provides a review of the relevant literature and concepts within family-centred care, TBI, and family involvement in rehabilitation. It integrates the literature on these topics and highlights the gaps in research, establishing the need for the present study. Moreover, it provides the foundation for the development of the research questions, conceptual framework, and study design.

I begin this chapter with an overview of the evolution of the role of families in health care, when health care became more partnership driven and new philosophies to inform healthcare delivery emerged, including family-centred philosophies. I then review the concept of family-centred care and discuss relevant frameworks. Following this section, I introduce the important health problem of TBI. I explain what TBI is and discuss the impact it can have on the patient with the injury and outline rehabilitation for this type of injury. In the third section of this chapter, I bring together the concepts of families in health care and rehabilitation for TBI. I provide the definition of family that I adopted for this study and discuss the impact of TBI on the family, their need for support, and their involvement in TBI rehabilitation. I also introduce important factors to consider in regards to family involvement in TBI rehabilitation and in an adult rehabilitation setting. To end this chapter, I present a conceptual framework that I developed based on the reviewed literature to guide the study and summarize the ideas brought forward in the chapter.

Families in Health Care

From expert-driven to partnership-driven health care. While the involvement of families in health care is not new, its consideration has become more prominent in recent years as the participation of families in care processes for patients becomes better recognized and

understood. Carl Rogers' client-centred therapy (see Rogers, 1951) informed the general concept of consumer involvement in health care. The intention of client-centred therapy is to respect patients' abilities to foster changes within themselves and define valued outcomes from their own perspectives (Bowles, 2012). In health care, patient-centred care became a central element of quality care. This approach to care gave new meaning to the relationship between the patient and the healthcare professional, emphasizing the patient's active participation in their care and patient-healthcare professional collaboration (Epstein & Street, 2011; Gottlieb & Feely, 2006). Unlike paternalistic views of care where healthcare professionals maintain a position of authority over the patients, such humanistic views place patients and families at the centre of the healthcare system in an effort to improve the quality of care and interactions (Hughes et al., 2008).

Pediatric health care moved beyond this initial step when the Association for the Care of Children's Health (ACCH) embraced patient-centred care but also stressed the importance of families in caring for children, particularly in their role as their advocates (Bamm & Rosenbaum, 2008). The ACCH, founded in 1965, had the goal of bringing about changes in the United States' healthcare system to ensure the fulfillment of children's and families' needs. Societal movements for the recognition of families in the care of their children also stimulated important legislative changes throughout North America (e.g., Individuals with Disabilities Education Act in 1990) and international political agendas such as the United Nations 1994 International Year of the Family (Briar-Lawson, Lawson, Hennon, & Jones, 2001; Rosenbaum et al., 1998). Together, efforts such as these saw families playing an entirely new role in health care by advancing perspectives on families and highlighting their capabilities, strengths, needs, challenges, and resilience (Briar-Lawson et al., 2001). These proved to be important strides in health care

considering that most pediatric hospitals did not accept families onto their wards until the 1950s or later (Young, 1992).

In conjunction with the humanistic movement in health care, the emergence of Bronfenbrenner's ecological systems theory offered a more comprehensive approach to research on human development by considering the interaction between individuals and their environments (Bronfenbrenner, 1977). The fundamental argument of this theory is that healthcare professionals and researchers should examine each individual as a multiperson system of interaction, and in consideration of multiple settings and different levels of environmental systems. Specifically, Bronfenbrenner (1977) argues that the social interactions that take place between an individual and others, the settings in which these interactions take place, as well as other relevant settings, directly or indirectly influence an individual's development. With this understanding, Bronfenbrenner (1977) highlights the importance of considering the influence of an individual's immediate family and other social networks on their development. Although Bronfenbrenner's theory and research focused on child development, researchers have considered his propositions for adults receiving healthcare services (see for example, Fleury & Lee, 2006; Grzywacz & Fuqua, 2000; Howe & Briggs, 1982; McLeroy, Bibeau, Steckler, & Glanz, 1988). The push for a systemic view in adult health care, such as that of Bronfenbrenner, stems from criticisms of individually oriented perspectives, calling for broader and more inclusive perspectives.

Often at the forefront of research and practice involving families, the field of psychology has long fought for the recognition of families in mental health care (Young, 1992). Recognizing that individuals often present with issues involving a larger system, Celano (2012) and Nutt (2012) argue that an understanding of family interactions is essential for interventions to

efficiently and effectively meet the needs of patients because they can have an impact on their recovery. Nutt (2012) also argues the importance of a systemic perspective in respect of collectivist cultures where families do not view a person as an isolated individual, but rather as embedded within their family. Drawing on Bronfenbrenner's systems theory, healthcare professionals consider systemic approaches fundamental in couple's therapy, family therapy, and child and adolescent psychology (Celano, 2012; Harway & Kadin, 2012). Others have also called for the recognition and application of systemic approaches by psychologists working in primary and specialty health care because they have shown to be more effective than individual treatments (Celano, 2012; Gottlieb, 2012; Harway & Kadin, 2012; Nutt, 2012). Research in the field of psychology has shown that a family systems perspective and family-focused therapy are effective in the treatment of adult patients with TBI (Dausch & Saliman, 2009; Laroi, 2003). From a systemic view, healthcare professionals may consider families as advocates or information partners and families may even participate in therapy (Celano, 2012; Harway & Kadin, 2012).

The advances in perspectives on patients and families in health care and in the understanding of family systems led to the implementation of patient- and family-centred philosophies to inform healthcare delivery in which their roles are formally recognized. The purpose of this shift within health care and subsequent development of new philosophies to inform healthcare delivery is to promote an environment where healthcare professionals and organizations view health care as a mutual endeavor inclusive of patients, their families, and healthcare professionals.

Family-Centred Care

Defining family-centred care. Family-centred philosophies were introduced to inform healthcare delivery and uphold families' role as part of the healthcare team. To operationalize a family-centred philosophy, family-centred care has been widely implemented in contemporary pediatric health care (Bamm & Rosenbaum, 2008). These changes have echoed across the healthcare sector and many now consider family-centred philosophies to be appropriate for informing the delivery of health care for all age groups (Hughes et al., 2008). Over the years, adult health care has experienced the same shift in philosophy and healthcare professionals, researchers, and advocates alike are calling on adult healthcare organizations to incorporate a family-centred philosophy and family-centred care in all settings, including rehabilitation (Bamm & Rosenbaum, 2008). Importantly, this past year we witnessed another meaningful shift in the healthcare sector. Supporting the IPFCC and its mission, the CFHI announced the launch of a Canadian national campaign in the fall of 2015 called “Better Together: Partnering with Families”. This campaign aims to promote more patient- and family-centred care in Canadian hospitals by encouraging hospitals to review their visitor policies and adopt a family presence policy. A key message of this campaign is the need to move away from the concept of “families as visitors” and embrace the concept of “families as partners in care” (IPFCC, 2017b). Many hospitals across Canada have made a commitment by taking the “Better Together Pledge” since the launch one year ago.

However, adopting a family-centred philosophy in health care can be difficult due in part to the varying interpretations of family-centredness in the literature (Franck & Callery, 2004). Many have made the effort to capture the meaning of family-centredness in order to inform policy and practice in their settings (see for example, Allen & Petr, 1998; Briar-Lawson et al.,

2001; Dunst, 1997; Rosenbaum et al., 1998; Shelton, Jeppson, & Johnson, 1987) and some have even had to address misinterpretations of their view of family-centred care (Dunst, 1997). These researchers did so based on the understanding that a family-centred philosophy brings forth certain requirements of an organization (e.g., changes to policies, procedures, and practices) and that family-centred care looks somewhat different depending on the setting and population (e.g., pediatric versus adult; Allen & Petr, 1998). Bamm and Rosenbaum (2008) thus argue that in order for healthcare organizations to properly implement a family-centred philosophy within any of their settings, patients, families, and healthcare professionals must all have an understanding of the definition and principles of family-centred care. Researchers believe that a common language developed through an understanding of the meaning, ideas, and practices of family-centred care will help facilitate processes of care within a given setting (Bamm & Rosenbaum, 2008). The overall focus of family-centred care is to emphasize the role of families in health care and recognize their partnership with healthcare professionals (Johnson, 1990; Law et al., 2003a). Table 1 below outlines definitions of family-centred care from various disciplines. These definitions indicate that while different terminology may be used to describe family-centred care, it is clear that the same ideas are being articulated, such as family expertise, partnership, and joint decision making (Bamm & Rosenbaum, 2008). Broadly, family-centred care “is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care” (IPFCC, 2017a).

Table 1.

Definitions of Family-Centred Care

Source	Discipline	Term	Definition
Allen & Petr (1998, p. 9)	Social work	Family-centered service	Family-centered service delivery, across all disciplines and settings, recognizes the centrality of the family in the lives of individuals. It is guided by fully informed choices made by the family and focuses on the family's strengths and capabilities.
Dunst (1997, p. 75)	Psychology	Family-centered care	A particular approach to intervention that aims to support and strengthen parents' abilities to nurture and enhance child well-being and development.
IPFCC (2017a)	Across health care	Patient- and Family-centered care	Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care.
Law et al. (2003a, p. 2)	Pediatric rehabilitation	Family-centred service	Family-centred service is made up of a set of values, attitudes, and approaches to services for children with special needs and their families. Family-centred service recognizes that each family is unique; that the family is the constant in the child's life; and that they are the experts on the child's abilities and needs. The family works with service providers to make informed decisions about the services and supports the child and family receive. In family-centred service, the strengths and needs of all family members are considered.
Shields, Pratt, & Hunter (2006, p. 1318)	Nursing	Family-centre care	Family-centred care is an approach to the planning, delivery, and evaluation of health care that is governed by mutually beneficial partnerships between healthcare providers, patients, and families. Family-centred care applies to patients of all ages, and it may be practiced in any healthcare setting.
Viscardis (1998, p. 44)	Pediatric rehabilitation – parent advocacy group	Family-centred service	The family-centred approach is one that begins with the child's and family's strengths, needs, and hopes, and results in a service plan which responds to the needs of the whole family. It involves education, support, direct services, and self-help approaches. The role of the service provider is to support, encourage, and enhance the competence of parents in their role as caregivers.

Family-centred frameworks. Researchers have developed family-centred frameworks to provide an understanding of family-centred care and guide healthcare professionals in implementing its principles into their daily practice. Various frameworks have been developed to address the varying perceptions of families within different cultural, political, and practice environments, and tailored to different health issues and age groups (Bamm & Rosenbaum, 2008). In order to better illustrate family-centred care, I describe below two well-known family-centred frameworks: The Institute for Patient- and Family-Centered Care framework and the CanChild framework.

The Institute for Patient- and Family-Centered Care. The IPFCC, a not-for-profit organization founded in 1992, is a leader in the advancement of the understanding and practice of patient- and family-centred care in the United States. The IPFCC aims to strengthen family-healthcare professional collaborations, change care in hospitals, improve healthcare facility design, transform medical education, and advise on health policy (Johnson, 2000). The Institute explains that healthcare professionals working within a family-centred philosophy recognize the importance of families and the role that they play in ensuring the health and well-being of patients. The Institute also believes that emotional, social, and developmental supports are integral components of health care and that it is important to promote the health and well-being of both patients and families (IPFCC, 2017a). Based on these beliefs, the Institute developed their family-centred framework that many adult healthcare organizations have since adopted, including those in Canada.

Along with the development of various programs and activities to stimulate change in the healthcare system, the Institute developed a framework encompassing core principles and tenets for the understanding and practice of family-centred care. This framework has evolved

over the years, becoming more refined and simplified to meet the needs of those who use it (Johnson, 2000). The earlier version of the framework, developed in 1987, consisted of eight elements of family-centred care in pediatric health care. These eight elements were later refined and simplified in 1996 and became the four core principles of family-centred care, accompanied by four tenets to guide its implementation. The IPFCC again revised the framework in 2010 when the Institute broadened its focus to both patient- and family-centred care. Acknowledging the importance of family-centred practices for all age groups, the Institute also moved from focusing solely on children to broadening the application of its framework to adults as well. The framework now rests on the principles of Respect and Dignity, Information Sharing, Participation, and Collaboration, each of which are accompanied by a brief description of how healthcare professionals can incorporate them into their practice (see Appendix A).

The CanChild Centre for Childhood Disability Research. While the IPFCC was established for advancing the understanding and practice of family-centred care across health care, the CanChild Centre for Childhood Disability Research was founded in 1989 to advance research and knowledge specifically in the field of childhood disability (CanChild, 2014). Through this effort, CanChild became a well-known proponent of family-centred care. Its definition of family-centred care (see Law et al., 2003a in Table 1) recognizes families as the experts on their children and highlights the fact that families play an important role in the care provided for their children. As such, CanChild (2014) considers research on family-centred care a main priority within their organization.

To complement the development of educational materials, measures of family-centredness, and many other resources, CanChild put forward a three-level framework for family-centred care that many Canadian pediatric healthcare organizations have adopted.

Rosenbaum and colleagues developed the original framework in 1998, which they updated in 2003, based on the family-centred care and pediatric rehabilitation literature available at that time; they integrated the literature on what constitutes family-centred care and reviewed the research evidence that supports the specific elements of family-centred care in rehabilitation. Considered the backbone of their framework, the three assumptions are that (1) parents know their children best and want the best for their children, (2) families are different and unique, and (3) optimal child functioning occurs within a supportive family and community context: the child is affected by the stress and coping of other family members (Law et al., 2003a, p. 4). The framework also consists of the following five guiding principles (“should” statements) that are rooted in the above three assumptions: (1) each family should have the opportunity to decide the level of involvement they wish in decision-making for their child; (2) parents should have ultimate responsibility for the care of their children; (3) each family and family member should be treated with respect (as individuals); (4) the needs of all family members should be considered; and (5) the involvement of all family members should be supported and encouraged (Law et al., 2003a, p. 4). Finally, the framework includes elements that outline the rights of families in health care according to a family-centred philosophy as well as offer healthcare professionals key behaviors that they can incorporate into their practice to become family-centred (Law et al., 2003a). Please see Appendix B for the detailed CanChild framework. Together, the three-level framework facilitates the understanding and practice of family-centred care in pediatric rehabilitation (Rosenbaum et al., 1998).

Family-centred framework for adult inpatient TBI rehabilitation. Despite the advances made thus far in the area of family-centred care, a framework that provides an understanding of family-centred care in adult inpatient TBI rehabilitation has yet to be developed. It is important

for us to fully understand this view of healthcare delivery in this type of setting because TBI can have an important impact on families and lead to their involvement in the rehabilitation process. The IPFCC framework, for example, may not be ideally suited to guide family-centred care in adult inpatient TBI rehabilitation. The IPFCC developed their framework in the United States with the goal of achieving a broader application of family-centred care across all healthcare fields with much of its evidence and applicability directed at, for example, intensive care, critical care, and primary care. As such, it lacks the evidence base and consideration of the unique rehabilitation context, as well as issues related to TBI and the Canadian healthcare context. The generalized nature of this framework is evidenced by its four core principles; respect and dignity, information sharing, participation, and collaboration, that have not been rooted in clear philosophical assumptions. The framework also does not offer clear behaviors that healthcare professionals can enact to facilitate family-centred care in this type of setting, thus making it more difficult for them to utilize from a practice standpoint. Instead, the framework offers general practice tenets relating to each of the four core principles such as, “Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care” (IPFCC, 2016b).

The CanChild framework also may not ideally contribute to the understanding and practice of family-centred care in adult inpatient TBI rehabilitation. Although a Canadian effort, CanChild developed this framework, including its assumptions, principles, parent rights, and practice behaviors, for and based on evidence from the pediatric population and context, in which there lie important differences from the adult population and context. Important differences include, for example, the adult patient’s right to make his or her own decisions and right to privacy. While we typically consider parents the primary decision makers for their

children, we view adult patients as independent and their own decisions makers (with exception when an alternate decision maker is required). Therefore, the adult patient can decide if and how he or she wants their family involved, identify their own rehabilitation needs, goals, and interventions, and can decide the type and amount of information to share with their family.

Given the recent adoption of a family-centred philosophy and push for family-centred care in adult health care, it is imperative that we try to understand this philosophy to properly inform practice in the adult inpatient rehabilitation setting. In particular, as a major component of family-centred care, it is important to understand the involvement of families in the rehabilitation process. The inpatient rehabilitation setting is unique in that it interconnects many programs and disciplines as well as healthcare professionals to work with patients and their families; while families can generally play an important role in health care, they can play an especially active role in the care and services provided to adult patients in this setting (Foster et al., 2012). This highlights the importance of exploring family involvement in this type of setting. As such, this study focuses on family involvement and in future, can potentially inform studies looking further at family-centred care practices in adult inpatient rehabilitation.

Involvement frameworks. In partnership with the IPFCC, the CFHI supports quality improvement initiatives that involve patients and families with the goal of improving the quality of care (CFHI, 2016). Through this endeavor that began in 2010, the CFHI has gathered an array of resources and tools to help researchers and organizations work with patients and families, including frameworks for understanding the level of patient and family involvement in health care. Essentially, these frameworks allow the user to understand the level at which involvement is operating (e.g., direct care, organizational, policy making) as well as the level of involvement that is occurring (e.g., information, consultation, collaboration).

For the purpose of this study, I used the framework developed by Health Consumers Queensland ([HCQ], 2012) to inform my understanding and discussion of family involvement. This framework allowed me to understand the extent to which families were involved in the rehabilitation process for patients with TBI and thus, allowed me to understand and describe the current nature of their involvement. To develop the framework, HCQ brought together an advisory group composed of stakeholders with vested interests in the effective engagement of consumers in health care. For example, they brought together representatives from disability, community, and mental health services, various hospital associations, and Local Health and Hospital Networks. This framework provides the following four levels within the healthcare system upon which to focus: (1) the individual patient level at the point of care; (2) the program, service, and facility level; (3) the regional network level; and (4) the broader system and policy-making level. It also consists of five levels of involvement: information, consultation, involvement, collaboration, and empowerment. Table 2 outlines adapted descriptions of the five levels of involvement included in this framework. Focusing on the individual patient level, which centers on “engaging with the individual consumer and/or their family/carer as partners in their own healthcare, support, and treatment” (HCQ, 2012, p. 15), this framework and its five levels of involvement informed my interpretation of family involvement in adult inpatient TBI rehabilitation, allowing me to discuss the level of involvement of families in this setting.

Table 2.

Levels of Involvement

Level	Information	Consultation	Involvement	Collaboration	Empowerment
Individual health care	Information is a one-way exchange where information is given to families.	Consultation is a two-way exchange and information is gathered from families.	Involvement is about shared decision making where families are involved in the process.	Collaboration is where families and healthcare professionals work together in partnership.	Empowerment is where families make decisions and these decisions are implemented.
Descriptor	Nil	Low	Moderate	High	Control

Note. Adapted from “Consumer and Community Engagement Framework,” by HCQ, 2012.

Traumatic Brain Injury Rehabilitation

Before turning to a review of the literature on the involvement of families in adult inpatient TBI rehabilitation, it is important to first understand what TBI is, the impact this type of injury can have on the patient, and the nature of rehabilitation for the remediation of impairments incurred after TBI.

What is traumatic brain injury? Traumatic brain injury is a substantial cause of death and disability worldwide with an annual incidence of 100 to 300 per 100,000 people (Abelson-Mitchell, 2008). In Canada, the annual incidence of mild and severe TBI is estimated to be 600 and 11.4 per 100,000 (Canadian Institute for Health Information [CIHI], 2007), respectively. In the province of Ontario alone, healthcare professionals treated more than 18,000 individuals for TBI in 2006 and 2007 (Colantonio et al., 2010). Moreover, TBI is most common among young and middle-aged adults (i.e., under the age of 60; CIHI, 2007). Traumatic brain injury is generally defined as an injury to the brain caused by an external force to the head such as in motor vehicle crashes, falls, sports injuries, blast injuries, or violence (Ontario Neurotrauma Foundation, 2013). A TBI can occur from either an open or a closed injury to the head. In an

open head injury, the skull is penetrated by an external force often causing a focal injury to the brain. In a closed head injury, the skull is typically not fractured and a diffuse injury to the brain may be observed (Degeneffe, 2001). Traumatic brain injury also ranges in severity from a mild, moderate, to a severe injury. Neurological dysfunction resulting from TBI may last only for a short period or be permanent (Cicerone, Levin, Malec, Stuss, & Whyte, 2006). With its impact on cognitive, behavioral, psychosocial, and physical functioning, we must recognize the implications for the patients, their families, and society.

The impact of traumatic brain injury on the patient. After TBI, a patient can experience a range of impairments. It is recognized that each patient's experience of TBI is unique for many reasons, one being the clinical presentation of the injury (Degeneffe, 2001). Factors contributing to the observed variability in clinical presentation include the location and severity of the injury, as well as the open or closed and focal or diffuse nature of the injury. All of these factors contribute to a unique effect on brain structure and function, which in turn translates to the impairments that each patient will experience (Rees, Marshall, Hartridge, Mackie, & Weiser, 2007). Patients with TBI often experience impairments in cognitive, behavioral, psychosocial, and physical functioning. The impact of these impairments on a patient's life is yet another factor contributing to their unique experience of TBI as the consequences and personal meaning of the losses patients may endure will be different in every case. These impairments can affect a patient's ability to return to work, maintain social relationships, participate in the community, and function independently (Dams-O'Connor & Gordon, 2010). Focusing on family life, impairments experienced after TBI can lead to marital dysfunction, difficulty carrying out parental responsibilities, and reduced overall productivity in the home (Cicerone et al., 2011; Kieffer-Kristensen, Teasdale, & Bilenberg, 2011). With each

type of impairment, there exists a range of potential deficits that contribute to the challenges faced by the patient and their family. Below, I briefly review the potential deficits related to cognitive and behavioral impairments.

Cognitive impairments. Commonly experienced by patients with TBI, cognitive impairments can significantly affect the ability to function, making it difficult to participate in daily activities and in society in general. The human brain processes information with a series of systems that together form human cognition (Eysenck & Keane, 2005). When the environment provides information, the brain processes this information to generate a response. For example, if a person encounters a problem, various cognitive processes will occur and produce the required response, such as navigating a vehicle down a street filled with children playing, or remembering on which floor the physician's office is located. When the brain is injured, cognitive performance typically becomes impaired, making it difficult to process information and function appropriately. Cognitive processes frequently affected by TBI include attention, executive function, memory, and cognitive communication (Bragge et al., 2014).

More than 60% of patients with moderate to severe TBI report some form of attentional difficulty, often lasting many years post injury (Ponsford et al., 2014a). While our understanding of attention is still evolving, it is currently viewed as comprising the processes of arousal, selective attention, speed of information processing, sustained attention, shifting and dividing attention, and working memory (Ponsford et al., 2014a). We commonly see impaired executive functions in patients with moderate to severe TBI (Tate et al., 2014). Executive functions include the ability to plan and organize, to problem solve, and to initiate, monitor, regulate, and adapt behavior, as well as reasoning, abstract thinking, cognitive flexibility, and self-awareness (Tate et al., 2014). Memory, generally characterized by the processes of encoding, storing, and

retrieving information from a person's short- and long-term memory systems, is also often affected by TBI (Velikonja et al., 2014). Memory impairments can affect a patient's ability to encode, store, and retrieve new information, causing difficulty learning new information (Tsaousides & Gordon, 2009). Finally, these attentional, executive, and memory impairments can also lead to problems with communication, often causing difficulties listening, speaking, reading, writing, conversing, or interacting socially (Togher et al., 2014).

Behavioral impairments. Traumatic brain injury can lead to important changes in an individual's behavior. Generally, behavior is described as a person's observable actions. According to the Acquired Brain Injury Evidence-Based Review ([ABIEBR], 2014a), challenging behavior occurs in 25% to 50% of patients with brain injury. Some behavioral changes can be linked to cognitive impairments and often negatively affect a patient's interpersonal relationships and independent living. For example, impairments in executive functioning can affect a patient's ability to regulate their own behavior and consequently lead to inappropriate behaviors, such as inappropriate sexual behavior (Tate et al., 2014). We also observe behavioral disturbances while patients with TBI are in a state of posttraumatic amnesia (PTA) after injury. The cognitive disturbance experienced during PTA is widespread and as such, contributes to an increased presence of agitated behavior (Ponsford et al., 2014b).

In addition to the behavioral changes linked to cognitive impairments, we observe other behavioral changes when injury occurs to the frontal lobes of the brain. After frontal lobe injury, patients with TBI can exhibit internalizing or externalizing behaviors, although researchers have shown that adults with TBI tend to more frequently exhibit externalizing behaviors (Ylvisaker et al., 2007). Examples of internalizing behaviors include carelessness, reduced self-confidence or self-esteem, frustration, and social withdrawal. Examples of externalizing behaviors include

irritability, impulsiveness, aggressiveness, disinhibition, and sexual inappropriateness (Cattelani, Zettin, & Zoccolotti, 2010; Ylvisaker et al., 2007). Researchers have also focused on behavioral changes related specifically to communication because of their impact on these patients' social lives, such as swearing, inappropriate disinhibited responses, and interrupting (Ylvisaker et al., 2007). It is equally important to recognize that research has shown that behavioral disturbances impact compliance with rehabilitation, potentially resulting in early discharge (ABIEBR, 2014a; Lane-Brown & Tate, 2009; Ylvisaker et al., 2007).

Rehabilitation for traumatic brain injury. Along the continuum of care, patients with TBI typically first receive in-hospital care during the acute stage of recovery in the emergency department and/or the intensive care unit. If the patient meets rehabilitation criteria, the patient is then transferred to an inpatient rehabilitation unit or centre for rehabilitation services during the postacute stage of recovery. Following acute care or inpatient rehabilitation, the patient is commonly discharged back into the community where they might continue to receive services such as outpatient, community, or vocational rehabilitation (ABIEBR, 2014b). This study focuses on inpatient rehabilitation.

Patients with TBI are admitted to inpatient rehabilitation with the goal of improving cognitive, behavioral, psychosocial, and physical functioning. In doing so, healthcare professionals aim to prevent disability and the need for long-term care and promote independence. In his effort to describe the complex healthcare intervention of rehabilitation, Wade (2005) offers the following working definition: "Rehabilitation is an educational, problem-solving process that focuses on activity limitations and aims to optimize patient social participation and well-being, and so reduce stress on carer/family" (p. 814). Depending on demographic and injury characteristics, a patient with TBI is typically treated in inpatient

rehabilitation for 12 to 109 days (Arango-Lasprilla et al., 2010). Inpatient rehabilitation begins shortly after the patient is medically stabilized; a program tailored to the patient's individual needs is developed (Stucki, Stier-Jarmer, Grill, & Melvin, 2005). Recovery from all levels of TBI is a long-term, intensive process that can include occupational therapy, physiotherapy, therapeutic recreation, speech-language therapy, and cognitive and/or behavioral rehabilitation (Fleming et al., 2012).

Cognitive rehabilitation. Given the impairments experienced after TBI, healthcare professionals use cognitive rehabilitation as the treatment of choice for patients with this type of injury. Bragge and colleagues (2014) define cognitive rehabilitation as “interventions addressing deficits in attention, executive function, cognitive communication, and/or memory” (p. 162). The goal of cognitive rehabilitation is to assist the patient with TBI to improve their functioning, such as their ability to perform cognitive tasks, and therefore reduce the impairments experienced (Dams-O'Connor & Gordon, 2010; Tsaousides & Gordon, 2009). This can be achieved via a combination of interventions. Depending on patients' individual needs, healthcare professionals may teach them compensatory strategies, arrange to modify their home or work settings to suit their abilities, and/or retrain skills (Tsaousides & Gordon, 2009).

Cognitive rehabilitation for attention typically involves performance or management training where learned strategies allow patients with TBI to compensate for their attentional deficits. Strategies can include reducing background noise, asking for repetition, reducing workload, allowing additional time to complete tasks, among others (Ponsford et al., 2014b; Rees et al., 2007). Remediation of executive functions often focuses on awareness of deficits, problem solving, planning, organization, and multitasking abilities, as well as improving goal-directed behaviors. Strategies can include direct feedback, self-monitoring and regulation, and

external cueing (Cicerone et al., 2006; Tate et al., 2014; Tsaousides & Gordon, 2009). Cognitive rehabilitation for memory impairments generally consists of restorative, retraining, or compensatory interventions. Strategies can include computer-based repetitive exercises, structured programs, verbal or visual elaboration, self-recitation, self-cueing, association, and environmental supports such as diaries, memory notebooks, calendars, and assistive technological tools (e.g., pagers, computers, and voice recorders; Rees et al., 2007; Velikonja et al., 2014). Strategies specific to the remediation of communication skills include yes/no response-system and encouragement strategies to meet patients' basic needs and improve verbal expression and discourse. Augmentative and alternative communication strategies include various forms of communication boards (e.g., alphabet, picture) or more high-tech options such as voice output communication aid devices. Additionally, certain rehabilitation strategies for the remediation of attention, executive function, memory, and behavior are also relevant to the rehabilitation of communication deficits (ABIEBR, 2014c; Togher et al., 2014).

Behavioral rehabilitation. The overall aim of rehabilitation for behavioral disturbances is to reduce inappropriate behavior and increase appropriate behavior, to the extent possible, in hopes of assisting the patient to live independently and reenter school, work, and other community-based activities (Cattalani et al., 2010; Ylvisaker et al., 2007). Healthcare professionals are urged to choose the most appropriate intervention based on the needs of the patient with TBI, their stage of recovery, and the setting in which rehabilitation will take place (Cattalani et al., 2010; Ylvisaker et al., 2007). Behavioral interventions have received less attention than those for cognitive and motor functioning and consequently, evidence supporting their effectiveness is limited. However, researchers have begun to shed light on the effectiveness

of and further priorities for interventions targeted to behavioral disturbances (Cattelani et al., 2010; Ylvisaker et al., 2007).

Applied behavior analysis is an approach that emphasizes the modification and management of inappropriate behaviors such as agitation, non-compliance, inadequate self-care, aggressiveness, and impulsiveness. Interventions typically focus on increasing or decreasing behavior by using strategies such as praise, token-economies, extinction/time-out, response-cost, feedback, prompting, stress coping training, redirection, and positive communication (Cattelani et al., 2010; Ylvisaker et al., 2007). Cognitive-behavior therapy (CBT) is an approach that focuses on identifying and changing problematic behaviors such as aggression, anger, reduced self-esteem, reduced social participation, and avoidance. Intervention techniques used within CBT include education, cognitive restructuring, self-monitoring, self-talk training, and supporting communication (Cattelani et al., 2010). Finally, Comprehensive-holistic rehabilitation programs (CHRP) aim to develop alternative or compensatory behaviors. They focus primarily on lifestyle changes; healthcare professionals target interventions to the needs of the patient with TBI and those within their environment, including their family. A CHRP includes both individual and group interventions where patients learn to self-manage and enhance motivation and cooperation. Interventions also aim to improve patients' levels of insight, realism, emotional adjustment, and acceptance of deficits (Ben-Yishay et al., 1985; Cattelani et al., 2010).

Families and Traumatic Brain Injury Rehabilitation

The resulting impairments from TBI and the complex nature of inpatient rehabilitation led to the consideration of the role of families in this process as many view them as important stakeholders whom TBI also affects (Bayley et al., 2014a). It is for reasons such as these and many others that health care, including rehabilitation, has moved in the direction of adopting a

family-centred philosophy to care where the involvement of families in care processes is a major component. Before reviewing the literature on family involvement in adult inpatient TBI rehabilitation, it is important that we first understand who families are in this type of setting and in the context of this study.

Defining family. The family unit is recognized as a staple of human society and is traditionally understood as a group of two or more persons who are related by birth, marriage, or adoption (Nam, 2005; Tillman & Nam, 2008). However, perceptions of what constitutes family vary across cultures, and with the passing of time, perceptions have evolved considerably (Tillman & Nam, 2008). Canada's ever-growing cultural diversity has expanded our view of the family unit. Allen and Petr (1998) argue that we should define family openly and broadly and that the family itself should define its boundaries, such that families should determine who constitutes family.

This same sentiment was previously expressed in health care by Johnson (1990) who stated "ACCH recognizes broad definitions of family to acknowledge these societal changes..." (p. 236). The supportive interactions that take place among related and non-related persons in hospitals and other healthcare settings are very apparent. Within rehabilitation settings in particular, relatives, friends, and significant others may take on active roles both during inpatient care and during the later phases of recovery after discharge (Foster et al., 2012). As such, for research in rehabilitation, it is important to adopt a definition of family that is representative of families' experiences in this type of setting. For the purpose of this study and guiding my research activities, I adopted the definition of family as outlined by Foster et al (2012) which states that "family broadly includes all those who influence recovery including [relatives], ...friends, and significant others who may take on a caregiving or support role" (pp. 1855-1856).

While I used this definition to inform my research activities, the definition remained flexible recognizing that it could evolve over the course of this study. Finally, following the argument brought forward by Allen and Petr (1998), individuals who identified themselves as or were identified as family (i.e., relatives, friends, and significant others) by a patient were considered family for the purposes of this study.

The impact of traumatic brain injury on families and the need for support. Given the nature of TBI and its consequential impairments, not only is the patient with TBI affected, but their family is as well. The literature has long demonstrated that families of patients with TBI often experience depression, anxiety, and stress, among other negative impacts (Simpson & Jones, 2013). The Brain Injury Association of Canada (2015) thus highlights the importance of improving the quality of life of all those affected by TBI. Acknowledging this reality, much of the TBI literature has focused on the well-being of families, bringing attention to family functioning, resilience, and psychosocial well-being (see for example Barclay, 2013; Degeneffe, 2001; Gan, Campbell, Gemeinhardt, & McFadden, 2006; Simpson & Jones, 2013). Moreover, we know that family functioning and relationships with healthcare professionals can have an impact on patient outcomes (Foster et al., 2012; Lefebvre et al., 2005; Sander et al., 2002; Sander et al., 2012; Sherer et al., 2007), thus emphasizing the need to support families. Importantly, research efforts have led to the development of intervention programs to help support families of patients with TBI, namely counselling and support groups as well as targeted interventions (see for example, Gleckman & Brill, 1995; Kreutzer et al., 2009; Kreutzer, Marwitz, Sima, & Godwin, 2015; Stejskal, 2012; Tyerman & Booth, 2001). The focus on family well-being has led to a well-developed body of literature on this topic. Equally important, however, are efforts to understand family involvement in the rehabilitation process.

Family involvement in traumatic brain injury rehabilitation. While the theoretical literature has long called for the recognition of families in adult rehabilitation, many have highlighted the gap between theory and practice and the lack of empirical literature on this topic (Fleming et al., 2012; Foster et al., 2012; Horwitz, Horwitz, Orsini, Antoine, & Hill, 1998; McNeill, Shuyler, & Ezrachi, 1997). Current understanding of family involvement in adult inpatient TBI rehabilitation is fragmented. Literature narrowly contributing to this understanding has focused in so far on *perceptions of family involvement* (D’Cruz et al., 2016; Levack et al., 2009; Shaw, Chan, & Lam, 1997), *perceptions of how families can be involved* (Cicerone et al., 2006; Degeneffe, 2001; DePompei & Williams, 1994; Foster et al., 2012; Harvey-Krefting, 1990; Quine, Pierce, & Lyle, 1988; Sohlberg, McLaughlin, Todis, Larsen, & Glang, 2001), *family needs in rehabilitation* (Gagnon, Lin, & Stergiou-Kita, 2016; Keenan & Joseph, 2010; Kreutzer et al., 2015; Kreutzer & Marwitz, 1989; Kuipers et al., 2014; Rotondi et al., 2007; Sander, 2014; Tverdov, McClure, Brownsberger, & Armstrong, 2016), *family experiences in rehabilitation* (Fleming et al., 2012; Horwitz et al., 1998; Ishikawa, Suzuki, Okumiya, and Shimizu, 2011; Knox, Douglas, & Bigby, 2015; Martone, 2001), and *the impact of family involvement* (Braga et al., 2005; Dams-O’Connor & Gordon, 2010; Foster et al., 2012; Galvin et al., 2009; Harris et al., 2010; Horwitz et al., 1998; Kinsella, Ong, Murtagh, Prior, & Sawyer, 1999; Maeshima et al., 2003; McKinlay & Hickox, 1988; McNeill et al., 1997; Rosenbaum et al., 1998; Stein & Jessop, 1991; Winter et al., 2016). I review this literature below to highlight how research has thus far contributed to our understanding of family involvement in adult inpatient TBI rehabilitation, but to also illustrate the shortcomings of this literature.

Perceptions of family involvement. Arguing that, in practice, disagreement between families and healthcare professionals on family involvement can lead to conflict; Shaw (1990)

reviewed the literature and developed the family involvement questionnaire. The goal of this questionnaire is to determine perceptions of family involvement in inpatient brain injury rehabilitation and it includes the following scales: Input, Information/Education, Treatment, Advocacy, Contact, and Counselling/Support. Using this questionnaire, Shaw and colleagues (1997) determined that families perceive their involvement needs to be more substantial and diverse in these areas than what healthcare professionals perceive to be appropriate. Specifically, while families and healthcare professionals seem to agree on involvement related to information provision, receipt of information/education, and advocacy, they differ in their perceptions of involvement relating to treatment, access to the patient, and counselling (Shaw et al., 1997). While the work of Shaw begins to highlight the activities in which families might be involved and issues related to family involvement, there are important limitations of this work. Shaw (1990) describes the development of the questionnaire as exploratory as there was very limited literature on family involvement to inform its development and content. Moreover, family members and healthcare professionals who responded to the questionnaire were those of both pediatric and adult patients with various types of brain injuries. We must note that there are important differences between the pediatric and adult populations and settings, highlighting the importance of considering the population in future explorations of this topic.

In the area of adult rehabilitation, Levack and colleagues (2009) explored healthcare professionals' perceptions of family involvement in goal setting for stroke and TBI. Given the limited amount of literature on this topic, the authors argue that it is important to conduct further research to understand how best to engage families. Recognizing that the literature advocates for the involvement of families in goal setting because this may assist with the transfer of skills and knowledge, the authors were interested in elucidating how healthcare professionals talk about

involving families in this process (Levack et al., 2009). They found that although healthcare professionals consider family valuable members of the care team, they also view them as potential barriers to progress because family members often have their own objectives that are different from those of healthcare professionals. Therefore, healthcare professionals tend to focus on the patient and much less on the family during the goal-setting process (Levack et al., 2009). More recently, D'Cruz and colleagues (2016) explored patients', family members', and healthcare professionals' perceptions of patient engagement in goal setting for inpatient stroke and TBI rehabilitation. This study revealed that in nine of 23 goal-setting interviews, the healthcare team set the goals; in five of them, the healthcare team and the patient set the goals; and in six of them, the healthcare team and the family member set the goals. Further, the authors specified that, overall, healthcare professional views dominated the goal-setting process in this study. These studies provide preliminary insight on the perceptions of patients, family members, and healthcare professionals in regards to family involvement; however, they focus solely on goal setting thus warranting exploration of their perceptions of other types of involvement as well as further exploration of patients' and family members' perceptions as they have been limitedly explored in relation to this topic.

Perceptions of how families can be involved. The literature has documented to a certain extent how healthcare professionals believe families can be involved in adult inpatient TBI rehabilitation. In general, the research and healthcare communities believe that families play an especially active role in the rehabilitation of patients with TBI (Foster et al., 2012). In fact, Degeneffe (2001) suggests that families provide most of the care to the patient with TBI. To contribute to the limited amount of literature on family involvement in this type of setting, DePompei and Williams (1994) discuss family-centred collaboration in inpatient TBI

rehabilitation and outline the roles that they believe family members can play. With the goal of providing healthcare professionals with information on how to involve families, the authors suggest that family members can provide information, actively participate in assessment and treatment, advocate for patients, participate in goal setting, and learn to be expert communication partners (DePompei & Williams, 1994). Somewhat similarly, Sander (2014) recommends that neuropsychologists collaborating with family members in TBI rehabilitation should regularly provide information to family members as well as educate and train them to properly use rehabilitation strategies.

Others have echoed the belief that families can be valuable for goal setting, especially if the patients are not themselves able to participate in this activity (Cicerone et al., 2006; Sohlberg et al., 2001). Harvey-Krefting (1990) also argues that families should be involved in therapy during inpatient rehabilitation to help facilitate their ability to provide family directed therapy following discharge. In the same line, Quine and colleagues (1988) believe that family members can potentially provide a source of continuity of care for patients with severe TBI. As such, they examined the extent to which family members could contribute as lay-therapists in inpatient rehabilitation and determined that they can provide a major time commitment to therapy, approximately 2-3 hours per day (Quine et al., 1988). However, despite recognizing the cost effectiveness of this approach and families' motivation to provide therapy, the authors caution that safeguards need to be in place to protect the patients and families from harm (e.g., burden, unrealistic expectations; Quine et al., 1988). While the above work provides insight into how healthcare professionals believe families can be involved, it provides a one-sided perspective on the topic. More specifically, family-centred care highlights the importance of allowing family members to participate in deciding how they would like to be and are able to be involved; the

above literature neglects this concept. Moreover, much of the above literature focuses on recommending family involvement for the specific purpose of generalizability because family members are often the main caregivers after discharge.

Family needs in rehabilitation. Research has shown that family well-being can influence patient outcomes (Barclay, 2013; Sander et al., 2002; Sander et al., 2012). The literature also indicates that meeting individuals' needs can positively influence their well-being (Rotondi et al., 2007; Sander, 2014). As such, in an attempt to further support families of adult patients with TBI, researchers have become interested in examining their needs. This important research has not only evidenced families' need for information and various forms of support, but has also revealed their need to be involved in care processes. Based on the literature describing family reactions to brain injury, Kreutzer and Marwitz (1989) developed the family needs questionnaire with the goal of providing information about families' needs after TBI, including their perceived importance and the extent to which these needs are satisfied. During the development process, they identified "Health Information" and "Involvement with Care" as two of six scales to include on their questionnaire. Researchers are now beginning to use this questionnaire to measure the extent to which families' needs are met in relation to brain injury rehabilitation. For example, in the community setting, Tverdov and colleagues (2016) found that while family members' needs regarding the receipt of information were mostly met, their needs related to involvement in care were not met. They further specified that these needs were not satisfied because family members did not have the opportunity to participate daily in care or provide their opinions regularly to the healthcare team.

Further exploring family needs, Keenan and Joseph (2010) used semi-structured interviews to determine families' needs in critical and acute care after TBI. The findings of

Keenan and Joseph (2010) revealed the category “Involvement in care” as part of the needs of families during both critical and acute care, although families saw their involvement needs as being very different during each of these time points and were described as most involved during acute care. Rotondi and colleagues (2007) examined families’ expressed needs during the TBI recovery phases of acute care, inpatient rehabilitation, return home, and community living through semi-structured interviews. The authors detail a wide range of needs of families during all phases of recovery. Focusing on the inpatient rehabilitation phase, families identified a number of needs relating to involvement, including the need to know how to facilitate rehabilitation, to be informed, and to be involved in decision making and discharge planning (Rotondi et al., 2007). These studies highlight that families themselves identify involvement as an important factor in meeting their needs after TBI. However, these studies did not focus on exploring families’ needs specifically in relation to their involvement in rehabilitation processes and thus they offer little insight in relation to these involvement needs.

Providing slightly more insight into family needs, Kuipers and colleagues (2014) recently explored family members’ experiences in brain injury rehabilitation, highlighting family members’ need for healthcare professionals to engage them more effectively. More specifically, this research evidenced family members’ need for readily accessible information from healthcare professionals (i.e., information that is always available when needed) as well as their support in involving them better in decision making, provision of care, and discharge planning. Somewhat similarly, Gagnon and colleagues (2016) explored family members’ experiences of involvement in their family member’s community reintegration and return to productivity after TBI and family members expressed a need to be active members of the healthcare team. That is, they want to be able to express their concerns, ask questions, receive regular updates, help with goal

setting, and receive community resources. This work helps bring to light the importance of this topic and demonstrates how the sparse literature on family involvement in adult inpatient TBI rehabilitation would benefit from further research on the needs of family members related to their involvement in rehabilitation processes to grow our understanding of this important topic and better engage families in this process.

Family experiences in rehabilitation. As discussed above, TBI also affects the families of patients. In consideration of this as well as the lack of literature describing the family experience, Ishikawa et al (2011) and Fleming et al (2012) sought to explore and describe the experiences of family members in the inpatient rehabilitation setting. In both studies, the authors conducted interviews with participants. Ishikawa and colleagues (2011) and Fleming and colleagues (2012) similarly identified participation in rehabilitation as part of the family experience. Unfortunately, however, since family involvement was not the focus of their study, Ishikawa et al (2011) do not offer a discussion of the family experience of involvement. Rather, they simply list the identified sub-categories, which include seeking information, making decisions, understanding rehabilitation, and undergoing rehabilitation. With a similar focus to their study, Fleming and colleagues (2012) also do not describe the family experience of involvement in rehabilitation, limiting our understanding of this particular experience. Knox and colleagues (2015) recently sought to develop a comprehensive understanding of the decision-making process between survivors of TBI and their family members. By exploring the experiences of survivors, who were many years post injury, and their spouses of their involvement in decision making, the authors revealed that the decision-making process is a shared process. They specifically describe decision making as a “socially mediated and relational

process” (p. 755) and therefore, highlight that family members should play a key role in this process.

In a powerful personal account of a mother’s and father’s experience of involvement in their adult daughter’s rehabilitation following TBI, Martone (2001) describes the profound impact that their inability to be involved in decision making had on both their daughter and themselves. Martone (2001) describes that although she and her husband were their daughter’s surrogate decision makers, they had little to no input on their daughter’s care, therapy planning, schedule, or amount of therapy. She explains how the healthcare professionals believed that because they had informed her and her husband about their decisions, they had included them in the decision-making process for their daughter. Martone (2001) states, “Family members are widely believed to be the best decision makers for those with brain injuries, but the rehabilitation process does not in fact give them that authority” (p. 36).

Conversely, in a personal account of another mother’s and father’s experience of being involved in their adult daughter’s rehabilitation following TBI, they describe their involvement in all aspects of the rehabilitation process as “collaborative” and their personal treatment as “respected, valued, and part of the team” (Horwitz et al., 1998, p. 75). The authors indicate that the parents’ experience was rewarding for them as it reduced worry and stress and increased their satisfaction with care (Horwitz et al., 1998). These contrasting experiences highlight the high degree of variability that family involvement can take across treatment settings. Given this variability and an increased emphasis on family-centred care in Canadian healthcare facilities, an examination of family involvement in the current Canadian context is warranted.

The impact of family involvement. Evidence of the impact of family involvement on the patient and their rehabilitation has begun to emerge over the years. The impact of this

involvement is highly recognized in the rehabilitation of children with disabilities as research has shown that family involvement has a positive impact on outcomes (Braga et al., 2005; Rosenbaum et al., 1998). Specifically, research has shown that pediatric patients with TBI have better cognitive and physical functional outcomes when their families are actively involved in their rehabilitation (Braga et al., 2005). Children with chronic illness are able to adjust significantly better when they receive a homecare program where their families are actively involved in their care as compared to standard care (Stein & Jessop, 1991). Research has also demonstrated that the family environment is an important predictor of behavior change for pediatric patients during the early stages of recovery from TBI (Kinsella et al., 1999). While this research has been instrumental in understanding the impact of family involvement in the pediatric population, it is important to examine its impact specifically in the adult population because there are important differences between these populations and settings.

There are indications that family involvement improves outcomes for adults with TBI. A recent study by Winter and colleagues (2016) examined the efficacy and acceptability of a home-based, family-inclusive intervention for veterans with TBI. This intervention focuses on including family members in the use of rehabilitation strategies, keeping them informed, and addressing their identified needs. It aims to improve veterans' community re-integration, ability to manage TBI-related problems, and competency in functioning. The study revealed positive outcomes related to community-reintegration and ability to manage TBI-related problems and the veterans were favorable of the family-inclusive intervention. Healthcare professionals in the area of stroke rehabilitation, a related field, believe that family involvement is an important contributor to rehabilitation because it may help facilitate treatment carryover outside of formal therapy sessions (Galvin et al., 2009). In their studies, Maeshima and colleagues (2003) and

Harris and colleagues (2010) found that stroke patients participating in their studies had better functional improvements when their families were involved in their physiotherapy. Harris and colleagues (2010) further explained that they believe that involving families in adult inpatient rehabilitation after stroke may increase patient participation in therapeutic activities, resulting in greater potential for improvement.

McKinlay and Hickox (1988) were interested in examining the impact that family involvement in therapy might have on the generalization of treatment effects to other environments. In their study, family members participated in therapy sessions for the remediation of memory impairments and anger management difficulties after severe TBI. However, the authors were unable to draw any conclusions from their study primarily because of the small sample size ($N = 4$). Despite this, they argue that family members participating as cotherapists may aid in the achievement of goals because they can encourage and help the patients to practice therapeutic techniques outside of the rehabilitation setting (McKinlay & Hickox, 1988). Dams-O'Connor and Gordon (2010) recently echoed this same sentiment with the belief that involving families in the treatment of TBI impairments may help with the carryover of learned skills to other settings. Because so many intervention strategies for the rehabilitation of cognitive and behavioral impairments are now applicable to environments other than rehabilitation units or centres, many consider it important to educate and train families. Healthcare professionals believe that this will enable family members to continue to monitor and support these strategies in the home or other environments (Bayley et al., 2014b; Ponsford et al., 2014a; Togher et al., 2014; Tsaousides & Gordon, 2009; Ylvisaker et al., 2007). Further research is required to demonstrate the impact that family involvement, not only in therapy, but in all aspects of the inpatient rehabilitation process, might have on the carryover of treatment effects and on

outcomes for adult patients with TBI as this remains unclear. It will also be important to understand the impact of family involvement on the families themselves.

Regardless of these efforts, we still know very little about the impact of family involvement in adult inpatient TBI rehabilitation. McNeill and colleagues (1997) argue that the lack of empirical evidence on the impact of family involvement in adult inpatient TBI rehabilitation is due in part to the lack of methods for assessing family involvement. As such, the authors developed the family involvement assessment scale based on items previously generated by Shaw (1990) and on healthcare professional perceptions of involvement. The development of this scale is important to consider given its limitations. Shaw (1990) cautions that a limited amount of literature informed the items that she included on her questionnaire. The focus on healthcare professional perceptions in the development of this scale is also an important limitation to consider since research has shown that families and healthcare professionals differ in their views of involvement needs (Shaw et al., 1997). Notably, the scale includes negatively charged items such as “attempts to dictate patient’s therapy” and “expresses anger/hostility toward patient”. A literature review revealed no further literature on this scale or studies using it in adult inpatient TBI rehabilitation. Further, before we can properly understand the impact of family involvement in adult inpatient TBI rehabilitation, we first need to understand how families are actually involved in this process. Despite the work discussed here, our view of the involvement of families remains limited, as there is little empirical literature on how they are currently involved in the rehabilitation process. Notably, there is minimal documentation regarding this involvement from the perspective of patients and families themselves, thus underlining the need for research to further elucidate their involvement.

In a more recent attempt to better support families within their own facility and achieve better outcomes, Foster and colleagues (2012) developed what they termed “family-support strategies” over the course of a three-year period. They did so by following an informal process that involved team meetings, case debriefings, retrospective note reviews, satisfaction questionnaires, and other forms of data collection. These processes led the authors to identify eight areas of focus: (1) early engagement; (2) meeting cultural needs; (3) keeping families together; (4) actively listening; (5) active involvement; (6) education; (7) skills training; and (8) support for community reintegration (Foster et al., 2012, p. 1856). The authors note that a lack of academic and theoretical bases for their research processes limited their research and that limited resources constrained the development process of the strategies. It is evident that research on how families are involved in adult TBI rehabilitation would assist in refining the focus for efforts to support family involvement.

Clinical and therapeutic factors influencing family involvement. In addition to the need to understand how families are involved in adult inpatient TBI rehabilitation, we must also recognize that certain clinical factors can influence family involvement in this type of setting, so contributing to its complexity (Degeneffe, 2001). The nature and extent of family involvement in rehabilitation can be influenced by many factors, such as the severity of the injury, the impairments present, and the impact the impairments have had on the patient’s and family members’ lives. For instance, family members are often expected to become more involved in the rehabilitation process for patients who have more severe injuries and may have greater difficulty feeding themselves, getting to unit activities, or passing their time between therapies; patients with milder injuries may not need such assistance. The cognitive and behavioral impairments resulting from the injury can impede a patient’s ability to participate in many

different non-unit activities such as banking, scheduling, household activities, parenting, and social gatherings (Kieffer-Kristensen et al., 2011; Rees et al., 2007; Togher et al., 2014). A family member often takes responsibility for these activities, or assists the patient to participate in these activities. The transient or lasting nature of the impairments can influence the length of time a family member might be involved. Family involvement might also vary depending on the choice of intervention strategies used in the remediation of the patient's impairments, as some require monitoring, support, or participation from another person.

When considering the nature of certain cognitive and behavioral intervention strategies as well as how they may affect the family, the potential for family involvement becomes apparent. When patients are in a state of PTA, Ponsford and colleagues (2014b) stress the importance of educating families to help them understand PTA and learn how to minimize triggers of agitation. In certain regions, patients may be discharged even before they emerge from PTA and therefore, Ponsford et al (2014b) argue that it is important to guide families on how to help the patient during this period. Family involvement and the availability of support is also an important consideration when patients suffer from attentional disturbances as certain intervention strategies for these issues require alterations to their environment (e.g., home) to help reduce associated difficulties (Ponsford et al., 2014a). Moreover, healthcare professionals believe that families are ideally positioned to help set rehabilitation goals, especially if the patient suffers from executive impairments which can impede their own ability to participate in goal setting (Tate et al., 2014).

Healthcare professionals commonly use compensatory strategies to help reduce problems associated with memory impairments. While a family's involvement might be lessened if the patient is equipped with internal aids which he or she has learned and can apply independently to enhance encoding and recall of information, a patient suffering from a severe TBI will most

likely require external aids (i.e., environmental supports) and thus, require monitoring and support with their use (Velikonja et al., 2014). The use of external aids for memory impairments as well as the use of assistive devices for communication impairments would typically require some form of training for the families (Cicerone et al., 2005; Velikonja et al., 2014). Healthcare professionals might train families in conversational skills to positively influence the patients' skills and abilities in social communication (Togher et al., 2014). Similar to cognitive intervention strategies, families often need to monitor and support strategies used for behavioral disturbances that aim to assist a patient regain their independence (Ylvisaker et al., 2007). Healthcare professionals might ask families to participate in group-format behavioral interventions such as in CHRP (Cattalani et al., 2010).

Personal factors influencing family involvement. The experience of TBI can be very distressing for families (Simpson & Jones, 2013), and although the family's role in inpatient TBI rehabilitation is recognized, another factor influencing family involvement is their ability and inclination to be involved. Family-centred philosophy advocates that families' abilities and preferences for participation should define family involvement (Dunst, Trivette, & Deal, 1988). Research in pediatric rehabilitation shows that family involvement can improve patient outcomes; however, if family participation is forced or dictated, involvement can lead to negative outcomes for all involved (Corlett & Twycross, 2006). This is when healthcare professionals have the responsibility of balancing the best interests of the patient with the recognition of family perspectives and needs, and professional expertise (Allen & Petr, 1998). A family-centred philosophy as well as family-centred care should inform this careful balancing act to better support patients, families, and healthcare professionals to work collaboratively together in this type of setting. While recognizing that patients' and families' needs are unique and

constantly changing, it is important to understand how to engage and integrate families in the inpatient rehabilitation process for those who can and want to be involved as well as those who need to be involved.

Dunst (1997) avows that family involvement in care processes is the only thing that differentiates family-centred practices from good clinical practices. That said, there remains much to understand about family involvement in the rehabilitation of adults with TBI. Levack and colleagues (2009) pointed out that rehabilitation services in Western countries have failed to prioritize family involvement and empower families to become actively involved in the rehabilitation process. Our lack of understanding of family involvement in this type of setting might be a contributor of our failure to prioritize the involvement of families in practice.

Inpatient TBI rehabilitation is a unique and complex healthcare intervention and setting, and equally so is the involvement of families in this process, thus necessitating further research to fully understand this topic. Intersecting with the unique challenges of inpatient TBI rehabilitation are issues related to family involvement with adult patients in general. In adult health care, it is important to consider the notion of independence, adults' right to make their own decisions and to privacy, and family relationships. The overall goal of TBI rehabilitation in Western countries is to improve functioning and thus help the adult patient attain independence (Levack et al., 2009). Therefore, interventions typically focus on the adult with TBI and are individual in nature (i.e., the patient learns and applies the strategies), thus promoting the independent adult (Cicerone et al., 2006; Cicerone et al., 2010; Levack et al., 2009; Rees et al., 2007). In the same line, we view adult patients as their own decision makers. They can decide, for example, if and how they want their family involved, make their own decisions related to their rehabilitation, and decide the type and amount of information to share with their family.

Complex family relationships (e.g., multiple family members wanting to be involved, relationship strains, estrangements) can also bring forth certain challenges in practice (Barclay, 2013; Degeneffe, 2001). Within family-centred care, healthcare professionals thus need to ensure that the rights and best interests of the patients and family members are respected (Allen & Petr, 1998). These issues make examining family involvement in adult TBI rehabilitation an important area of focus.

Given the adoption of a family-centred philosophy as well as the potential benefits of family-centred care for patient and family outcomes, it is important to understand this involvement to guide the provision of family-centred health and rehabilitation services. As the first step in a program of research that is devoted to understanding family involvement in adult inpatient TBI rehabilitation, this study aims to elucidate how families are currently involved in this process so that, in future, we can explore and understand how to effectively engage families in the rehabilitation process.

Conceptual Framework

The literature reviewed above demonstrates that there is very little empirical research on family involvement in adult inpatient TBI rehabilitation. There is, however, research on the topics of family-centred care and brain injury rehabilitation. Based on the literature as well as what we currently know in the field, I developed a conceptual framework (see Figure 1) to guide this study. This framework informed the study design, including the development of data collection tools and analyses. However, the characteristics and components of this framework remained flexible to allow for unanticipated relationships between concepts or emergent ideas not captured in the literature.

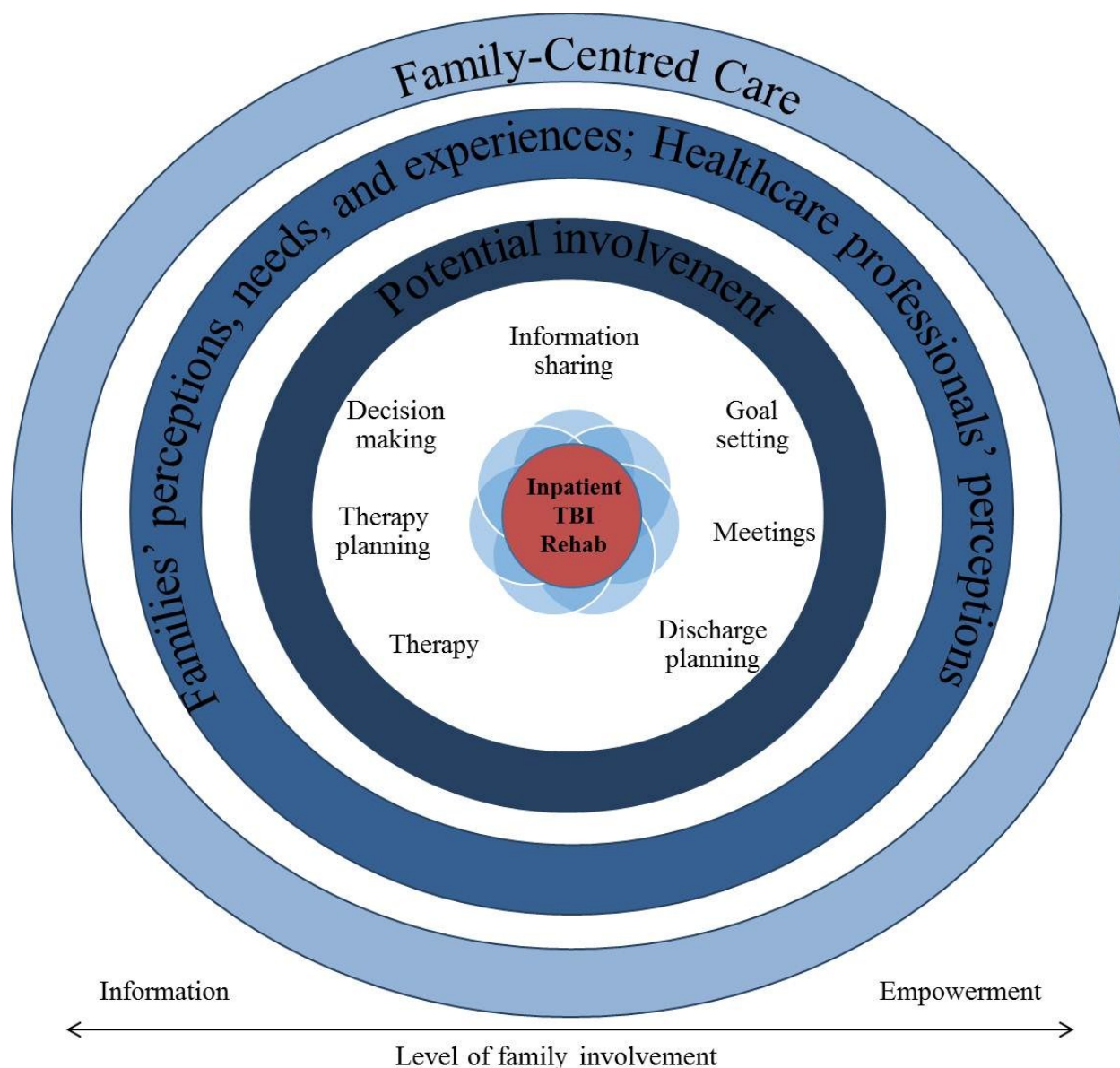


Figure 1. Visual diagram of the conceptual framework that informed the present study.

Inspired by Bronfenbrenner's ecological model, I shaped my conceptual framework with concentric circles that represent the various levels and factors of potential influence on family involvement. The framework consists of five primary components: (1) inpatient TBI rehabilitation, (2) the activities in which families are potentially involved, (3) family perceptions, needs, and experiences and healthcare professional perceptions, (4) family-centred care, and (5)

the level of family involvement. The outer layer of the framework represents the philosophy that informs healthcare delivery that can facilitate family involvement: family-centred care. The two middle layers of the framework represent the concepts in the literature that have contributed to our understanding thus far of family involvement in adult inpatient TBI rehabilitation; perceptions, needs, and experiences. The interconnected circles represent the various activities in which families are potentially involved as presented in the theoretical and empirical literature and the potential relationships between them. The middle component of the framework represents the context in which these activities and interactions take place: inpatient TBI rehabilitation. Finally, the double-headed arrow at the base of the circular diagram represents the potential level of family involvement.

Summary

The literature review above demonstrates how I have framed my perspective on family involvement in adult inpatient TBI rehabilitation by incorporating relevant concepts within family involvement in rehabilitation, TBI, and family-centred care. The literature review, however, also highlights the many knowledge gaps that exist on the topic of family involvement in adult inpatient TBI rehabilitation. Although family-centred care has made great strides over the years, it has made greater advances in pediatric health care than adult health care resulting in a lesser understanding of family-centred philosophy and care in the adult context. Of specific interest to this study, we do not have a good understanding of family involvement, a major component of family-centred care, neither in the adult healthcare context nor in the rehabilitation process for adult patients with TBI as research in this area is limited. In fact, the literature review above highlights the gap between theory and practice and the lack of empirical literature on how families are involved in the rehabilitation process for adult patients with TBI. Notably, there is

minimal documentation regarding this involvement from the perspective of patients and families themselves, thus underlining the need for research to further elucidate their involvement.

Chapter 3: Overview of Study Design and Philosophical Assumptions

Following the literature review above, Chapter 3 now provides an overview of the underpinning philosophy and design of the present study. This chapter first presents my position statement as a researcher in the context of the study as well as the philosophical assumptions underlining the present study. It also provides a detailed overview of the research context where I conducted the study. Following this, I present a section on qualitative research where I define this type of research and discuss its benefits. Importantly, I then discuss the design of the study. I end this chapter with a discussion of the ethical considerations of the present study and a short summary of the chapter.

Researcher's Position Statement and Philosophical Assumptions

When conducting research to explore a question, and thus fill a gap in research and contribute to the development of knowledge, researchers bring forward a certain perspective. This perspective acts as a sort of background, underlying the research process from beginning to end. This perspective and its embedded assumptions or beliefs are what guide a researcher's actions throughout the research process. I discuss below my perspective and philosophical assumptions that guided the present study.

I developed this study from a constructivist viewpoint, one that aims to understand a person's perspective of a specific phenomenon. Constructivism assumes that knowledge and truth are the direct result of perspective, and thus a person's experience (Gephart, 1999). Therefore, in conducting research from a constructivist viewpoint the researcher recognizes that they draw participants' descriptions of the phenomenon of interest from the participants' perspective. The researcher then makes an interpretation of what he or she discovers, an interpretation also molded by his or her experiences and background (Creswell, 2013).

Moreover, in qualitative research, the researcher is viewed as the instrument as he or she collects, analyses, and interprets the data him or herself. This creates the need for qualitative researchers to “position themselves” by acknowledging and describing their experiences (Creswell, 2013). As such, in developing the present study, I recognized the importance of acknowledging and describing my experiences. Additionally, it was important for me to recognize the potential impact they may have on all phases of the study, from conception through to interpretation. Although my experiences and positions facilitated access to the study site and participants for the present study, acknowledging them also allowed me to enhance methodological rigour.

In the context of the present study, I identify myself as an insider-researcher because I have previous experience with patients with TBI and rehabilitation settings, as both a clinician and a family member (Ritchie, Zwi, Blignault, Bunde-Birouste, & Silove, 2009). I completed a clinical psychology practicum on an inpatient rehabilitation unit with patients admitted to an acquired brain injury program. I worked with patients with various forms of brain injury and their family members from admission through to discharge. I have also practiced as a counselor to children of patients with brain injury and I am a family member of two brain injury survivors. Moreover, as a researcher in an academic healthcare setting and a student in a rehabilitation sciences program, I consider myself a stakeholder in the involvement of families in TBI rehabilitation. I have been involved in numerous studies on the topic of brain injury and have developed collaborative relationships with healthcare professionals and researchers in the rehabilitation and brain injury communities. I am also an advocate for family involvement in health care, including the planning, delivery, and evaluation of healthcare services and the teaching and assessment of healthcare professionals. I support the adoption of a family-centred philosophy in adult healthcare settings as I believe that family members have expertise that is

invaluable to the delivery of healthcare services. Their experiences provide them with a unique perspective that can benefit the process for the patients, family members, and healthcare professionals alike. I also believe that the rehabilitation setting and process are unique and complex; ideally rehabilitation processes encourage the involvement of family members. Since the adoption of a family-centred philosophy in adult healthcare settings, including rehabilitation settings, is still in its infancy, it is imperative that we make efforts to explore family involvement in these adult settings to understand how to integrate this philosophy within the setting and practice.

Research Context

The present study explored family involvement in adult inpatient TBI rehabilitation. As such, I conducted this study at a Canadian adult rehabilitation centre that is part of an academic hospital. I chose to conduct this study at this centre because I believed it would provide a good example of current family involvement in adult inpatient TBI rehabilitation. This centre provides rehabilitation services to the adult population (18 years and older). It offers four interdisciplinary programs and services, including an Acquired Brain Injury (ABI) service. The ABI service aims to maximize function for patients with acquired brain injuries including, for example, TBI, intracranial hemorrhage, and toxic and anoxic encephalopathy. It offers goal-oriented therapeutic assessment and intervention that addresses cognitive, behavioral, psychosocial, and physical needs. The ABI service offers both inpatient and outpatient services. The present study focused on the inpatient ABI service. The interdisciplinary inpatient ABI team provides expertise in psychiatry, psychology, neuropsychology, social work, nursing, clinical pharmacy, occupational therapy, physiotherapy, speech-language pathology, therapeutic recreation, and clinical nutrition. The inpatient ABI ward has approximately 15 beds. The inpatient ABI service admitted 66

patients with TBI last year (2015-2016) and admitted approximately 2 – 6 patients with TBI per month. Patients with a primary diagnosis of TBI accounted for approximately 56% of the inpatient ABI service's patient population. The average length stay of a patient with TBI on the inpatient ABI ward was 43.8 days.

Considering the focus of this study, it is important to recognize that the academic hospital has adopted the IPFCC patient- and family-centred framework to inform healthcare delivery at its campuses and centres. The hospital's visitor guide attests that, "Family members are an important part of the healthcare team and contribute to the caring and healing process of the patient". With the aim of supporting families, the hospital also recently implemented a Family Presence policy as part of the CFHI's Better Together: Partnering with Families campaign, stating "we want to invite patients and families to be engaged in care". As part of this hospital, the rehabilitation centre also aims to support the active involvement of patients and families in the rehabilitation process. As such, the inpatient ABI service at this centre aims to involve both patients and families as rehabilitation partners and views this involvement as a "means of success". As a resource at time of admission, the ABI service offers family members an information booklet that outlines their potential role in the management of symptoms and complications, including how to recognize symptoms and complications and what to do when they occur. Although this document is intended for general informational purposes only, it is one piece of evidence of the ABI service's recognition of the role that families play in inpatient brain injury rehabilitation.

Prior to study commencement, I sought support from the Medical Director and the Clinical Manager of the inpatient ABI service (whom did not participate in this study), as well as

the inpatient ABI team. Support from these individuals facilitated both the entry into the research context and participant recruitment.

Qualitative Research

Qualitative research is an approach to inquiry that researchers have traditionally conducted in the social sciences but has gained popularity in other disciplines over the years, namely in health and health services research. There is increasing interest in qualitative approaches as evidenced by the growing number of qualitative research studies in medical journals and others alike (Mays & Pope, 2000). Theorists often refer to qualitative research as interpretive research (Creswell, 2013). It is a way of conducting inquiry in which the researcher is comfortable with uncertainty because multiple interpretations may be uncovered. Qualitative researchers aim to gather an in-depth understanding of the phenomenon they are examining. Therefore, qualitative research is accepting of a phenomenon's complexity rather than attempting to minimize or reduce it (Schram, 2006). There is a wide variety of approaches to qualitative inquiry, such as narrative, interpretive, phenomenology, and many more. While some list as few as four approaches others, such as Tesch (1990), list as many as 28 approaches to qualitative inquiry. There are also various data collection methods, including interview, observation, and document analysis, and many approaches to data analysis.

With so many ways to approach a single study, the way in which a qualitative researcher chooses to design a study, including the qualitative approach, data collection methods, and approach to data analysis, is based not only on the researcher's perspective, but also on the specific aim of the study and the research questions posed. As Schram (2006) explains,

...claiming a particular methodological label as a first step is inadvisable. Doing so suggests that your chosen research approach can serve as an all-purpose vehicle suitable

for any problem, without apparent regard for what that problem or the accompanying research question might be. Your decision about how to proceed should always follow decisions about why, where, around what concerns, and from what perspective you are proceeding (p. 92).

Further, Mays and Pope (2000) argue that “the status of all forms of research depends on the quality of the methods used” (p. 50). To ensure that qualitative research is of sound quality and that knowledge users are able to judge the transferability of research findings to their populations and settings, Mays and Pope (2000) recommend that qualitative researchers adopt a systematic and self-conscious approach to research design, data collection, interpretation, and reporting.

Design of the present qualitative study. This study was the first step in a program of research that is devoted to understanding family involvement in adult inpatient TBI rehabilitation. To begin to understand family involvement in this type of setting, this study aimed to elucidate how families were involved in the rehabilitation of adult patients with TBI. To fulfill this aim and answer the research questions, I employed an interpretive qualitative approach (Merriam, 2002), with a two-phased sequential design, from within a constructivist perspective. As there is little empirical literature specifically on this topic and our understanding of family involvement in this type of setting is limited, I used this approach to provide a comprehensive description and gain a better understanding of how families were involved. This approach offered great potential to answer my research questions and contribute to the knowledge base and understanding of family involvement in adult inpatient TBI rehabilitation.

Merriam (2002) describes qualitative researchers as interested in understanding individuals’ interpretations of a phenomenon, at a particular point in time and in a particular context. Further, she explains that when a researcher is interested in understanding how

individuals experience and interact with their environment, and the understanding they have constructed from it, the approach is interpretive (Merriam, 2002). An interpretive qualitative approach aims to understand a phenomenon by uncovering and interpreting individuals' experiences and thus, understand how they view these experiences (Merriam, 2002). As such, this approach allowed me to elucidate how families were involved in adult inpatient TBI rehabilitation from the perspective of those who had knowledge of and experience with family involvement, thus improving our understanding of family involvement in this setting.

Recognizing that individuals' realities are constructed through experiences and perspectives, a constructivist viewpoint also allowed for a rich understanding of the participants experiences and perspectives of family involvement (Gephart, 1999). In sum, this approach allowed me to not only explore participants' perceptions of family involvement with interviews, but also observe conversations, interactions, and activities as they happened in practice and thus provided a firsthand encounter with family involvement.

I designed this study as a two-phased sequential study, with the findings from Phase 1 informing Phase 2. This design allowed me to capture and build upon findings in the first phase of the study as I moved into the second phase, also allowing my understanding of family involvement to develop iteratively as I progressed through the study. In Phase 1, I conducted one-on-one semi-structured interviews with patients, family members, and healthcare professionals, thus providing multiple perspectives on how families were involved in this setting. This data collection method allowed me to speak with those who had knowledge of and experience with family involvement. Moreover, the semi-structured design of the interviews allowed me to focus the interview on the topic of family involvement, with the goal of answering the research questions, while remaining flexible to allow for additional ideas that would

potentially help me understand the topic (Rubin & Rubin, 1995). In Phase 2, I conducted observations of patient, family member, and healthcare professional activities and interactions. In discussing observations as a qualitative data collection method, Merriam (1998) explains that this method provides researchers with an opportunity to collect meaningful data from participants in the natural setting of interest to the study. This data collection method allowed me to experience family involvement first hand as it happened in practice. More specifically, it allowed me to “see” and “hear” family involvement in this setting. To begin to develop an understanding of family involvement in adult inpatient TBI rehabilitation, the following research questions guided this two-phased study:

Phase 1

1. In what ways are families involved in adult inpatient TBI rehabilitation?
2. What are the similarities and differences between patients’, family members’, and healthcare professionals’ perceptions of family involvement?

Phase 2

3. What are the similarities and differences between patients’, family members’ and healthcare professionals’ perceptions of family involvement and what is observed in practice?

Figure 2 outlines the research process for this two-phased study that is further detailed below in Chapters 4 and 5. The figure illustrates the various components of the research process for each phase of this study; instrument development (see dark blue sections), data collection (see medium blue sections), and data analysis (see light blue sections).

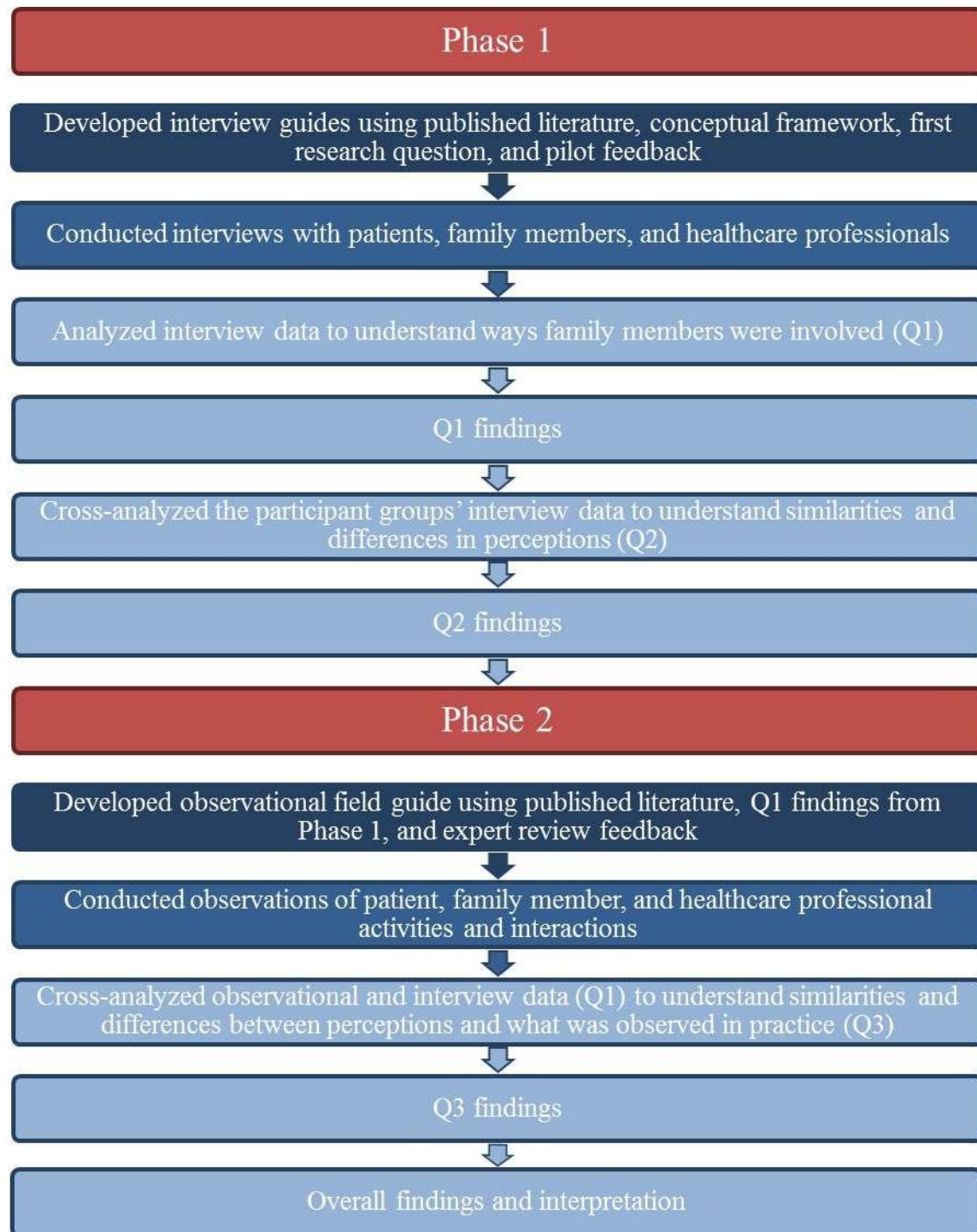


Figure 2. Visual representation of the two-phased research process followed in the present study.

Ethical Considerations

I sought ethics approval from the hospital's local research ethics board prior to commencing each phase of this study. I also sought departmental approval from the rehabilitation centre and administrative approval from my local university research ethics board. All oral and written communication with the Medical Director and Clinical Manager of the ABI service and study participants detailed the purpose of the study and discussed confidentiality, anonymity, as well as participants' rights to withdraw from the study. I required participants to review and sign an informed consent form prior to participating in Phase 1 of the study. I replaced any potentially identifying information with pseudonyms in all interview transcripts to protect participants' identities. Due to my prolonged presence while conducting the observations, I wore my student ID badge and kept a copy of a research ethics board approved letter of support from the Clinical Manager acknowledging my presence on the ward and in the rehabilitation centre during the data collection period. I did not record any personal, identifying, or confidential information in Phase 2 observational field notes. I downloaded and erased the digital audio-recordings of the interviews from the audio-recorders immediately after each interview. I stored all audio-recordings and study data on a password-protected computer and in a locked cabinet in a locked research office. Only I and the study team have access to the data. I will conserve data for 10 years after the publication of research findings. After this time, I will shred and appropriately discard the data.

In addition to the ethical considerations discussed above, there were four main ethical issues related to participation in this study. To ensure that patients and family members were comfortable with their participation in the study, I accommodated the presence of their family member (i.e., family member present with patient participant or patient present with family

member participant) during their participation in the interview, if it was preferred. However, I ensured that the patients and family members understood that only the participant could answer the interview questions and asked that the family member present not interject during the interview in any way to protect the one-on-one nature of the interview and ensure that I captured the participant's perceptions. While no serious risks were anticipated, it was also important to recognize that participants could experience fatigue during the interviews as the sessions were quite lengthy. I encouraged participants to inform me if they felt at all fatigued. Participants were able to request that the interview be halted at any time or rescheduled. Given that patients with TBI can be particularly susceptible to fatigue, I limited interviews with patients to no more than 30 minutes (Carlsson, Paterson, Scott-Findlay, Ehnfors, and Ehrenberg, 2007).

Patients with TBI experiencing communication impairments could also have difficulty understanding the informed consent process. Following Carlsson and colleagues' (2007) recommendations, I spent extra time with patients discussing the information to ensure that they understood what was written in the informed consent form. Patients with TBI experiencing memory problems could forget that they signed a consent form to participate in an interview. Therefore, throughout the interview process I confirmed with patients that they continued to consent to participating in the study (Carlsson et al., 2007). It was also possible for participants to find the observations intrusive, as these occurred during their activities and interactions on the inpatient ABI ward and other pertinent areas of the rehabilitation centre. I informed participants that they could inform me at any time if they did not or no longer wanted me to observe them during an activity or interaction.

Summary

In Chapter 3, I described the research context of the present study and discussed ethical considerations. Importantly, I also discussed my perspective and philosophical assumptions surrounding the study as well as provided an introduction to qualitative research and overview of the study design. I designed the present qualitative study as two sequential phases. In Phase 1, I sought to explore the ways in which families were involved in adult inpatient TBI rehabilitation through one-on-one semi-structured interviews. I also sought to understand the similarities and differences between the participant groups' perceptions of how families were involved. Building on the findings from Phase 1, in the second phase of the study I sought to understand the similarities and differences between participants' perceptions of how families were involved as well as what was happening in practice through observations. I further detail Phases 1 and 2 of the present study below in Chapters 4 and 5.

Chapter 4: Phase 1

This chapter provides an overview of Phase 1 of the present study where I conducted one-on-one semi-structured interviews with patients, family members, and healthcare professionals on the inpatient ABI ward at an adult rehabilitation centre. In this phase of the study, I aimed to understand the ways in which families were involved in adult inpatient TBI rehabilitation. I also aimed to understand the similarities and differences between the participant groups' perceptions of how families were involved. The following research questions guided Phase 1:

1. In what ways are families involved in adult inpatient TBI rehabilitation?
2. What are the similarities and differences between patients', family members', and healthcare professionals' perceptions of family involvement?

In the sections below, I detail the three participant populations in this phase of the study: patients, family members, and healthcare professionals. I also explain the process I followed for developing the interview guides for data collection. Following this, I describe the data collection and analysis processes as well as the steps I took to establish trustworthiness. Finally, I present the findings from the interviews.

Participants

Recognizing that the aim of this study was to elucidate how families were involved in adult inpatient TBI rehabilitation, I focused on understanding this phenomenon from the perspective of those who had knowledge of and experience with family involvement: patients, family members, and healthcare professionals. The recruitment period lasted from November 2015 to May 2016. For this study, I recruited a purposeful sample of participants to provide rich information on family involvement in this setting (Patton, 2015). More specifically, to identify

and recruit participants for this study, I employed a comparison-focused, criterion-based sampling strategy (Patton, 2015). Patton (2015) explains that in comparison-focused, criterion-based sampling, the researcher selects participants based on certain criteria of interest for in-depth, qualitative study. Further, he explains that the researcher is interested in comparing and contrasting the participants, from different participant groups for example, to learn about similarities and differences and gain an in-depth understanding of the phenomenon of interest (Patton, 2015). Participants in each group had to meet the below-described inclusion criteria. It should be noted that the participants were not recruited as dyads or triads; the patients and family members who participated in this study did not necessarily have a relationship.

Patients. With the assistance of the triage nurse on the inpatient ABI team, I aimed to recruit up to 10 patients from the inpatient ABI service (Mason, 2010). In selecting patients for this study, I considered seven criteria for inclusion. First, the patient had to have a primary diagnosis of TBI as this study focused on patients with TBI. Second, it had to be the patient's first admission to the inpatient ABI service to ensure that their reflections on family involvement related to their current admission. Third, given that patients must meet a certain level of functioning to be admitted to the inpatient ABI service and participate in their rehabilitation, their admission to this service was in itself a pre-existing inclusion criterion for this study. Fourth, the patient's rehabilitation team had to judge and indicate to me that the patient was capable of participating in an interview. Fifth, the patient's rehabilitation team also had to judge and indicate to me that the patient was capable of providing consent to participate. Sixth, the patient had to be able to give consent during the informed consent process to participate in the study. Finally, given the objective of this study, at least one family member, who identified

themselves as being involved in the patient's rehabilitation, had to be associated with the patient for the patient to be included in the study.

Family members. I aimed to recruit up to 10 family members from the inpatient ABI service (Mason, 2010). In selecting family members for this study, I considered the following four criteria for inclusion: (1) the family members had to identify themselves as a family member of a patient admitted to the inpatient ABI service with a primary diagnosis of TBI; (2) it had to be the patient's first admission to the inpatient ABI service; (3) the family members had to identify themselves as being involved in this patient's rehabilitation; and (4) the family members had to be able to give consent to participate in the study.

Healthcare professionals. I also aimed to recruit a sample of up to 10 healthcare professionals from the inpatient ABI team (Mason, 2010). All healthcare professionals who worked on the inpatient ABI team and with patients with TBI were eligible to participate in this study.

Instrument Development

Interview guides. I used the published literature and my conceptual framework, as well as the first research question of Phase 1, *In what ways are families involved in adult inpatient TBI rehabilitation?*, to inform the development of one interview guide for each participant group: patients, family members, and healthcare professionals. At the beginning of each interview, I asked participants general demographic information in order to report on their characteristics. I asked patients their age, gender, family composition, and employment status prior to injury. I asked this same information of family members as well as their relationship to a patient admitted to the inpatient ABI service. I asked healthcare professionals their age, gender, position at the rehabilitation centre, number of years of experience, number of years working at

the rehabilitation centre, and the proportion of work hours devoted to the inpatient ABI team. Each interview guide comprised major questions and probing questions (see Appendices C, D, and E). The patient and family member interview guides included questions to explore participants' understanding of the injury and rehabilitation in order to contextualize the interview. The patient, family member, and healthcare professional interview guides included questions to explore participants' perceptions of the rehabilitation team and family, again to contextualize the interview, as well as questions to explore the types and level of family involvement. Table 3 demonstrates which interview questions relate to each of the major domains.

For the patient interview guide, I followed Carlsson and colleagues' (2007) recommendation to use simple wording and grammatical structure. I piloted the patient and family member interview guides with two patients and two family members from the inpatient ABI service at the rehabilitation centre. These individuals were admitted to and discharged from the service prior to commencing the present study. I piloted the healthcare professional interview guide with two occupational therapists, two physiotherapists, and two speech-language pathologists from a healthcare centre not associated with the study. During the pilot, I conducted interviews and sought feedback on the interview guides pertaining to the quality, clarity, and appropriateness of the questions. I asked pilot participants about, for example, their understanding of the interview questions and whether they believed the questions were appropriate given the focus of the interview. Based on the feedback received from the pilot, I made the necessary minor wording revisions and finalized the interview guides.

Table 3.

Interview Guide Domains and Questions

Domains	Patient interview guide	Family member interview guide	Healthcare professional interview guide
Participant Characteristics			
Demographics	4 line items	5 line items	6 line items
Contextualizing the Interview			
Understanding of injury and rehabilitation	qq. 1, 1a, 2, 2a	qq. 1, 1a, 2, 2a	---
Perceptions of rehabilitation team and family	qq. 3, 3a, 4, 4a, 5, 5a	qq. 3, 3a, 4, 4a, 5	qq. 1, 1a, 2, 2a
Ways families were involved			
Types of involvement	qq. 6-13	qq. 6-13	qq. 3-10
Level of involvement	qq. 6a-13a	qq. 6a-13a	qq. 3a-10a

Note. A dash (i.e., ---) indicates that the interview guide did not include questions related to the respective domain.

Data Collection

I conducted interviews from the beginning of November 2015 through March 2016. The inpatient ABI team triage nurse screened admissions according to patient inclusion criteria described above in the Participants section. The triage nurse approached eligible patients to provide them with a short explanation of the purpose and aim of the study (see Appendix F). If eligible patients expressed interest in participating, the triage nurse asked for permission to provide their names and room numbers to me. I then met with them to further explain the study and schedule an interview. The triage nurse also approached patients' family members for

participation in the study. After explaining the purpose and aim of the study, the triage nurse verified with family members that they identified themselves as a family member of a patient admitted to the inpatient ABI service (see family inclusion criteria described above). The triage nurse asked interested family members for permission to provide their names and contact information to me. I then contacted or met with them to further explain the study and schedule an interview. Finally, a short explanation of the purpose and aim of the study was circulated to the healthcare professionals working on the inpatient ABI team. They were instructed to contact me directly if interested in participating, at which time I contacted or met with them to further explain the study and schedule an interview.

Interviews. I conducted a one-on-one semi-structured interview with each participating patient, family member, and healthcare professional in a quiet and private room on the inpatient ABI ward at the rehabilitation centre. I conducted the interviews with patients at approximately one week prior to discharge from the service. Recognizing that patients with TBI could experience fatigue during the interviews, I limited their interviews to no more than 30 minutes (Carlsson et al., 2007). I also conducted interviews with family members approximately one week prior to patient discharge from the service and I scheduled them to last approximately 60 minutes. This timeline allowed the patients and family members an opportunity to experience the inpatient ABI service and the rehabilitation process prior to participating in the interview. I conducted the interviews with healthcare professionals at a time that was most convenient for them and I scheduled them to last approximately 60 minutes. Although I offered French as a language option, all participants preferred I conduct the interviews in English. One family member requested that the patient be present during the interview. I sought informed consent from all participants prior to commencing the interviews (see Appendices G, H, and I). The

interview guides allowed for multiple probes and queries. I audio-recorded all interviews and transcribed them for analysis.

Data Analysis

As there are many approaches to qualitative inquiry, there are also many for qualitative data analysis. Miles and Huberman's (1994) systematic approach to qualitative data analysis is well known by qualitative researchers and discussed in length in the literature. It is widely used and recommended. It provides a detailed, step-by-step process to analyzing word-formed data. This analysis approach is highly recommended for graduate students and beginning researchers as the resource book keeps "them in mind" to help them work through the complex task of qualitative data analysis (Miles & Huberman, 1994, p. 3). For the purpose of answering the research questions and in turn, fulfilling the aims of this study, I allowed my conceptual framework and the research questions inform the analysis while remaining open to new information emerging from the data. Further, throughout this process, I continually reflected on what I was seeking to learn and what the data were telling me about it, which enabled me to refine my categories and frame my findings (Srivastava & Hopwood, 2009). The following research questions guided the data analysis for Phase 1 of this study: (1) In what ways are families involved in adult inpatient TBI rehabilitation? (2) What are the similarities and differences between patients', family members', and healthcare professionals' perceptions of family involvement?

I uploaded the transcribed interviews into NVivo 10, a qualitative data management program (QSR International, 2014). At this time, I classified each transcript using the source classification function in NVivo based on my participant groups (i.e., patients, family members, healthcare professionals). I kept a log and memos in NVivo as well as in hard copy to document

my coding decisions throughout the analysis process. In NVivo, active coding uses Nodes that provide storage areas for references to the coded text (Bazeley, 2007).

To answer **Question 1** of Phase 1, I analyzed the individual interview transcripts and followed Miles and Huberman's (1994) three steps for data analysis: data reduction, data display, and conclusions and verifications. Beginning with data reduction, which is the "process of selecting, focusing, simplifying, abstracting, and transforming the data" (Miles and Huberman, 1994, p. 10), I developed an initial coding scheme based on my conceptual framework and research question using Free Nodes (i.e., unstructured Nodes that do not assume relationships with any other concepts) in NVivo (Bazeley, 2007). Examples of Free Nodes based on my conceptual framework included *Decision Making*, *Involvement in Therapy*, and *Involvement in Meetings*. After each interview, I wrote a summary illuminating other Free Nodes to add to my initial coding scheme. I then reviewed the interview data multiple times to develop a general understanding of it (Tesch, 1990). Following this, I conducted an in-depth review of the interview data and coded the data into the existing Free Nodes. I also allowed for additional Free Nodes that I did not identify a priori from the interview summaries and literature review to emerge from the data. This allowed me to ensure that I did not miss any key ideas and further develop my coding scheme.

To further reduce the data, I sorted and connected the existing Free Nodes and new Free Nodes into a hierarchical system called Tree Nodes (Bazeley, 2007). Recognizing that, at this point, I had a significant number of Free Nodes that required organization in order to make sense of the data, I created a hierarchical structure using overarching categories (i.e., Nodes) and subcategories (i.e., Sub-Nodes; Bazeley, 2007). To demonstrate my understanding of the overarching Nodes, I developed a definition for each of them. This systematic process produced

categories related to how the participants perceived that family members were involved in adult inpatient TBI rehabilitation. To display the data and understand the results of the data reduction process, I then ran a matrix query in NVivo. This matrix query allowed me to create a model and examine how the various Nodes distributed across all transcripts to determine if there were patterns in the ways that family members were involved (Bazeley, 2007). I set up this matrix query with the Nodes as rows and the transcripts as columns. I reviewed the findings of the matrix query and drew conclusions about the patterns demonstrated in the data, thus creating the categorical findings for this research question (Miles & Huberman, 1994). I also pulled quotations that supported and illustrated the key findings from the transcripts.

To answer **Question 2** for Phase 1, I ran a new matrix query in NVivo using the assigned classification for each participant group to compare and contrast the Question 1 findings for patients, family members, and healthcare professionals (Bazeley, 2007). I set up this matrix query with the Nodes as rows and the participant groups as columns. The purpose of this matrix query was to understand the similarities and differences between patients', family members', and healthcare professionals' perceptions of how families were involved. I reviewed the findings of the matrix query and drew conclusions about the patterns demonstrated in the data, thus establishing the findings for this research question (Miles & Huberman, 1994). I also pulled quotations that supported and illustrated the key similarities and differences from the transcripts.

Trustworthiness

Qualitative researchers use the concept of trustworthiness to evaluate the quality of their research and to ensure that their findings represent the experiences of the participating individuals (Lincoln & Guba, 1985). They do so by satisfying four criteria: credibility, dependability, confirmability, and transferability.

Qualitative researchers can take certain steps to enhance *credibility* in effort to produce plausible research findings (Guba, 1981). To enhance the credibility of my research process, I used various strategies. Firstly, I used prolonged engagement where I spent an extended period on the inpatient ABI ward to orient myself to the setting and allow everyone to adapt to my presence on the ward. I entered the setting well in advance to commencing the study, presented the study to the inpatient ABI team, and developed relationships with and sought support from key individuals. Secondly, I used in-vivo member checking. During one-on-one interviews, I regularly verified my understanding of participants' descriptions of family involvement.

I also used member checking to solicit feedback from participants on my preliminary findings and interpretations of the interviews to verify accuracy. After completing the interviews, I developed a short summary of my findings and interpretations for each the family member and healthcare professional participant groups and provided it to the respective participants. I asked participants to review the summary findings and interpretations and to contact me if they had any feedback to provide. I also indicated to them that if I did not hear from them I would assume this to mean acceptance of my findings and interpretations. Only one family member contacted me to provide feedback, asking me to add information to the interview she previously forgot to mention. Unfortunately, due to the necessary timing of the patient interviews (i.e., approximately one week prior to discharge) as well as the transient nature of this participant group post-discharge, it was not feasible to contact the patients who participated in the present study to obtain their feedback on my findings and interpretations. I discuss this further in the Strengths and Limitations section of this dissertation. Finally, I used peer debriefing to enhance credibility. Specifically, two research colleagues, one with expertise in brain injury rehabilitation and one with expertise in family involvement in healthcare settings, reviewed the interview transcripts. I

met regularly with these colleagues to review my analysis and interpretations, obtain their feedback, and discuss the challenges I encountered throughout this process.

To demonstrate *dependability*, that is, the stability of my findings over time, I detailed my study design and processes and used auditing (Lincoln & Guba, 1985). For dependability, it is specifically recommended to report in detail the study design and processes so that other researchers may judge the quality of the research processes followed and repeat a similar study. Therefore, I have richly detailed each section of the present thesis. It is also recommended to develop an audit trail to provide a transparent description of the research process (Rogers & Cowles, 1993). Therefore, I created an audit trail made up of the following information: instrument development, raw interview data, field notes, detailed notes of data collection processes, detailed logs of data analysis and interpretation processes, and copies of evolving coding schemes.

In qualitative research, it is important to demonstrate that the data support the study findings and thus, represent the descriptions of the participants. Therefore, the above-described audit trail also served to demonstrate *confirmability* of my research process and findings (Lincoln & Guba, 1985). Finally, I used rich description in the present thesis to provide readers with sufficient detail of the participants, research context, and findings for them to evaluate the *transferability* of this study and its findings to other populations, settings, and situations (Lincoln & Guba, 1985).

Findings

As previously mentioned, I conducted one-on-one semi-structured interviews with patients, family members, and healthcare professionals on the inpatient ABI ward at an adult rehabilitation centre. In this phase of the study, I aimed to explore the ways in which families

were involved in adult inpatient TBI rehabilitation. I also aimed to understand the similarities and differences between the participant groups' perceptions of how families were involved. The following research questions guided Phase 1:

1. In what ways are families involved in adult inpatient TBI rehabilitation?
2. What are the similarities and differences between patients', family members', and healthcare professionals' perceptions of family involvement?

I conducted 20 interviews. Interviews with patients each lasted approximately 30 minutes. Interviews with family members each lasted between 30 and 75 minutes. Interviews with healthcare professionals each lasted between 30 and 60 minutes. These interviews resulted in a total of 15.65 hours of audio-recorded data and 369 pages of interview transcripts.

Participant characteristics. A total of 12 patients, 12 family members, and 45 healthcare professionals were eligible and approached to participate in this phase of the study. Six patients, four family members, and 10 healthcare professionals agreed to participate and as such, a total of 20 participants participated in one-on-one semi-structured interviews for Phase 1. Table 4 outlines age and gender characteristics of all participants.

Table 4.

Participant Demographic Characteristics

Characteristics	Patients	Family Members	Healthcare Professionals
Age			
Age range	18-61	37-66	46-55
Mean age	41.7	49.8	50.8
Gender			
Men	6	1	0
Women	0	3	10

Most of the patients (5/6) who participated in this phase of the study were employed full-time and many of them (4/6) were living with family members at the time of their injury, including parents, spouses, siblings, and/or children. The patients identified parents, spouses, siblings, children, and/or friends as the family members involved in their rehabilitation. The family member participants consisted of one spouse and three parents and most (3/4) were living with the patient and other family members at the time of the patient's injury. The family members' employment status varied for each, ranging from unemployed to retired. The healthcare professionals who participated in this phase of the study represented seven different healthcare and rehabilitation professions. However, I do not specify these professions in order to ensure participant anonymity. Most healthcare professionals (7/10) provided service exclusively to the site's inpatient ABI team. Their work experience ranged from 17 to 29 years in their respective professions and less than two years to 29 years at the study site.

In what ways are families involved in adult inpatient TBI rehabilitation? In this phase of the study, I sought to understand family involvement in the adult inpatient TBI rehabilitation setting from the perspectives of patients, family members, and healthcare professionals. After one-on-one interviews with the participants, I interpreted the data, identified recurring patterns in the data, and developed categories that provide a comprehensive description of this involvement (Merriam, 2002; Morse, 2015). I present these categories below and illustrate their meaning through participant quotations.

The ways in which families were involved. From the perspectives of the patients and family members who participated in this study, families were involved in adult inpatient TBI rehabilitation in the following ways:

Being with and supporting the patient. The patients and family members discussed family involvement in terms of being with and supporting the patients throughout their rehabilitation. Illustrating this family presence and support, a family member stated, “I was here every day. Never missed. I was here from 10 in the morning to 10 at night...we think we’re a good family, we think we’re there, you know, to give the right support.” The participants described how they brought home-cooked food for the patients or came to the centre to have meals with the patients. As one patient explained when speaking about his family member, “like she says, I’m a picky eater and so she brings about 80% of the food here for me to eat...” Families also brought entertainment for the patients, including books, music, and movies, especially if they were activities the patients enjoyed. As one family member exclaimed, “He [the patient] was very big into electronics...” Doing this also provided ways for families to spend time with the patients, “You can watch a movie together, sit there for an hour and half, or watch two movies together, for three hours. Never said a word, but it was a great day.” Families also encouraged the patients as a form of support. For example, one family member explained,

So, almost every night [family member] gives him the ‘you can only help you’ lecture-or, not lecture, but talk. And we have friends and family that come in and same thing.

Every little bit that he does we always say, you know, ‘awesome good job’. We are never negative in front of him.

Another family member shared how she created handmade signs with encouragement slogans on them that she would place around the patient’s room. She felt as though it was important to do these types of things and for their family to be there with the patient to “heal him”.

The patients and family members explained that families also supported the patients by taking care of the patients’ personal responsibilities outside of the rehabilitation centre. For

example, a family member illustrated managing the patient's home and finances as well as taking care of his pets: "As an adult, he has a house, so there's a mortgage, so there's bills and loans coming, as any adult does... I mean, taking care of his house and his pets and stuff." The patients discussed similar points while expressing their appreciation for this type of help from their family members,

So pretty much anything I can't do, which is picking up my mail, umm paying my bills, stuff like that, they're helping out with. Anything I can't do, they're super helpful with. Like they make my life in here stress free I guess you could say... I have no stress outside...like from my house.

Another patient said,

...I also did all of the financing. I also did all of the small stuff around the house that needed to be done. Umm, as far as paying the bills, or talking to this person, or talking to that person, I did it all. And now she's [the family member is]...she's picking up that slack and paying the bills and doing things... I don't think it's every person. I think it's her that's realized that this is what it's about and is trying to help me, you know.

The patients and family members spoke a fair amount about families being with and supporting the patients. As one patient candidly expressed, "...it would be pretty boring alone...pretty shitty." In the same line, a family member questioned, "...how do you get better, if you don't have love and support...without family support, I don't know how people get through stuff, I really don't." Providing a glimpse of a patient's thoughts about his own family's support and involvement in his rehabilitation, the patient explained, "It's [rehabilitation is] probably something that you could do by yourself, but it's the last thing that you'd want to do... I could probably do it all by myself, but it's the last thing I'd want to do." Also illustrating the

significance of families being with and supporting the patients, another patient expressed his perspective on the lack of support from some of his family members, “They are not the best sisters, they keep telling me they’re going to come but they never show up...I only really see my mom. My mom comes almost every day now.” To summarize, from the patients’ and family members’ perspectives, families were involved in adult inpatient TBI rehabilitation by being present and by supporting the patients throughout their rehabilitation in various ways, such as encouraging them, bringing them different comforts from home, and by taking care of the patients’ personal responsibilities, including their home and finances.

Informing others and keeping themselves informed. The patients and family members also highlighted that families were involved by informing others and keeping themselves informed about the patients and their rehabilitation. Families informed other family members, such as extended family and friends, about the patients and their progress. They did so to keep them up to date, but also to inform them for when they came to visit the patients in order to best support the patients. For example, as one family member explained,

...when [the patient] got hurt, his close friends, that are a little more mature, and he can trust, ...we put the word out, if you come to visit [the patient] let’s not talk party...they knew he was not allowed to have any alcohol or that because of the brain damage. So this is how I get the word out...

Another family member elaborated further on a similar point, explaining how she,

make[s] sure that each person who comes to see [the patient] is fully informed and kept up to date, that way when they come they know what is going on, what to do, what not to do, what he is supposed to or not supposed to do...

The family member added that in order for the patient to maximize his opportunity in rehabilitation, she wanted to make sure that “he doesn’t get away with anything” and this by ensuring that all those who visit with him are well informed.

The patients and family members voiced that families approached the patients’ healthcare team members to inform them about their perceptions of the patients, including their behaviors, challenges, abilities, and progress. For example, in discussing how he informed the healthcare team about the patient’s personality and behaviors, to help them get to know him, a family member stated, “I felt it was necessary to do it, for his development.” He further illustrated with an example of an incident he was concerned about, saying, “...when I found out...that’s the day that I went and found the [healthcare professional] and contacted a couple of [healthcare professionals] I got along with very well, I felt I could confide in...” A patient explained how his family member approached his healthcare team to inform them about the mental health challenges he had been experiencing. The patient explained that his family member recognized that he “was not [him]self” and that she was quite concerned. In a similar situation, a family member discussed approaching the patient’s healthcare team, “I’ve also mentioned to the [healthcare professionals] a couple of times that he needs to be on something for depression as well...” because “...he comes home and he’s very depressed.” Another family member spoke openly about how she approached the healthcare professionals directly to communicate her thoughts, feelings, and ideas about the patient’s status and progress as she felt she knew “...his skills, his abilities...his limits, his progress, his changes...” In fact, to be able to do this, the family member showed how she documented everything by taking detailed notes and photos to track the patient’s progress.

Families also wanted the healthcare professionals to inform them and sought out information. As one patient said about his family member, “She wants to know everything that’s going on with me...” And another stated, “My dad always asks lots of questions...” In the same line, a patient positively described how his family member sought information and asked questions to inform not only herself, but the patient as well:

She’s been great! She’s been fantastic. Anything that I need to know or that she needs to know, umm she’ll ask. You know, and she’ll ask right in front of me, she’ll ask behind my back, she’ll ask anywhere that she can ask to benefit me. If it’s the fact that I might need a psychologist, she might go and talk to [healthcare professional] alone. If it’s the fact that I need, you know a box of Kleenex, she’ll ask a nurse right in front of me. She’s been a huge part of that and I owe all of my thanks to her, for sure.

Families sought information to understand what was going on and to know what they “can do to best help [the patient]”. For example, families wanted “...to know who the therapists [are] and their role with [the patient]”. They also wanted information about “test results, their plans for rehab and what their goals are”. Families also wanted and asked for meetings to obtain information. As one family member expressed, “I wish that somebody would have a meeting with us, and like, tell me what’s going on. I feel very, like, out of the loop.” Another family member described her efforts to keep informed,

Because they tell him everything because they see him every day during the day. We come at night; we don’t get told those things. Because he’s an adult, they don’t necessarily tell us those things...Like, okay, what else don’t we know?

And further explaining,

So, we made a meeting, umm...just so we could meet them all and we went through his therapy with them...well I phone- I would phone to the front desk. And ask them questions and that's how I set up the meeting in the first place is like I know we haven't met any of the therapists. We really don't know...

Families also sought out information on the internet, including resources, information about brain injury, as well as information about impairments and symptoms. To review, from the patients' and family members' perspectives, families were involved in adult inpatient TBI rehabilitation by informing: (a) other family members about the patients and their progress, (b) the healthcare team of things they viewed as important and relevant, and (c) themselves about the patients' rehabilitation and progress.

Helping to make decisions. The patients and family members explained that families were involved in making decisions with the patients, and the patient and family members were key in this process. Although the patient participants in this study were capable of making their own decisions, they described how they wanted their families to help them make decisions. As one patient briefly explained, "...kinda want her to be [involved in making decisions], because it's easier that way..." In discussing how he involved his family members in making decisions with him about goals another patient explained the importance of this, "Everybody gives priority for my health, not just...not only me. My wife, my sister, my friend, everybody gives priority to my life. I give priority to my life too." He further explained how he felt including his family in decisions helped him to focus a little bit on other things, such as his young child:

They all know my issue. I think it's [involving them in decisions] very helpful, good communication, you know, to be free from stress or something, you know. To be free to [from] think[ing] too much about the issue, you know.

Another patient expressed his perceptions of his own situation, “I’ve been lucky to be able to make my own decisions as far as going someplace, or taking something, or doing something, umm, so I’ve been lucky that way.” However, he explained that despite his abilities, he involved his family member in making decisions about anything important, explaining that they considered their options and “talk about what’s next...or gear up for what we got next.”

Families tried to be involved in helping the patients to make decisions because, as one family member expressed, “You have to be involved, somebody’s got to be involved, because [the patient’s] not capable of making the right lifestyle decisions.” The family member elaborated further on this point, expressing concern for the patient’s ability to make important decisions at that point in time:

...we’ll have to do something for him. And like I said, cognitively, I don’t think he’s ready to make those- he’ll make the wrong decisions, I know he will. Because he thinks he’s superman. He’s always been a daredevil. Like, scary.

Families made decisions collaboratively with the patients, recognizing that the decisions may affect the patients’ life and advocated for what they believed the patients’ would want. For example, as one family member explained,

...everything goes through him [the patient]. He makes the final decision, umm, we tell him what the pros and cons of whatever it is...Like, saying ‘do you want to come home or do you want to go to your own spot- your own place or here’s your options’... so huge decisions like that are- we discuss them with him, so he knows everything... It’s his life; he’s going to have to live with it, right?

Another family member similarly explained how she believed that their family “advocate[s] for activities and goals that he [the patient] would want”. She also explained how she felt as though

she had to negotiate solutions related to what she thought and wanted and what the healthcare team thought and wanted while making decisions. To recap, from the patients' and family members' perspectives, families were involved in adult inpatient TBI rehabilitation by helping the patients make decisions around goals and rehabilitation activities, as well as life decisions.

Participating in care and therapy. In addition, the patients and family members described that families wanted to be directly involved in the patients' care and therapy and help the patients. Families accompanied the patients to offsite medical appointments, to "get his [the patient's] x-rays", for example. Families also helped the patients with their personal and medical care. For example, a family member expressed, "But to [family member], feeding him [the patient] and wiping his mouth, and helping him to the bathroom, and...you know, the sibling bond is so strong." Another family member explained that she "...help[s] care for him [the patient] and with his ADLs to ensure he is comfortable." Families also accompanied the patients on weekend passes, picking them up and dropping them off: "They wanted the presence on my return home of one of my brothers... He took that on..." During these weekend passes, families continued to help the patients with their personal and medical care. A family member illustrated this well,

...we have all the equipment now, like, for him [the patient] to go to the bathroom and the ramp and wheelchair and bed. When he's here, you know, I just have to make sure that I feed him and take him to the bathroom when he needs to go, and – because he can't do up his own pants or anything like that. And, uh, I have to give him a needle for blood thinner. And they send home, like, his medications, so I make sure I do those on time.

As suggested in the above quote, families also acquired the needed equipment for the patients. While discussing the patient's weekend passes, a family member explained,

The next morning, he had to go to the bathroom, and he had no bath bench. No, no bath bench and no commode. So his girlfriend texts me, and she says ‘uh, I don’t know what to do...’ So I went in as soon as I got the text- I went over, and I borrowed a commode and a bath bench.

Families monitored the patients during weekend passes to ensure that they also adhered to the rehabilitation strategies put in place as part of their program. A patient described his family member’s efforts to ensure he used his strategies, “She said ‘no, you’re not supposed to do that’. So I gotta listen to her. Right now, she’s had more pull than I do... She still wants to help. She’s scared that I’ll slip and fall.” Families supported patients’ rehabilitation and the strategies used within the rehabilitation setting as well. One family member explained her family’s role as, “...to learn, to be a cheerleader, to reinforce what he [the patient] is learning and what they are doing with him. We need to establish continuity because he will come home at some point.” For example, a family member described how she and her family supported the patient’s therapy and the strategies put in place,

We try to do what- like we’re not therapists by any means, but I mean, we try to get him to do things that we thought would help him with his speech and his- his motor skills and his mouth and his muscles and his whatever, you know, smile.

Family members attended therapy sessions to observe as they were invited by the patients to attend when they were present visiting with them. One patient described this well,

So I said ‘Oh, I have therapy, you’re welcome to come.’ So he [family member] just comes and sits and watches... A couple of times my dad’s just showed up earlier in the day and he’s like ‘Yeah, I’m here for the day’. He’s come along lots too. If they’re here,

like if they drove an hour to come here, I'm not going to say 'Oh I have therapy for a half hour or an hour, see you later', so I invite them to come...

Another patient joyfully described his grandson participating in a session with him while he was at the centre visiting with him – the patient's daughter observed the session:

The therapist gets something that involves me like putting the alphabet together and then the throwing of the sacks...the little sack balls in the hole...in the sandbox, I guess or holes. So he was giving them to me and saying 'number 20' or '50' or '25'. I was trying to do what he was telling me...but umm him telling me to do it forced me more to do it.

Families attended patients' therapies to help themselves understand what the patients' were doing and how they were doing. For example, a family member described how she "like[s] to be there to see his progress" when speaking about observing the patient's therapies. Families also attended therapies with an invitation from the healthcare professionals to learn about the equipment needed for the patients. A patient explained that his family member, "...went to the occupation, because – to see what she needed to, umm, for let's say to go to bed, you know. And plus the table or bench to take a shower..." In sum, from the patients' and family members' perspectives, families were involved in adult inpatient TBI rehabilitation by helping the patients' with their care as well as by acquiring equipment, observing therapy, and supporting the rehabilitation strategies in place as part of their rehabilitation.

Table 5 provides a summary of the findings from the patients and family members described above. Specifically, it illustrates the specific ways in which families were involved in adult inpatient TBI rehabilitation for each category.

Table 5

Summary of Patient and Family Member Categories

Categories	Specific ways families were involved
Being with and supporting the patient	• Families were present • Families brought food and entertainment • Families encouraged • Families took responsibility for the patients' home and finances
Informing others and keeping themselves informed	• Families informed other family members • Families informed the healthcare professionals • Families asked questions • Families sought information
Helping to make decisions	• Families helped the patients make decisions • Families advocated for decisions
Participating in care and therapy	• Families accompanied the patients to offsite medical appointments and to and from weekend passes • Families helped with personal and medical care • Families acquired equipment • Families monitored and reinforced rehabilitation strategies • Families observed therapy

From the point of view of the healthcare professionals, they noted that families were involved in adult inpatient TBI rehabilitation in the following ways:

Being with and supporting the patient. Similar to the patients and family members, the healthcare professionals discussed that families were involved by being with and supporting the patients throughout their rehabilitation. The healthcare professionals described families bringing food as well as personal items from the patients' home. As one healthcare professional expressed, "I find, like, a lot of family members bring a lot of food in, or worry about the food the person is getting from the cafeteria here." Another stated, "So, providing that touch of home,

or umm – I guess you can say with the families, some of the families actually help by bringing things in from home; decorating the rooms. To help make it more homey for them.” The healthcare professionals also described families being involved by “just being here in the downtime”. One healthcare professional illustrated this by expressing the importance of not being alone: “There’s this huge human aspect of being family; not being alone in a tough time. Like, there’s the whole emotional support part of the family and the familiarity, right.” As part of family support, the healthcare professionals similarly described family members as a source of encouragement for the patients, stating for example,

I mean, the support that the family gives like the moral support, the encouragement is really, really, umm, really important... So, when the family comes in you get that little bit of sunshine for them then...they provide that family love.

The healthcare professionals also described the families as being involved by ensuring that the patients stayed connected with friends and that they had visitors during their stay. A healthcare professional described families as:

...being connectors for people back to their community as well. So, making sure that the person stays in touch with their friends...and they want to make sure that they’re not the only people who are coming to see that person because that’s not really normal either.

To summarize, from the healthcare professionals’ perspectives, families were involved in adult inpatient TBI rehabilitation by being present and by supporting the patients throughout their rehabilitation in various ways, such as encouraging them and bringing them different comforts from home.

Providing and receiving information. The healthcare professionals described family involvement in information sharing differently than the patients and family members. The

healthcare professionals discussed how they decided to approach the families for information or provide information to the families. The healthcare professionals approached families for information if they were unable to retrieve that information from the patients or if they needed to corroborate the information given to them by the patients. A healthcare professional explained,

...you'll ask [for] information and you're questioning the validity of it, or how accurate it is. And so you may actually make contact with the family to ask, to clarify, or to confirm information, um, and if the client, for example, is non-verbal, or truly unable to communicate information, then you may actually ask the family member, to answer those questions...

The healthcare professionals asked families to provide feedback after the patients went on a weekend pass. The healthcare professionals gave families a questionnaire and asked them to "...report back... write what went well, what was challenging, did they notice any changes?" Additionally, healthcare professionals asked families to provide photos of the home environment if a healthcare professional was not able to go to the home in order to understand the environment in which the patient would be living.

In terms of providing information to families, the one source of information that all families received was the caregiver booklet that the service provided when a patient was admitted. Additionally, the healthcare professionals shared any resource pamphlets that the service had that they felt were relevant to the patient. Beyond this, the healthcare team typically gave families information depending on various factors. This included whether they deemed that the patient was capable of making related decisions without the help of the family or whether a family member had Power of Attorney. The healthcare professionals explained that if the

patients were “capable” then the healthcare professionals tended to communicate directly with the patients and not the families. A healthcare professional explained,

If [a] patient can make decisions for themselves then its more – like we communicate with the patient and then they communicate with the family and that’s like the, the line of communication we have to follow. We would still provide information to your family, but it is the patient who directs the process.

However, when a family member had Power of Attorney and acted as a substitute decision maker, then “they have to be aware of what we do. They have to consent to everything we do... they have to be informed about any changes in patient status or through their stay here.”

In some cases, the healthcare professionals saw their role as responding to information requests from families. Similar to the patients and family members, the healthcare professionals briefly described that families asked questions and sought information themselves. As one healthcare professional explained, “...we are the front line who they approach to ask questions to or to express their worries to.” And so, “...if they have a specific – specific questions I will take the question and direct them to the appropriate team members to answer...” When family members had questions and sought information, the healthcare professionals expressed that, “Sometimes they’re interested in what you are finding in your sessions, and they’re curious and interested in how their family member is doing in your sessions.” They also described that family members had more specific questions at times. As one healthcare professional explained,

...they may really want to meet and talk with you specifically related to either a weekend home, or if there’s accessibility issues, they might be asking you about that. Um, it could be about, uh, equipment, a loan for the weekend, so they’re able to go home. I would say, generally, those are the reasons that family members are interested in meeting with you.

In addition to responding to family members' direct information requests, the healthcare professionals seemed to interpret family distress as a signal that the family members needed information. From family members approaching them with questions, the healthcare professionals explained how they would "get wind" if the families were experiencing any issues, "The family member comes [to the centre] and you see they're upset or they approach you." When this occurred, members of the healthcare team tried "...to sort, or deal with some of those concerns..." either by meeting with them in person or speaking with them over the phone. During these meetings or phone conversations, the healthcare professionals discussed the issues with the family members, answered their questions, and provided education. As one healthcare professional expressed, it is about "...taking them through and sort of normalizing the process for them."

The healthcare professionals also discussed how they offered families a family conference if they believed that the families would benefit from more information and/or if the healthcare team needed to discuss anything with the families prior to patient discharge. Family conferences were not scheduled for all families because, as a healthcare professional explained, "It's [the family conference is] usually based on needs. ...if we think you know they would benefit from it, we certainly offer it or they, ah, ask for it..." Therefore, if the healthcare team decided that a family conference was needed or if a family asked for one, the team scheduled "...a family conference, near to the discharge date, to discuss any issues that need to be resolved prior to discharge" as well as "...to discuss their [the patient's] progress and the expectations for discharge." During these family conferences, family members were present "...to ask questions if they have any questions at the end, um, or any concerns they might have before the person goes home." Further explaining the family conference, a healthcare professional said, "They're

able to ask questions, listen to the information; they're given written information as well so they can take it after and if they have further questions they can ask."

When the healthcare team believed that a family would benefit from additional information and education, beyond what they might receive during a family conference near discharge, the team organized a family day. Similar to the family conference, the family day was coordinated based on needs and availability. As one healthcare professional briefly explained,

...we identify [the need for a family day] either by the team, or by the family or the patient... It's been difficult. ...not everybody is offered that. I mean, if it is really something that would be a benefit then we'll try to coordinate it."

During a family day, the family would "...spend a whole hour of therapy with the patient and the therapist and look at what they're doing and ask questions freely." A healthcare professional described this activity further, explaining that a family day was:

...when a family could come and shadow their family member at various therapies. So there would be a schedule, and they'd actually go from therapy to therapy and also meet the [healthcare professional] or [healthcare professional]. There could be a variety of people that they spend time with...it's not just about observing, it's about giving them more information, getting information from them, um, you know, you might do some discharge planning when you are with them. You might give information about how they are doing. You might also give information about what your goals are...

To review, from the healthcare professionals' perspectives, families were involved in adult inpatient TBI rehabilitation by providing information to the team, particularly when the healthcare team needed them to participate in decision making as the patients' Power of Attorney. Additionally, the healthcare professionals perceived family members as recipients of

information. Family members received this information by directly asking for it or if the healthcare professionals believed they needed it. The healthcare team provided this information with pamphlets, during informal conversations, phone calls, or formal meetings.

Making decisions when required. Contrary to patients' and family members' descriptions of family involvement in decision making, the healthcare professionals believed that families were minimally involved in making decisions, "...for the most part, if the client is quite reliable and you feel they're able to make decisions for themselves, you may not involve the family members." However, they did specify that in a situation where a family member had Power of Attorney, the family would help make decisions around the patient's care and rehabilitation. A healthcare professional explained this process,

...there are the clients that you really don't feel are reliable, and so you are wanting to meet with family. Because you know that they are likely going to a) want to be involved in decisions making around certain topics, and b) you are wanting their input as well [about decisions].

The healthcare professionals described that, in these situations, the families were involved by providing input on decisions around rehabilitation goals,

...where the family might come into play is when a client really can't express that at all, and so you are wanting them to sort of speak on behalf of the client. Because they know them much better than I do. So, that's really when they would be involved in sort of goal setting. But that doesn't happen too too often, really...

The healthcare professionals described how families with Power of Attorney were involved in making personal and medical decisions,

...do you want your family member to have a flu shot – yes or no... is it alright for your family member to go out with this person? ...can they go off the unit? ...they might be the person who's making the decisions about whether or not somebody had other medical services done. ...they might be consulted about medications...

The healthcare professionals also discussed how families, not only those with Power of Attorney, sometimes made decisions around purchasing equipment and renovating the home. In terms of equipment, the families were provided "...which vendors to go with and then they can choose which ones." The healthcare professionals expressed that families were involved in these decisions "...especially if there is either huge care needs, or huge expense, in terms of what would be required to purchase expensive equipment or renovate the home to make it more accessible for the person." A healthcare professional described this involvement in further detail,

...sometimes there has to be modifications to the homes and it's their home that the patient may be going to, so they need to agree to have a bar installed in the bathroom, say, or a ramp put in front of their house. So, they would have to agree to have those things done. ...which contractor to use, what design of the – the ramp to go into the house, what type of railing, what type of bath bench. The staff would provide them with some options and then they would decide what would work for them.

To recap, from the healthcare professionals' perspectives, families were involved in adult inpatient TBI rehabilitation by helping to make decisions regarding day-to-day care and events when they had been granted Power of Attorney. Family members were also involved when equipment needed to be purchased or home renovations made. The healthcare professionals perceived family involvement in goal setting as important in some situations, but these were rare.

Learning care and therapy. The healthcare professionals described that, in some instances, families were involved in therapy because “they just show up with the client during their regular scheduled time...or ask to come to a session” and this because the families wanted to “see the progress” or “actually see...what their family member is capable of doing”. During these instances, families would “just sit in a chair and observe what we’re doing”. Otherwise, the healthcare professionals described families being involved differently than the patients’ and family members’ descriptions, that is by learning the patients’ care and therapy, and this for the purpose of continuity of care and rehabilitation strategies. More specifically, the healthcare professionals explained that families learned care and therapy in preparation for weekend passes and discharge. Weekend passes were coordinated for the purpose of the healthcare team to understand how the patients could manage at home. In addition, families were encouraged to “...take the person out of the institutional environment and start reintegrating them out of this environment. You know, in preparation for going home, for eventually going home.” In preparation for weekend passes, the healthcare professionals invited the family members who were going to be monitoring the patients’ during this time to attend therapy so that they could teach the family members the strategies and techniques in place as part of the patients’ rehabilitation. A healthcare professional illustrated this activity,

I had a client who was preparing to go home for a weekend but needed to know, could he do stairs and could he do a car transfer? So dad came and we did stairs, and he saw how he can do it. Then we went outside and practiced getting in and out of the car, and I taught dad how to fold the chair, so that kind of thing.

The healthcare professionals discussed this even more so in the context of discharge preparation:

...if the family is going to be the site for discharge then we really want to make sure that they're involved, that they receive the training, that they get the education that they need about understanding brain injury...training to how to do things that may be relevant to the patient like something like transferring into a car or helping the patient manage their medications or following through on the same type of strategies that we are using to help support that person.

Again illustrating how the healthcare professionals involved the family members in preparation for discharge, a healthcare professional stated,

So, you create a strategy, um, you demonstrate that for the patient, and the spouse, and then you might have the spouse do it independently, so that that person knows what's expected of them, and then you might also supply, uh, a tracking sheet for them to take home so that they can plan to do this activity so many times during the week...

The healthcare professionals further specified that families helped the patients with "any of the ADL activities" such as "assist[ing] the patients to dress themselves". Families also learned about patients' medications and their management, "...especially for the weekends home and then when they're discharged. If the patient is unable to do the medication part, the family would need to identify which pharmacy, and then make sure it's filled, make sure they understand..."

In sum, from the healthcare professionals' perspectives, families were involved in adult inpatient TBI rehabilitation by learning care and therapy to provide continuity for the patients. The healthcare professionals' perceptions about family involvement in learning care and therapy therefore centred on transferring the care of the patient to the family. They did so when the patient was being discharged to live with the family.

Table 6 provides summary of the healthcare professional categories described above as well as the specific ways in which they described families being involved in adult inpatient TBI rehabilitation.

Table 6.

Summary of Healthcare Professional Categories

Categories	Specific ways families were involved
Being with and supporting the patient	• Families were present • Families brought food • Families brought items from home • Families encouraged • Families supported the patients' connections
Providing and receiving information	• Families provided information to the healthcare professionals • Families provided feedback after weekend passes • Families received information from the patients • Families with PoA received information from the healthcare professionals • Families asked questions and sought information • Families received information through in-person meetings or phone conversations
Making decisions when required	• Families with PoA helped make decisions • Families provided input on goals • Families made personal and medical decisions • Families made decisions on equipment and renovations
Learning care and therapy	• Families observed therapy • Families learned care, including medications, for weekend passes and discharge • Families learned therapy, including strategies and techniques, for weekend passes and discharge

Overall perceptions of family involvement and potentially influential factors. In

order to further explain the patients', family members', and healthcare professionals'

descriptions of the ways in which families were involved in adult inpatient TBI rehabilitation, I present below the participants' overall perceptions of family involvement as well as the factors that they discussed that potentially influenced the ways in which families were involved.

Perceptions of family involvement. In describing the ways in which families were involved in adult inpatient TBI rehabilitation, patients, family members, and healthcare professionals highlighted the potentially limited nature of family involvement in this context. One family member illustrated this limited family involvement by speaking about family presence "...there's very little and very rarely family around." Another family member similarly spoke to this point, saying "...very few of people you see in here...I find it sad that I don't see many visitors for some of these people." As a family member was openly discussing her own limited involvement, she expressed that "I don't know what I'm supposed to be asking or what I'm supposed to be doing... I think there's probably more I could be doing, for sure." Recognizing that family involvement happened in many different ways, a healthcare professional spoke candidly about her perception of family involvement in rehabilitation therapy, "...to put this in perspective, it's very infrequent that family members actually participate in therapy like this, so when you are talking about them being involved, I find this is the minority rather than the majority..."

Factors that potentially influenced the ways in which families were involved. To put the idea of limited family involvement into perspective, patients, family members, and healthcare professionals discussed the following factors that potentially influenced the ways in which families were involved: (a) families' presence during formal rehabilitation hours, (b) patients' perceptions of family involvement, and (c) healthcare professionals' level of engagement with families.

Families' presence during formal rehabilitation hours. Families- "...when they're present, they are included in the interaction." Participants' descriptions of the ways in which families were involved in adult inpatient TBI rehabilitation illustrated how family involvement could often depend on families' ability to be present during formal rehabilitation hours. Suffice to say, "...usually it's [involvement is] when they're here, and they come to therapy." When considering the phenomenon of family involvement in the inpatient rehabilitation process for adult TBI as well as the fact that formal rehabilitation occurred Monday to Friday between the hours of 9am and 4pm, the potential influence this could have on the ways in which families were involved becomes evident.

Most of the patients discussed their families' difficulties with coming to the rehabilitation centre during the daytime and/or work week because of their distance from the centre, their work schedule, or their need to care for young children at home. One patient explained how his family member wanted to be more involved in his rehabilitation as well as attend therapy but she could not because "...she can't come that early..." Another patient similarly spoke about his family member's difficulty with being involved in rehabilitation, "...I mean, she's trying to deal with two kids at home herself...and we live [out] in the country...she comes to visit me once a week...she usually comes on Fridays because the kids will be in daycare." Further speaking to this need to be present in order to be involved in the rehabilitation process, many of the family members discussed these same topics. As one family member stated, "...unfortunately because I do work fulltime, umm, we only come to visit him- we try to come every night. Ah, but there's no therapist or, or anyone around at that time." Another family member discussed how it was difficult for her as well to be present during formal rehabilitation hours because "she's got the two little ones..." and so she felt "out of the loop." Corroborating this limitation placed on

family involvement in the rehabilitation process, a healthcare professional expressed, “It might be someone whose family has to work for a living, so they just don’t have the time to participate in therapy at that level.” Recognizing this, another healthcare professional touched on the potential impact on family member-healthcare professional interactions, “I think the nurses have more contact with the family than we do. Because we’re not here when the family is here, often in the evening, right.” Generally speaking, it appeared as though family involvement was often confined within the parameters of the formal rehabilitation hours, therefore placing a responsibility on families to be present at the centre during these hours in order to be involved in the rehabilitation process.

Patients’ perceptions of family involvement. The patients’ overall perceptions of their families’ involvement in the rehabilitation process differed from those of the family members in that they worried about the potential impact of involvement on their family members. Many of the patients discussed perceiving their families’ involvement as a burden on the family members, leading them to feel as though maybe their family members “...are involved a little bit too much.” When discussing his family member’s involvement in his rehabilitation, a patient expressed, “...and I don’t think he should be.” The patient then proceeded to explain his thoughts,

...I think he’s probably looking for a break from this type of activity. That’s where I’d put that...I think he’d like to get a bit more independence to his life...And he may look at this as ‘oh no, more of this’...He may.

In reflecting on his family, another patient emotionally expressed, “My family was always helping and I felt sorry...I have to count on them and...we’re supposed to be equal. Help each

other...My wife does everything, even more than she should...Sometimes I think it's too much, you know."

Many of the patients also conveyed that their families' involvement was unnecessary at times, relating this specifically to their perceptions of their independence. One patient in particular described his family member's involvement as "100% helpful", but specified that it was not necessary as he "feel[s] the same as before" and that "everything is going smooth". Other patients expressed similar thoughts about their families' involvement. As one patient stated, "She wants to know everything that's going on with me, but she doesn't really need to...there's no point. It's pretty basic. The nurses tell me everything and the doctors tell me everything." Some of the family members discussed their personal experiences with the patient's perceptions of their involvement and how this subsequently affected their involvement. As one family member openly explained,

I think he finds me too, too, uh, mothering. Not a good word maybe, but, if- I don't know how else to explain it. I think he finds I'm interfering in his, his work here, uh, because I'm around so much...So now I'll come in and see [him] two or three times every week. But I'm not coming in every day.

Many of the healthcare professionals similarly explained how sometimes the patients wanted their families to "step back". As a healthcare professional spoke to this point, she stated "...there are situations where you would like family particip- participation, but the client really doesn't want their family members involved too much."

Healthcare professionals' level of engagement with families. Many of the patients and family members believed that the healthcare professionals did not engage the family members and discussed how this influenced the ways in which the families were involved in the

rehabilitation process. One patient discussed how he himself involved his family member in his rehabilitation, as his healthcare team had not engaged his family member. He specified that his family member was only able to come to the ward in the evening and when she was present and approached the healthcare professionals, they most often directed her to other healthcare professionals who were no longer available. The patient expressed, "...I guess she needs to talk to [the healthcare team] more, that's what everyone [specific healthcare professionals] keeps telling her... I'm pretty much keeping her more informed than they [the healthcare team] are." Another patient explained that his family was not involved in his therapy because they believed this time was reserved for him to focus on his rehabilitation program, "...here it is scheduled, you know. When somebody is coming to here, there is a...I had a program with the therapist or someone...[and so] my friends and my parents have not accessed the therapists." Despite his family not being present during rehabilitation hours, he expressed how he did not believe that his healthcare team had ever met with his family nor had they communicated with his family.

Speaking similarly about the therapy schedule, a family member expressed, "...they take him away and they do this therapy with him, like, during the day and stuff, and he comes back, he's busy all day, but I don't really know what he's doing, you know?" When discussing how the lack of engagement from the healthcare professionals had affected her, a family member expressed, "...I'm pretty lost..." Wishing that the team had "made more of an effort", she explained her personal experience,

I guess I'm just not very impressed with, um, how unorganized they are when it comes to, you know, like I'm the one that's going to be takin him home at the end of this, and you know, I'm completely blind. Like I don't know what I'm supposed to be doing. And I just feel like they could have made more of an effort to, sort of like, have a meeting and

sort of say, 'this is what's happening, and this is what we need you to do.' I mean, I need direction right? ...they should have kind of kept me involved the whole time.

Another family member spoke to the limited engagement she perceived from the healthcare professionals, explaining that she did not fully understand the team's plan or goals for the patient. She felt as though she did not have a clear picture of the team's thoughts about the patient, his state, or his progress. She explained that the healthcare professionals did not keep her well informed as they only provided her with "rough updates" and so she herself had to "put two and two together" many a time. Feeling quite strongly about the lack of information and availability of the healthcare professionals, the family member expressed that she believed that families "...should not have to chase down the staff." Another family member had a similar experience, stating, "...it's people I've searched out. Uh, not that they've found me... sharing information is coming from us. It's not much coming the other way." In discussing this same idea, the healthcare professionals reflected on how well they were communicating with families, stating, "And I'm not sure how well we're meeting the family needs. Like, maybe there's room to improve that." They also touched on how working within their routine or habits could lead them to "forget to...follow through" with families. A healthcare professional expressed, "I think we could probably do a better job of reporting back [to the families] because sometimes it just gets lost, right..."

The possibility of a break in communication with families was one potential issue related to family involvement that the healthcare professionals recognized. The family members identified an additional potential issue: that is, the feeling of the healthcare professionals judging them. Family members described not always feeling trusted or involved by the healthcare professionals when providing them with information. As one family member described, "I felt

like I was being looked at like ‘who are you?’.” And she said to herself, “we are family...I know my kid!” Another family member discussed her experience with informing the healthcare team about her perceptions of the patient’s challenges, “...and they just sort of, gave me the run around thing...and then I just never heard back again about it.” Similarly, in describing how he approached the healthcare team to inform them about the patient’s behaviors, a family member shared, “...I’m wondering if it’s not counterproductive. Because then they look at me like, you know, ‘and you were there and you didn’t stop it, you don’t know better?’” It appears as though the healthcare professionals minimally engaged families in the rehabilitation process, and patients’ and family members’ discussions of this suggest that it potentially had a negative impact on families’ experiences. However, it is not clear whether the healthcare professionals were aware of these perceptions of family members.

What are the similarities and differences between patients’, family members’, and healthcare professionals’ perceptions of family involvement? Building on the findings from the previous research question, the present research question explored the similarities and differences between patients’, family members’, and healthcare professionals’ perceptions of how families were involved in the adult inpatient TBI rehabilitation setting. I present these similarities and differences below as well as illustrate them in a visual display (Figure 3). Generally, patients, family members, and healthcare professionals perceived family members as being involved in similar types of activities; however, the specific ways in which the healthcare professionals conceptualized family involvement in these activities differed from the conceptualizations of the patients and family members.

The similarities between patients’, family members’, and healthcare professionals’ perceptions of family involvement. When asked about their perceptions of how families were

involved in adult inpatient TBI rehabilitation, the patients, family members, and healthcare professionals all described that family members were involved in supporting the patients, information sharing, decision making, and care and therapy. Interestingly, as demonstrated in the previous findings section, the patients and family members shared similar perceptions of family involvement and the specific ways in which family members were involved in these types of activities. More specifically, they similarly described family members *being with and supporting the patient*. They articulated how family members supported the patients by being with the patients at the rehabilitation centre, providing emotional support to help the patients stay positive, and encouraging them in their recovery (e.g., encouraging them during therapy sessions, encouraging them to participate in all therapeutic activities offered). The patients and family members also similarly described family members *informing others and keeping themselves informed*. They discussed how family members were involved in sharing information about the patients' status and their progress with other family members as well as with the healthcare professionals. Both participant groups noted how family members actively kept themselves informed by seeking information about the patients and their recovery (e.g., medical status, progress in therapy) from the healthcare professionals.

The patients and family members equally expressed how family members were involved in decision making- by *helping to make decisions*. Family members helped the patients make decisions about, for example, living arrangements, equipment, and medications; an activity that patients and family members wanted the other to be involved in. Similarly, they also described how family members were involved in the patients' care and therapy by *participating in care and therapy*. Both groups noted that family members accompanied the patients to on-site and off-site appointments, provided care (e.g., giving them their medication, feeding them, helping

them with hygiene), observed therapy sessions, and monitored and assisted with the use of rehabilitation strategies (e.g., external cueing, use of notebooks and agendas, use of ADL strategies).

Like the patients and family members, the healthcare professionals noted that family members' involvement included *being with and supporting the patient*. They similarly described how family members supported the patients by visiting with them, provided emotional support, and encouraged them in their recovery. However, their conceptualizations of the specific ways in which family members were involved in the other activities (i.e., information sharing, decision making, care and therapy) differed from those of the patients and family members. I now turn to a description of these differences.

The differences between patients', family members', and healthcare professionals' perceptions of family involvement. Although the healthcare professionals described family members as being involved in the same general activities that the patients and family members noted, their perceptions of family involvement and the specific ways in which they were involved in information sharing, decision making, and care and therapy differed. In regards to information sharing, patients and family members perceived family members as primarily being responsible for informing other family members about the patients' status and their progress. In describing how his wife kept the rest of the family informed regularly, a patient said "I heard from my family that my wife took control!" However, it is not clear whether the healthcare professionals perceived this activity as part of family involvement.

There appeared to be contrasting perceptions regarding the accessibility of the healthcare professionals for sharing information. Family members described how they had to "try to find" and "searched out" the healthcare professionals to inform them about their perceptions of the

patients, including their behaviors, challenges, abilities, and progress as well as to seek out information about the patients and their recovery. A family member described how she had to “chase down” the healthcare professionals. Highlighting how family members sought out information, a family member described wanting to be informed but found it difficult to obtain information. She expressed that she would “seek out information from staff. I [family member] have to approach them and ask them myself.” While the healthcare professionals perceived that they sought all of the information needed for their work with the patients, the family members seemed to believe that they had additional information to provide to the healthcare professionals to ensure appropriate care. The family member quoted above further explained that she sought out the healthcare professionals and was “candid and open with them” to “tell them my feelings, all of my ideas...” She did so because she knew the patient and “wants the treatments he receives to be based on truth...”

In contrast to this, the healthcare professionals described family involvement in information sharing as family members *providing and receiving information*. The healthcare professionals perceived that they mainly initiated contact with family members, and this when they needed to ask the family members for information that they required. As one healthcare professional explained,

The first thing is, like, we ask for information from the family member. ...And, that's the information we get from the family because our patients are not able to give us that information. And that's where you get the first – like, you have to have the family member to help you, or friends.

They also described how they provided information to the family members when they felt necessary by means of one-on-one meetings, family conferences, family days, or telephone

conversations. As one healthcare professional articulated, the healthcare professionals met with the family members if they believed there was a need for information and/or education, “I think often times it’s [meeting with family members] if the family doesn’t understand maybe how much support the person needs. Umm, or the flip side, if they are providing too much support...”

When probed about their perceptions of family involvement in decision making, patients and family members discussed family members being involved by helping the patients to make important decisions, including living arrangements, medications, and medical procedures, and by advocating for decisions they felt the patients would want. While discussing with a family member the various decisions with which their family had helped, the family member illustrated this well, “Yeah, so that’s another decision [living arrangements] that we have to discuss with him [the patient] and decide what he wants...” Conversely, the healthcare professionals described family members *making decisions* only *when required*; such as in cases when family members had Power of Attorney or when the decisions directly affected the family members (e.g., purchasing equipment or renovating their home). As one healthcare professional stated, “I would say, for the most part, if the client is quite reliable and you feel they’re able to make decisions for themselves, you may not involve the family member.” And another healthcare professional further explained, “...that [family involvement in decision making] stems from the patient. So, if you’ve got a patient that’s not able to make decisions for themselves, family often will be the ones that will consent...”

Patients and family members perceived that family members were involved in care and therapy by participating directly in care and therapy because they wanted to be involved and help the patients. Specifically, patients and family members discussed how family members were involved in care by, for example, helping with personal care and giving medications and in

therapy by observing sessions, encouraging the patients during sessions, encouraging activities outside of sessions, and supporting the rehabilitation strategies in place for the patients. Patients and family members perceived family involvement in care and therapy as “...something that they [family members] need and that he [patient] needs” and as something that family members “want to be involved in”. A family member described how she and her family felt that “...a huge part of why he [the patient] is healing and improving is because we [family] are helping and supporting him” in his care and therapy. The healthcare professionals described family involvement in care and therapy differently: *learning care and therapy* for the purpose of continuity after inpatient rehabilitation. One healthcare professional illustrated the learning-focused purpose of family involvement in care and therapy in this setting, “I’ve had spouses who have attended therapy with the client, and the idea is that, um, the spouse will learn strategies as part of the therapy process, so that when they go home they can continue strategies with the patient...”

Figure 3 below provides a visual representation of the similarities and differences between patients’, family members’, and healthcare professionals’ perceptions of family involvement. Overall, the findings from Phase 1 reveal that the patients and family members had different understandings than the healthcare professionals of the ways in which families were involved in adult inpatient TBI rehabilitation. The outer light blue layer of the visual display represents the four types of activities in which patients, family members, and healthcare professionals similarly described family members to be involved in; supporting the patient, information sharing, decision making, and care and therapy. The inner section of this visual display is divided into three quadrants representing each of the three participant groups: patients, family members, and healthcare professionals. The dialogue bubbles within each of the three

quadrants represent the participants' perceptions of family involvement and the specific ways in which each participant group perceived family members to be involved in supporting the patient, information sharing, decision making, and care and therapy. These dialogue bubbles are color coordinated with the activity to which they relate; supporting the patient is represented in purple, information sharing is represented in red, decision making is represented in blue, and care and therapy is represented in orange. Finally, the wording of the specific ways in which patients, family members, and healthcare professionals perceived family members to be involved demonstrates how patients and family members similarly conceptualized family involvement, while the healthcare professionals conceptualized their involvement differently.

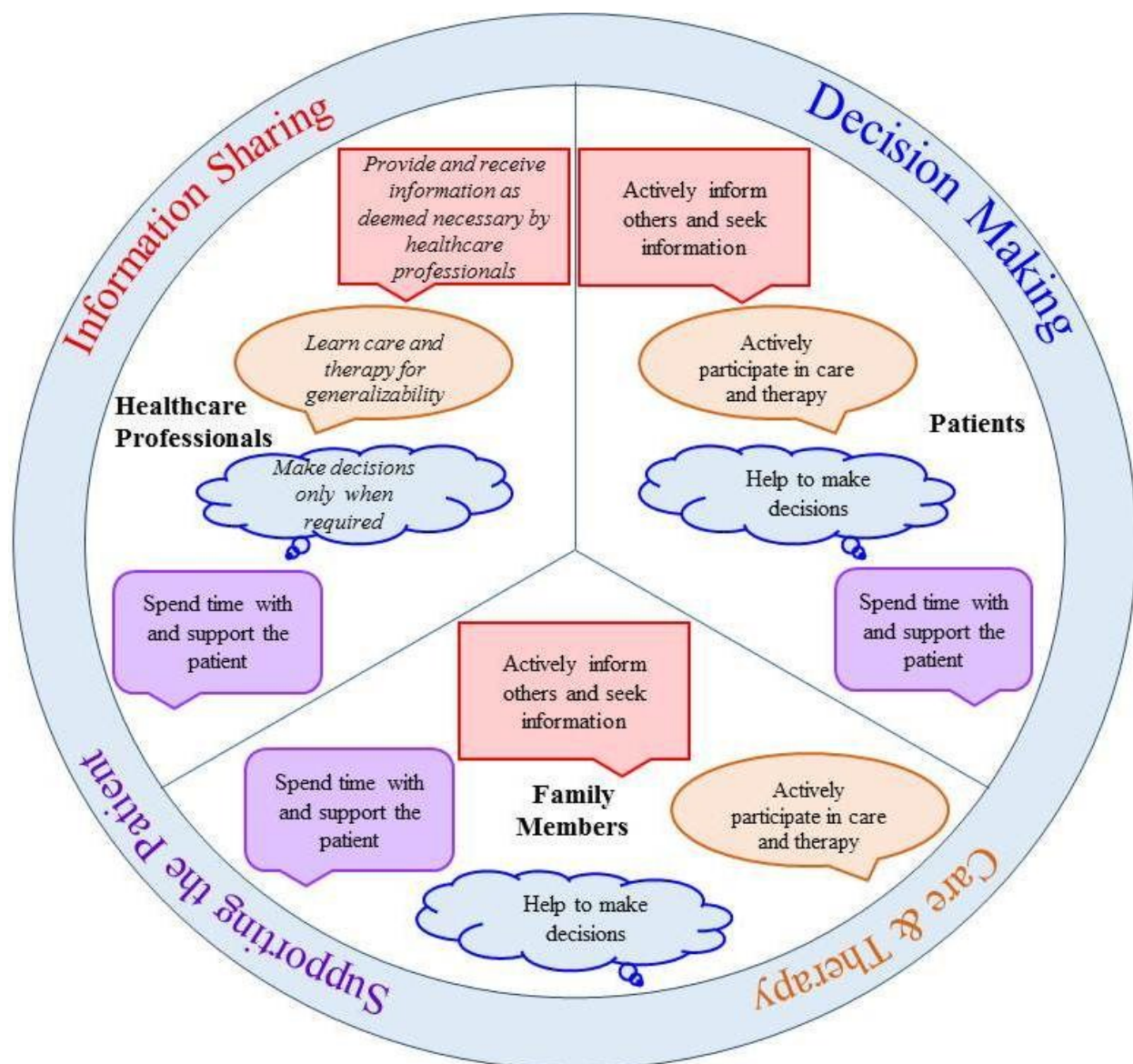


Figure 3. Visual representation of the findings for Phase 1, research question 2.

Chapter 5: Phase 2

This chapter provides an overview of Phase 2 of the present study where I conducted observations of patient, family member, and healthcare professional activities and interactions on the inpatient ABI ward at an adult rehabilitation centre. In this phase of the study, I aimed to understand the similarities and differences between participants' perceptions of how families were involved and what was happening in practice. The following research question guided Phase 2:

3. What are the similarities and differences between patients', family members' and healthcare professionals' perceptions of family involvement and what is observed in practice?

In the sections below, I briefly describe the three participant populations in this phase of the study: patients, family members, and healthcare professionals. I also explain the process I followed for developing the observational field guide for data collection. Following this, I describe the data collection and analysis processes as well as the steps I took to establish trustworthiness. Finally, I present the findings from the observations.

Participants

Similar to Phase 1, participants of interest in this phase of the study were patients, family members, and healthcare professionals from the inpatient ABI ward. All patients, family members, and healthcare professionals present on the inpatient ABI ward during the observation period were eligible to participate in this phase of the study. While these were the individuals present during my observations, the activities and interactions that illuminated family involvement were of specific interest in this phase of the study.

Instrument Development

Observational field guide. Using the findings from Phase 1 of this study, I developed an observational field guide to record data during observation sessions (see Appendix J; Creswell, 2009). Further informing the development of this guide, Merriam (1998) suggests that researchers should consider certain factors when collecting observation data, including the participants, activities and interactions, conversations, and the physical setting. As such, my observational field guide consisted of a contextual information section for recording information such as the date, day of the week, time of day, and location the observation occurred as well as the participants involved. I also included separate descriptive and reflective notes sections as well as a section to sketch the environment layout. I sought feedback on the observational field guide from two experts who were familiar with the inpatient TBI rehabilitation context. Feedback focused on the accuracy of the sectional categories included in the guide (e.g., location names, contexts) and I subsequently finalized the observational field guide.

Data Collection

I conducted observations on the inpatient ABI ward over the course of the month of June 2016. I considered this amount of time to be appropriate as it approximates an average length of stay for TBI on an inpatient rehabilitation unit (CIHI, 2008). I informed the healthcare professionals on the inpatient ABI team of the observation phase of the study prior to commencing the observations. Specifically, I presented this phase of the study to the team and the Medical Director and Clinical Manager of the inpatient ABI service additionally informed the team during a team meeting and through e-mail communication. The healthcare professionals informed the patients and family members of the observations ongoing on the inpatient ABI ward as well as other general and therapy areas within the rehabilitation centre. The healthcare

professionals informed patients and family members already admitted to the inpatient ABI service immediately prior to my commencing observations. They informed new patients and family members upon their admission to the service. Patients, family members, and healthcare professionals were all informed that they could express at any time if they did not or no longer wanted me to observe them.

Observations. As previously mentioned, I designed the present study so that I could capture and build upon the findings identified in Phase 1. After completing data collection and analysis for Phase 1 of the study, I conducted observations of patient, family member, and healthcare professional activities and interactions, taking note of behaviors and conversations relating to family involvement. I identified key activities and interactions to observe in Phase 2 of the study using participants' descriptions of family involvement in Phase 1, while remaining open and flexible to allow for additional ideas that would potentially help me understand the phenomenon. For example, a finding from Phase 1 was that families were involved in therapy sessions; as such, I observed instances of this type of activity. This strategy allowed me to ground my observations in the findings from the first phase of this study and focus them where I could learn the most about family involvement in this setting.

I conducted observations in the following spaces: bedside, ward desk, staff room, meeting rooms, patient lounge, television and game room, therapy and waiting areas, hallways, café, and entrance. I conducted observations at various times of the day (i.e., morning, afternoon, and evening) and during all days of the week (i.e., Monday through Sunday). To inform the timing of my observations, I initially consulted with key members of the inpatient ABI team and allowed my completed observation sessions to inform my future sessions. I placed myself where people were located within a specific space; I sat and observed as well as walked around the

spaces. I conducted observations in sessions lasting two hours, with each session immediately followed by approximately 60 minutes of time to reflect on my observation session. This allowed me to ensure that I spent an appropriate amount of time observing the various areas of the inpatient ABI ward and other pertinent areas of the rehabilitation centre, as well as reflecting on all that I had observed. It also helped ensure the quality of data recording. When entering a patient room, a healthcare professional accompanied me and I sought permission from the patient(s) and family member(s) to be present and observe. I did not record any personal, identifying, or confidential information during the observations. I also did not participate in the activities and interactions I observed and therefore, the reviewing research ethics boards deemed that participant consent was not required during this phase of the study (see Article 10.3 of the Tri-Council Policy Statement in Appendix K). I recorded all observations in the observational field guide, as field notes provided raw material for the analysis (Pope, 2005).

Researcher-participant relationship. As an observer it was important for me to understand that I would be involved in some way in what I was observing. Therefore, it was also important for me to establish prior to study commencement the type of relationship that I intended to have with participants. Creswell (2013) distinguishes four types of researcher-participant relationships: *complete participant*, *participant as observer*, *nonparticipant/observer as participant*, and *complete observer*. The chosen relationship can change over the course of the study as the researcher becomes more acquainted with the setting and participants over time (Pope, 2005).

For the purpose of the present study, I adopted a *nonparticipant/observer as participant* relationship. In this type of relationship, the researcher prioritizes the researcher role over the participant role. In fact, the researcher remains an outsider to the participant group and records

data from a distance. Although this distance could negatively affect rapport with the participants I observed, this type of relationship could be beneficial for the quality of data recording (Creswell, 2013). As such, by adopting this type of relationship, I was visible to all participants involved in the study and I prioritized my role as a researcher to ensure proper data recording. Although I could have chosen to adopt a participant-type role for the study because of my clinical training and familiarity with rehabilitation settings and TBI services, I did not believe that these types of relationships were the most appropriate in the context of this particular study (i.e., healthcare setting, inpatient rehabilitation ward). Patients in this study were following a carefully developed care plan and therapy schedule with the end goal of maximizing outcomes. Therefore, it was imperative not to be intrusive or cause disruption in this process. My *nonparticipant/observer as participant* role did not change over the course of the observation period.

Data Analysis

I allowed my findings from Phase 1 and the research question inform the analysis in this phase of the study while remaining open to new information emerging from the data. I also continually reflected on what I was seeking to learn and what the data were telling me about it, which enabled me to refine my categories and frame my findings (Srivastava & Hopwood, 2009). The following research question guided the data analysis for Phase 2 of this study: What are the similarities and differences between patients', family members' and healthcare professionals' perceptions of family involvement and what is observed in practice?

Following each observation session, I organized the observational field data and reflective notes to appropriately manage the data and facilitate analysis. Similar to the process used in Phase 1, I followed Miles and Huberman's (1994) three steps to data analysis to analyze

the observational field data and answer **Question 3**. Beginning with data reduction, I reviewed the data multiple times and developed an initial coding scheme based on my conceptual framework and Phase 1 findings. Like in Phase 1, I further developed this coding scheme through an in-depth review of the observational field data. To further reduce the data, I then sorted and connected these initial codes. I created a hierarchical structure using overarching codes and sub-codes. I developed a definition for each overarching code to demonstrate my understanding of them. To display the data and understand the results of the data reduction process, I created a data display table. This allowed me to create a sort of model and examine how the various codes distributed across all observation sessions. I set up this display table with the codes as rows and the observation sessions as columns. I then compared and contrasted the codes from Question 1 and Question 3 to understand the similarities and differences between participants' perceptions of how families were involved and what was happening in practice. I reviewed the findings and drew conclusions about the patterns demonstrated in the data, thus establishing the findings for this research question (Miles & Huberman, 1994). I also pulled examples that supported and illustrated the key similarities and differences from the data.

Trustworthiness

To enhance the *credibility* of my research process, I used prolonged engagement where I spent an extended period on the inpatient ABI ward to orient myself to the setting and to allow everyone to adapt to my presence on the ward. I entered the setting well in advance to commencing the study, presented the study to the inpatient ABI team, and developed relationships with and sought support from key individuals. I also used peer debriefing. Specifically, two research colleagues, one with expertise in brain injury rehabilitation and one with expertise in family involvement in healthcare settings, reviewed the observational field data.

I met regularly with these colleagues to review my analysis and interpretations, obtain their feedback, and discuss the challenges I encountered throughout this process (Lincoln & Guba, 1985). To demonstrate *dependability*, I detailed my study design and processes and used auditing (Lincoln & Guba, 1985). Specifically, I have provided rich detail in each section of this thesis. I also developed an audit trail to provide a transparent description of my research process (Rogers & Cowles, 1993). The audit trail is made up of the following information: instrument development, raw observation data, field notes, detailed notes of data collection processes, detailed logs of data analysis and interpretation processes, and copies of evolving coding schemes. This audit trail also served to demonstrate *confirmability* of my research process and findings (Lincoln & Guba, 1985). Finally, I used rich description in the present thesis to provide readers with sufficient detail of the participants, research context, and findings for them to evaluate the *transferability* of this study and its findings to other populations, settings, and situations (Lincoln & Guba, 1985).

Findings

As previously mentioned, I conducted observations of patient, family member, and healthcare professional activities and interactions on the inpatient ABI ward at an adult rehabilitation centre. In this phase of the study, I aimed to understand the similarities and differences between participants' perceptions of how families were involved and what was happening in practice. The following research question guided Phase 2:

3. What are the similarities and differences between patients', family members' and healthcare professionals' perceptions of family involvement and what is observed in practice?

I conducted 26 observation sessions in this phase of the study, with each session lasting two hours. Therefore, I conducted a total of 52 hours of observations and this resulted in 90 observation encounters. I provide an example of one of these encounters in Appendix L. Five observation sessions occurred during the morning, 17 occurred during early and late afternoon, and four occurred during the evening. Eighteen observation sessions occurred during a weekday and eight occurred during a weekend day. Each observation encounter included between two and five participants (patient, family member, and/or healthcare professional), with the exception of formal meetings which included between seven and 23 participants. Table 7 lists the locations as well as the general types of activities and interactions I observed in this phase of the study.

Table 7.

Locations and General Types of Activities and Interactions Observed

Locations	General Activities and Interactions
Ward areas	
Bedside	FMs visiting; FMs helping with care; FMs prepping for weekend passes; HCPs interacting with Pts
Hallway	Pick-ups and drop offs; FMs' arrivals and departures; FMs accompanying Pts
Ward desk	FMs approaching the ward desk; FMs informing HCPs of weekend passes; Pt sign-in; HCP interactions; HCPs providing Rx instructions to Pts & FMs; Pt D/C
Staff room	HCP interactions; conversations
Meeting rooms	IPM meetings; HCP interactions; FM conferences; HCP-Pt-FM interactions
Patient lounge	Group session; Pts eating meals; Pts & FMs watching television
Television and game room	No activities
Therapy areas	
OT waiting area	Pts & FMs waiting; HCPs looking for Pts
OT therapy areas	Pts in OT sessions; FMs observing; FMs interacting with Pts; HCPs informing Pts about equipment
PT waiting area	Pts waiting; HCPs looking for Pts
PT therapy areas	Pts in PT sessions; FMs observing; FMs interacting with Pts; HCPs informing Pts about equipment; FMs interacting with HCPs
RT waiting area	Pts waiting
SLT waiting area	Pts waiting
Psyc waiting area	Pts waiting
General areas	
Hallways	Pts & HCPs walking and talking
Café	HCPs on breaks; HCPs socializing
Entrance	FMs accompanying Pts

Note. Pt = patient; FM = family member; HCP = healthcare professional; OT = occupational therapy; PT = physiotherapy; RT = recreation therapy; SLT = speech-language therapy; Psyc = psychology; D/C = discharge.

What are the similarities and differences between patients', family members' and healthcare professionals' perceptions of family involvement and what is observed in practice? Building on the findings from the previous research phase, this phase of the study and the present research question sought to understand family involvement in the adult inpatient TBI rehabilitation setting through observations. After observations on the ward, I interpreted the data, identified recurring patterns in the data, and developed categories that provide a comprehensive description of this involvement (Merriam, 2002; Morse, 2015). I then compared and contrasted the participants' descriptions of family involvement from Phase 1 with observations from Phase 2 to understand the similarities and differences between patients', family members', and healthcare professionals' perceptions of how families were involved and what I observed in practice. I present these findings below as well as illustrate my observations of family involvement with a visual display (Figure 13). Generally, while there were some similarities between participants' descriptions of family involvement and what I observed in practice, I gleaned interesting differences, essentially providing further insight into family involvement in this setting.

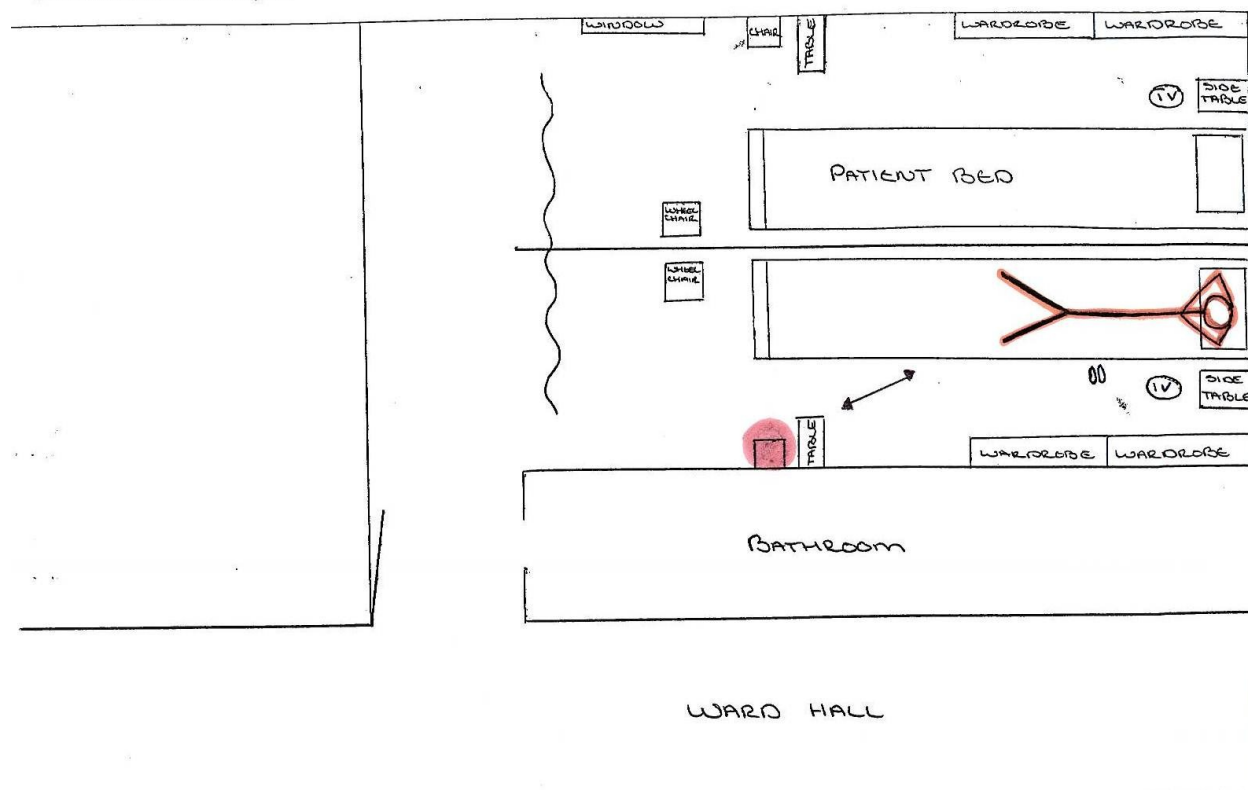
The ways in which families were involved. I present the similarities and differences through the specific ways in which I observed family members to be involved. I observed family members involved in adult inpatient TBI rehabilitation in the following ways:

Being with and supporting the patient. Similar to patients', family members', and healthcare professionals' perceptions of family involvement in supporting the patient, I observed some family members present on the ward and spending time with patients at selected times. During these observation encounters, family members were mostly present during weekday afternoons. There were most often one or two family members present for a particular patient; in

two encounters, three family members were present. During the majority of these observation encounters family members were spending time with the patients in their room. I specifically observed family members reading or talking with the patients in their room. As visits in the patients' room was how I observed family members most often spending time with the patients, I include below a sketch I made of this type of interaction in Figure 4.

During a few of these observation encounters, I observed family members accompanying patients on a casual walk down the halls of the rehabilitation centre, appearing to try to pass the time. These patients and family members walked quietly, raised the odd casual conversation topic, and did not seem to have a plan of where to go or what to do. I also observed family members waiting quietly with the patients in the therapy waiting areas and then proceeding back to the patients' room or the patient lounge area to wait while the healthcare professionals brought the patients into therapy. While many of these observation encounters consisted of family members spending up to a few hours on the ward with the patients, some were quite brief (i.e., about 20 minutes). During weekend evenings, I observed a number of family members arriving on the ward with the patient after a weekend pass and helping the patient get settled back in their room (e.g., unpacking their weekend bag) as well as spending a brief period of time with them in their room; after which the family members left the ward. In addition to being present and spending time with the patients on the ward, interviewees in Phase 1 discussed other specific ways in which family members were involved in supporting the patients, including bringing home-cooked food, bringing personal items from home for the patients' room, and encouraging the patients. I did not observe any instances of these specific types of involvement occurring during my observations.

Sketch room/environment layout



Note. The red dot on the chair in the sketch represents the family member and the orange figure lying on the bed represents the patient. The black double-sided arrow represents the directions of communication between the patient and family member.

Figure 4. Sketch of a family member visiting with a patient in their room.

Providing and receiving information. Similar to the healthcare professionals' perceptions of family involvement in information sharing, I observed family members providing information to the healthcare team as had been requested of them as well as receiving information from the healthcare professionals. More specifically, I observed patients and their family members approach and wait at the ward desk prior to leaving on weekend passes to inform an available healthcare professional about their confirmed plans for the weekend pass (e.g., confirmed time of return, confirmed where the patient was to stay). I also observed them upon return from weekend passes to inform an available healthcare professional about how the weekend pass went (e.g.,

adherence to medication schedule, significant events such as notable behaviors or falls). They reported briefly about the weekend pass to the available healthcare professionals on request of one of the patients' healthcare team members prior to leaving on the weekend pass. During these interactions, the healthcare professionals appeared to listen to the family members attentively and thanked them for the information that the healthcare professionals had requested. However, these interactions were brief and informal, taking place while standing at the ward desk. I also observed, during a few encounters, healthcare professionals asking their patients during therapy sessions to contact their family members to ask them to provide photos of the home environment, to confirm purchase and installation of recommended equipment in the home, and to follow-up when family members had not yet provided the requested information.

Additionally, I observed healthcare professionals providing information to family members. Immediately prior to leaving on weekend passes, I observed family members and patients approach and wait at the ward desk to retrieve the patients' medications for the weekend as instructed by the healthcare professionals, at which time the available healthcare professionals provided prescription instructions to the family members and patients. These interactions were again brief and informal, taking place while standing at the ward desk. I also observed healthcare professionals' discussions among each other in the staff room and ward desk areas as well as during team meetings about the need to meet with family members to provide information and education once issues had arisen. During several of these discussions, family members' "lack of awareness" of the patients' deficits and needs came up as a "barrier" to the rehabilitation process. For example, this type of discussion took place when a family member arrived on the ward very overwhelmed and upset about the patient's upcoming discharge date; the family member approached the ward desk visibly overcome with emotion. The family member's voice was

raised and shaky and face expressed panic. The family member walked away from the healthcare professionals after they reconfirmed that the patient was being discharged. The healthcare team held a family conference for this particular patient and family member a few days previously.

I also observed family members receiving information in the forum of these family conferences. During these meetings, the family members appeared comfortable. They seemed to be at ease in the room with the healthcare team, sitting relaxed in their chairs. They made eye contact with the healthcare team members and spoke comfortably. The healthcare professionals would first introduce the patients, their family members, and then themselves. The healthcare professionals typically positioned themselves to face the patients and family members as best they could during these meetings. They also invited the family members at the beginning of the meetings to ask questions at any time during the meetings and consistently asked the patients and family members throughout the meetings if they had any questions. The main activity of family conferences, however, was to provide information to the patients and their family members in preparation for discharge. Based on my observations, prior to the commencement of the family conferences, the healthcare professionals planned among themselves in advance of the meetings the information they would share; they did not consult family members regarding information requests.

During family conferences, the healthcare professionals provided a verbal and written summary of assessment findings, rehabilitation progress, and recommendations to the patients and family members present during the meetings. They also informed patients and their family members of what they believed still needed to be done in preparation for discharge (e.g., purchase equipment) and requested information from the patients and family members that they perceived they still needed. It is important to note that during my observations I learned that

family conferences were not held for all patients and their family members and when they were held, they were typically scheduled within the week prior to the patients' discharge date. During my observations, I noticed that family members most often received information in the forum of family conferences and as such, I include below a sketch I made of this type of interaction in Figure 5.

Patients and family members had discussed, in Phase 1 interviews, family involvement in information sharing somewhat differently than healthcare professionals; that family members were involved by informing other family members about the patients' status and their progress as well as the patients' healthcare team members about their perceptions of the patients. As mentioned, they also described family members seeking out information about the patients and their recovery from the healthcare professionals. Unfortunately, I did not observe any instances of these specific types of involvement occurring during my observations.

Sketch room/environment layout

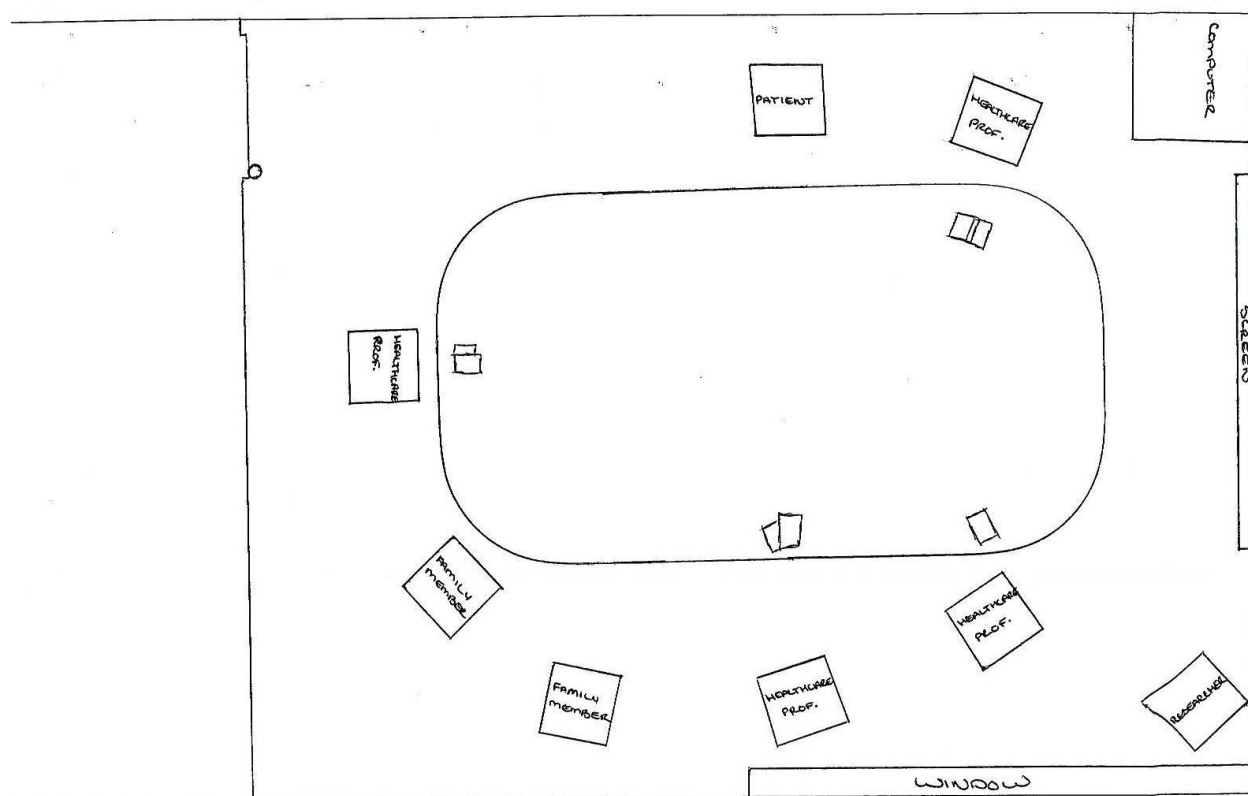


Figure 5. Sketch of a family conference held in a meeting room.

Making decisions when required. Similar to healthcare professionals' perceptions of family involvement in decision making, I observed family members making decisions when required by the healthcare professionals. During family conferences, I observed healthcare professionals asking family members to decide on a specific discharge date and time from the few discharge date options that the healthcare professionals provided to them. The healthcare professionals sometimes involved the family members in confirming these decisions as the patients were going to be living with these family members once discharged and the family members had to be ready for the patients to come to their home and able to pick them up from the rehabilitation centre. However, the healthcare professionals did not always provide the family

members with discharge date and time options as the ward's wait list and bed availability often dictated these.

Regarding discharge location, I observed healthcare professionals involving family members in deciding on living arrangements for the patients when these patients were unable to participate fully in these decisions. The healthcare professionals discussed this family member involvement in decision making for living arrangements among themselves during team meetings as well as with the family members during family conferences. During these same types of meetings, I observed healthcare professionals deciding that they wanted patients to go on a weekend pass as part of their rehabilitation. The healthcare professionals therefore asked the family members to decide if they were willing to take the patient home for a weekend pass and supervise them. I also observed healthcare professionals asking family members during one-on-one meetings to decide on a vendor to purchase needed equipment as these family members had to organize these purchases for the patients.

Patients and family members had discussed, in Phase 1 interviews, family involvement in decision making somewhat differently than healthcare professionals; that family members were involved by helping the patients to make important decisions, including living arrangements, medications, and medical procedures, and by advocating for decisions they felt the patients would want. I did not observe any instances of these specific types of involvement occurring during my observations.

Participating in care and therapy. Similar to patients' and family members' perceptions of family involvement in care and therapy, I observed family members participating in these activities in several different ways. I observed family members accompanying patients to and from weekend passes. The family members would help the patients get ready to leave for their

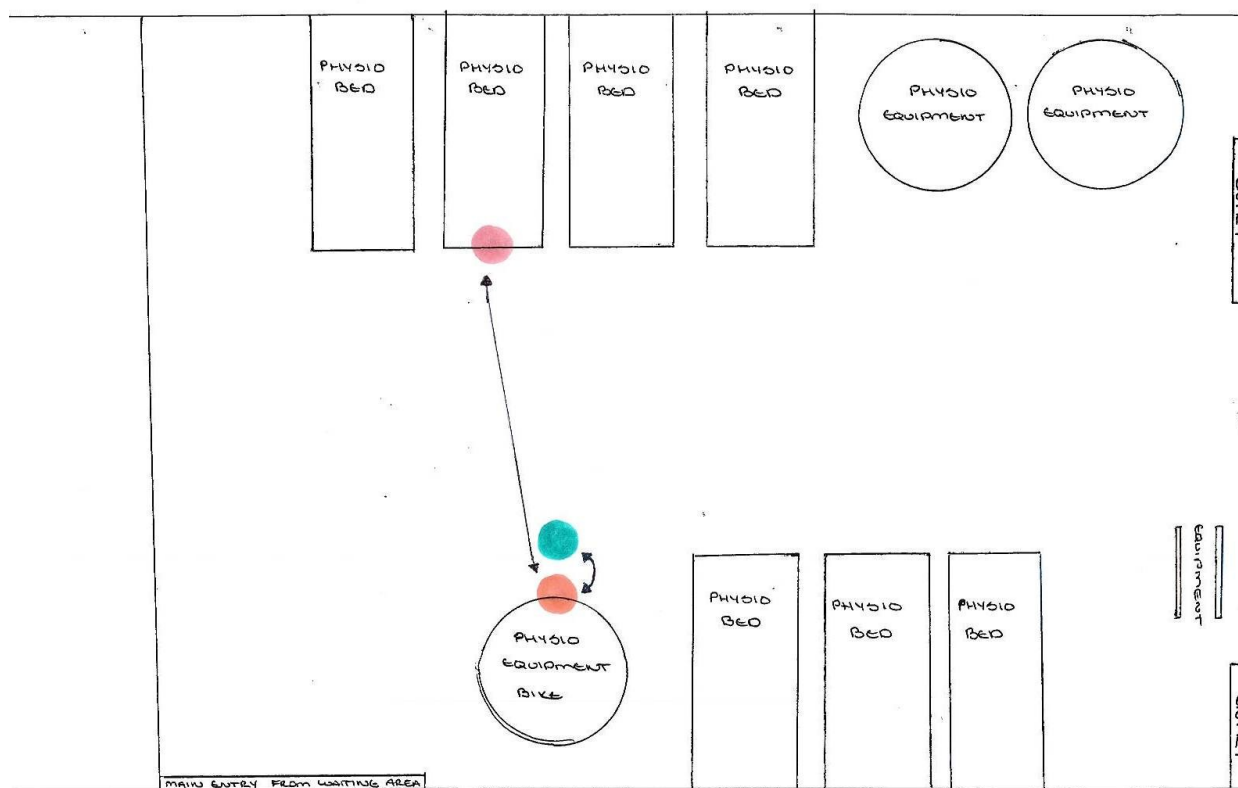
weekend pass (e.g., pack their weekend bag, get dressed) and they would help them settle back in their room when they returned from the weekend pass. I also observed family members helping patients with their personal care in their hospital room. For example, I observed family members helping the patients eat their meal and I observed family members helping the patients to clean themselves up after eating their meal and to go to the bathroom.

I observed family members observing equipment fittings (e.g., wheelchairs, bath and toilet benches) in the therapy areas. During these fittings, the family members sat or stood away from the patients and healthcare professionals, observed the fittings, listened to the conversations between the patients and healthcare professionals, and interacted with the patients. The family members asked the patients, for example, what they thought of the equipment and if they were comfortable. They also provided their input about the equipment to the patients. The healthcare professionals and family members interacted minimally with each other; the healthcare professionals spoke directly with the patients. I also observed family members observing patient therapy sessions. During these therapy sessions, the family members sat facing the patients, observed the sessions, listened to the conversations between the patients and healthcare professionals, and interacted with the patients. The family members socialized with the patients and at times reminded them of their improvements. The healthcare professionals and family members interacted minimally with each other; I observed only the friendly “hello” and occasional “Mhmm” from the healthcare professionals when the family members engaged in the occasional friendly conversation with them. I include below a sketch I made of this type of interaction in Figure 6.

During Phase 1 interviews, the healthcare professionals perceived family members’ involvement in care and therapy as primarily for learning how to provide care and support the

patients' therapy for continuity after discharge. I observed the healthcare professionals discussing the need to invite family members, those who they had identified as caregivers post-discharge, to attend sessions so that the healthcare professionals could teach them the patients' care and therapy. During my observations, however, this specific activity did not occur as no teaching sessions were scheduled.

Sketch room/environment layout



Note. The red dot in the upper section of the sketch represents the family members, the orange dot overlapping the physiotherapy equipment represents the patient, and the green dot above the orange dot represents the healthcare professional. The black double-sided arrows represent the directions of communication between the patient and family member as well as between the patient and healthcare professional.

Figure 6. Sketch of a family member observing a therapy session.

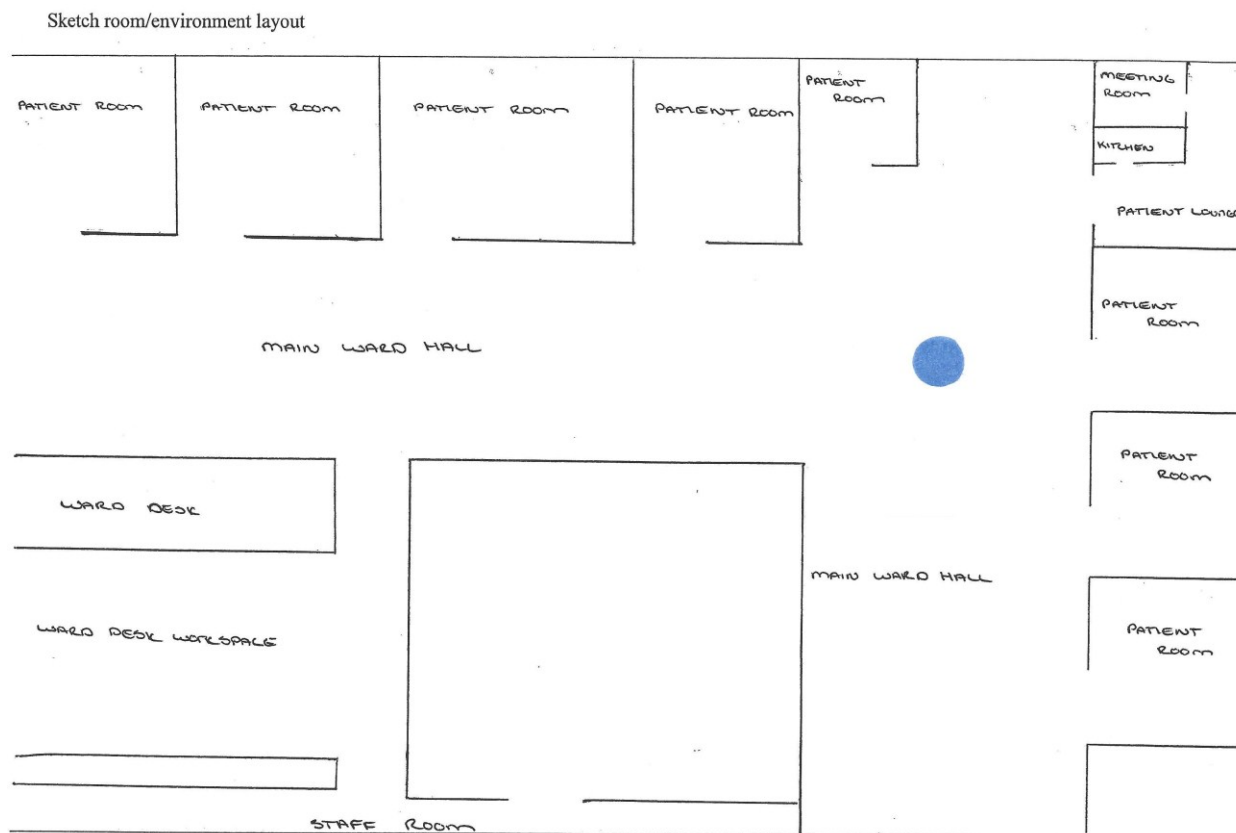
Overall perceptions of family involvement and potentially influential factors. In order to further explain my observations of the ways in which families were involved in adult

inpatient TBI rehabilitation, I present below the my overall perceptions of family involvement based on my observations as well as the factors that I observed that potentially influenced the ways in which families were involved.

Perceptions of family involvement. Similar to family members' and healthcare professionals' perceptions of family involvement in Phase 1 interviews, I observed family involvement to be limited. The above discussed observation findings reflect only a portion of my observation sessions. During nearly half of my observation sessions, there simply were no activities or interactions taking place involving family members. During my observation sessions, family members were rarely present on the ward and I did not observe any other forms of communication occurring between the healthcare professionals and family members (e.g., phone calls, note writing).

Factors that potentially influenced the ways in which family members were involved. To put the idea of *limited family involvement* into perspective, I observed the following factors that potentially influenced the ways in which families were involved: (a) families' presence, (b) healthcare professionals' level of engagement with families, and (c) the suitability of the environment for family involvement.

Families' presence. While patients, family members, and healthcare professionals noted that family presence was limited during formal rehabilitation hours (i.e., 9am to 4pm, Monday to Friday), I observed an overall limited family presence during my observations. More specifically, I observed family presence to be limited during all times of the day (i.e., morning, afternoon, and evening) and all days of the week (i.e., Monday through Sunday). In fact, during 11 of my 26 observation sessions, family members were not present on the ward. I include below a sketch I made of the often empty ward area and hallways in Figure 7.



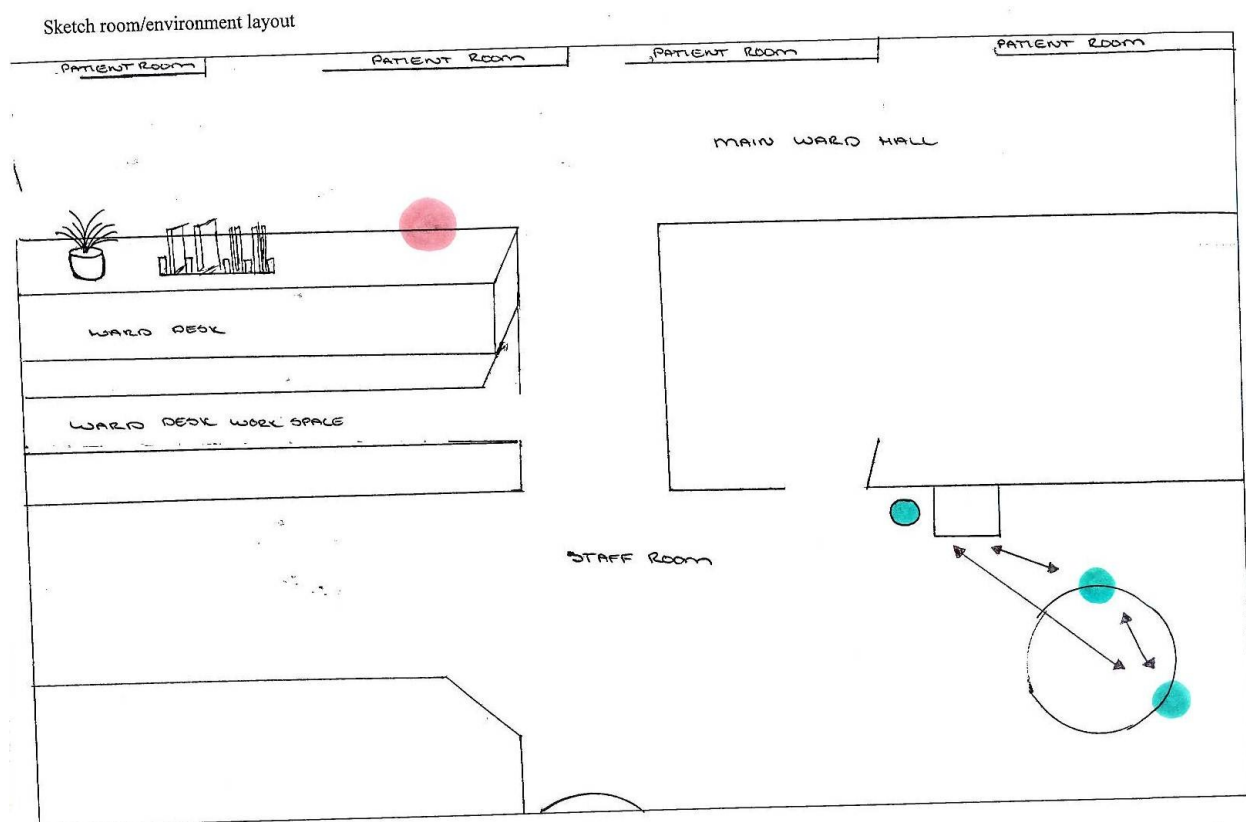
Note. The blue dot in the ward hall area of the sketch represents me, the researcher.

Figure 7. Sketch of the main ward area and adjacent hallways.

Healthcare professionals' level of engagement with family members. Similar to patients', family members', and healthcare professionals' perceptions of family involvement in Phase 1 interviews, I observed little family engagement initiated by the healthcare professionals. When family members arrived on or left the ward, I did not observe healthcare professionals and family members interacting with one another unless the family members approached the ward desk to speak with a healthcare professional, as had been requested of them. When family members did approach the ward desk, they often had to wait for an available healthcare professional to notice them. I include below a sketch I made of this type of activity in Figure 8. The ward desk was staffed from 7am to 3pm, Monday to Friday. Outside of these hours, there was no designated

staff member to greet them or field their inquiries. Rehabilitation staff were present on the ward 8am to 4pm, Monday to Friday (with the exception of rehabilitation therapists who covered evening and overnight hours with nurses), and so there were no opportunities to speak with occupational therapists, physiotherapists, speech-language pathologists, recreation therapists, psychologists, or social workers outside of these hours.

I also observed little interaction between the healthcare professionals and family members during therapy sessions when family members were present. The healthcare professionals interacted primarily with the patients and only interacted with the family members if the family members engaged them in conversation. Moreover, the ward had a sign-in/sign-out binder for family members present on the ward, however, I did not observe any family members sign the binder and they did not appear to be aware of the binder: only patients signed in and out in their designated binder. During formal team meetings, the healthcare professionals discussed family members primarily in relation to the patients' discharge plan (that is, if the patient was returning to the family member's home, if the family member was responsible for purchasing equipment or making any home modifications in preparation for discharge). At times, family members were also discussed in relation to the patients' "Health and Wellness Management" if, for example, there were any relevant personal issues of which the team needed to be aware. Examples of this included homelessness/transitional living, legal activities in process, or family separations. I observed the healthcare professionals interact with family members most during family conferences; the healthcare professionals interacted directly with the family members, introducing themselves, consistently making eye contact, providing them with information, and asking them if they had any questions. Again, however, family conferences were not held for all patients and their family members.

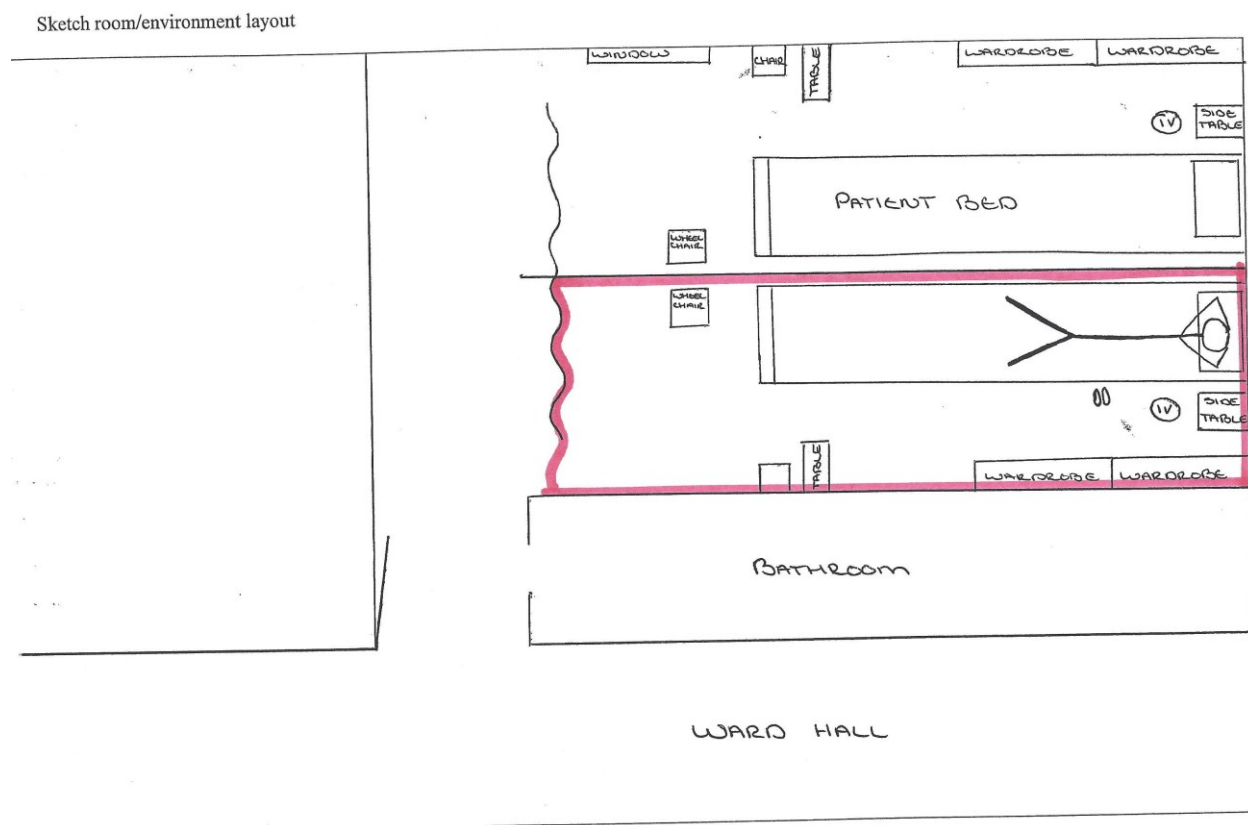


Note. The red dot at the ward desk in the sketch represents the family member and the green dots in the staff room area represent the healthcare professionals. The black double-sided arrows represent the directions of communication between the healthcare professionals.

Figure 8. Sketch of a family member waiting at the ward desk.

The ward environment and family involvement. In Phase 1 interviews, patients, family members, and healthcare professionals did not discuss the environment in relation to family involvement in this setting. However, the potential impact of the physical spaces on the inpatient ABI ward and other relevant areas in the rehabilitation centre proved to be an interesting factor to consider when reflecting on family involvement. For the inpatient ABI Service, the ward has two private patient rooms while all others are shared rooms with spaces divided by curtains. In these shared spaces, there is just a sufficient amount of space for the patient's bed, a nightstand, a closet, a single chair, and a portable table. Therefore, these rooms provide very little space for

family members to visit with the patients. When family members were visiting with the patients, patients were most often in their bed so that their family member could sit in the chair. All additional family members had to stand in the rooms, a situation that may have led to shortened visits. I include below a sketch I made of this type of space in Figure 9.



Note. The pink contouring in the sketch represents a single patient space.

Figure 9. Sketch of a patient room.

Patients and family members also had the option of spending time together in the common areas of the ward, including the television and game room and the patient lounge. However, the layout and location of these spaces were not conducive to the inclusion of family members as these common areas served multiple purposes or were not used at all. The television and game room, for instance, was small and cramped, consisting only of two chairs to watch

television, a small game table with one chair, and a small air hockey table. During my observations, patients and family members never used this room. It is located at the very back end of the ward, away from the main ward area, and almost hidden from sight. During my observations, I noticed that the healthcare professionals and other staff used it to store some pieces of extra equipment and they sometimes used this space for a private, quiet space to work. The ward also had a patient lounge in the main area for patients and family members to use. It consisted of four small tables pushed together to create one large dining space with chairs all around as well as seating for three people in front of a television. While patients and family members used this space more often than the television and game room, I observed that it served other purposes and therefore it was not always available. More specifically, the healthcare team regularly used this space for group sessions and sometimes used it for one-on-one sessions between patients and therapists during my observations. In addition, it is located off the team's main meeting room. Taken together, the use of this room for therapy and its location adjacent to a team meeting room may suggest that entry into the room may require a formal invitation (which is extended, for example, for family conferences). I include below a sketch I made of these two common spaces in Figure 10 to illustrate their layout.

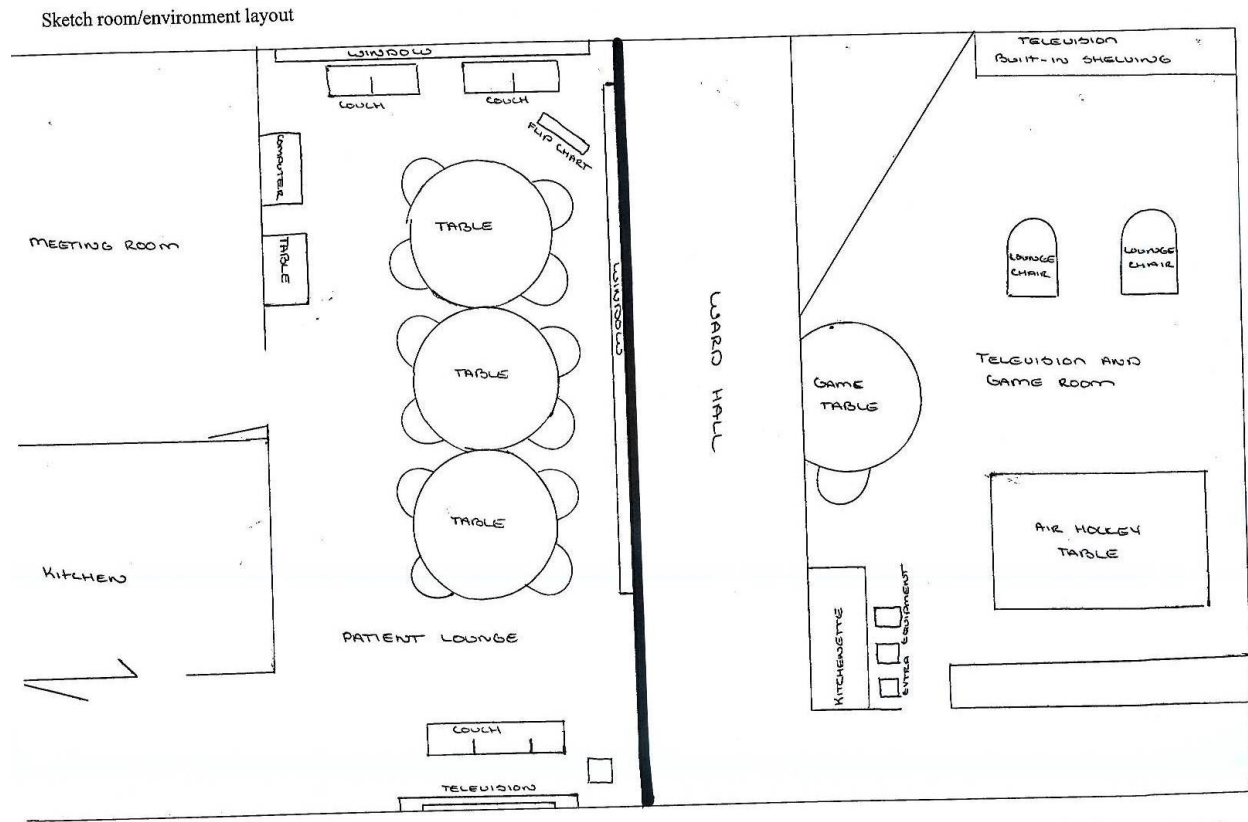


Figure 10. Sketch of common areas.

Many of these general spaces that are available to both patients and family members, including hallways, the patient lounge, and the television and game room had communication boards posted on the walls as well as resources available (e.g., pamphlets, flyers, reading materials). However, none of the materials displayed and available were geared specifically to family members. The main hall outside of the physiotherapy area was one of two general spaces in which one could find visual displays that acknowledged and celebrated family members' involvement. This hall had real-life patient stories that were published in the local newspaper and mounted on wall plaques. These stories described family members as a primary source of support for the patients and depicted them in photos with the patients during their rehabilitation. The second space was the ward's main hallway, which had wall space dedicated to displaying

photos from past annual ABI barbecues. These photos included past patients, their family members, and members from the inpatient ABI team.

The staff room also had communication boards with many resources available to the healthcare professionals. However, only one communication was related to family members; a banner exclaiming “Nursing Professional Practice - Committed to Patient/Family-Centered Care Through Nursing Excellence”. The staff room is a large closed-off space in the centre of the ward that is not visible or accessible to family members. The doorway to the staff room is separated from the ward hallway by the ward desk. Because the staff room is the healthcare professionals’ main workspace, they spent a significant amount of time in this area. Because of this physical layout, I observed that family members had to approach the ward desk to ask to speak with a team member. However, the ward desk, as previously noted, is only staffed by a clerk between the hours of 7am and 3pm, and thus family members, during my observations, were often left to wait at the ward desk until a healthcare professional happened to notice them. I include below a sketch I made of this space in Figure 11 to illustrate its layout.

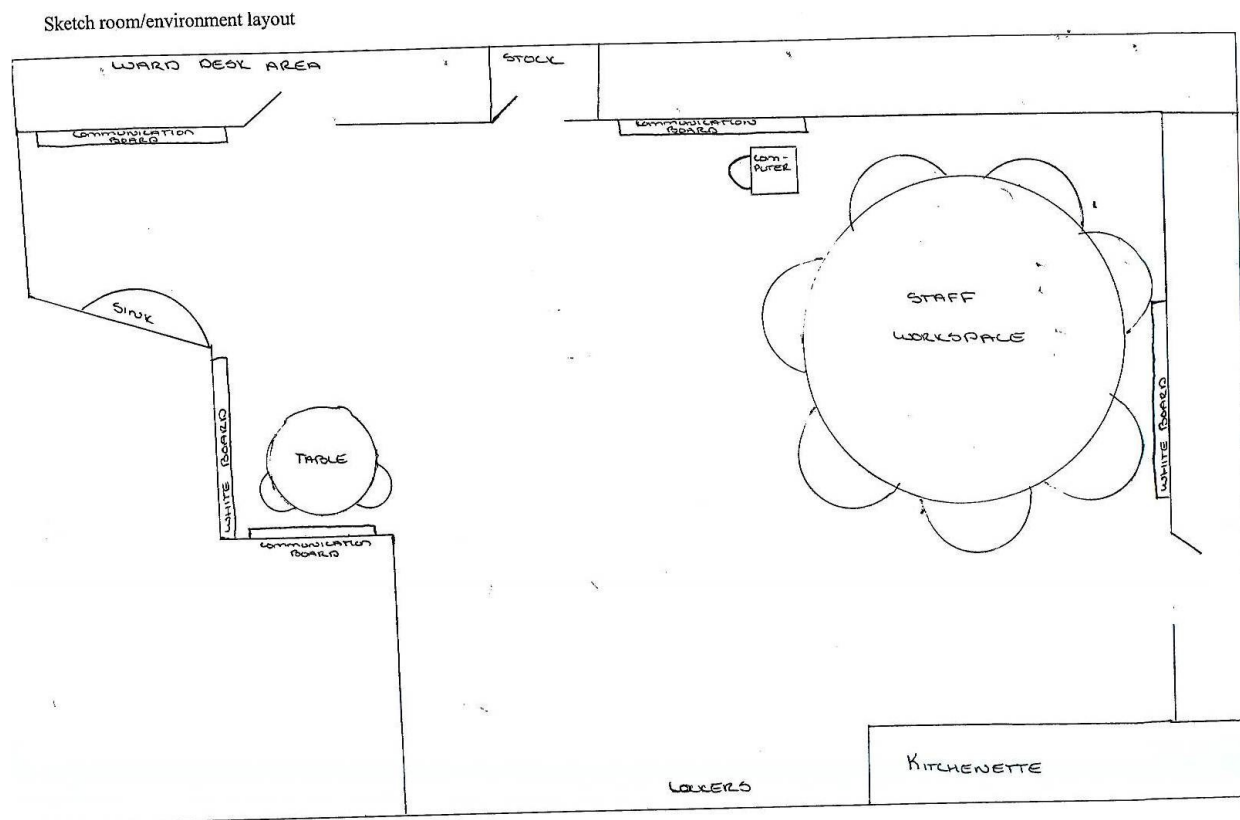
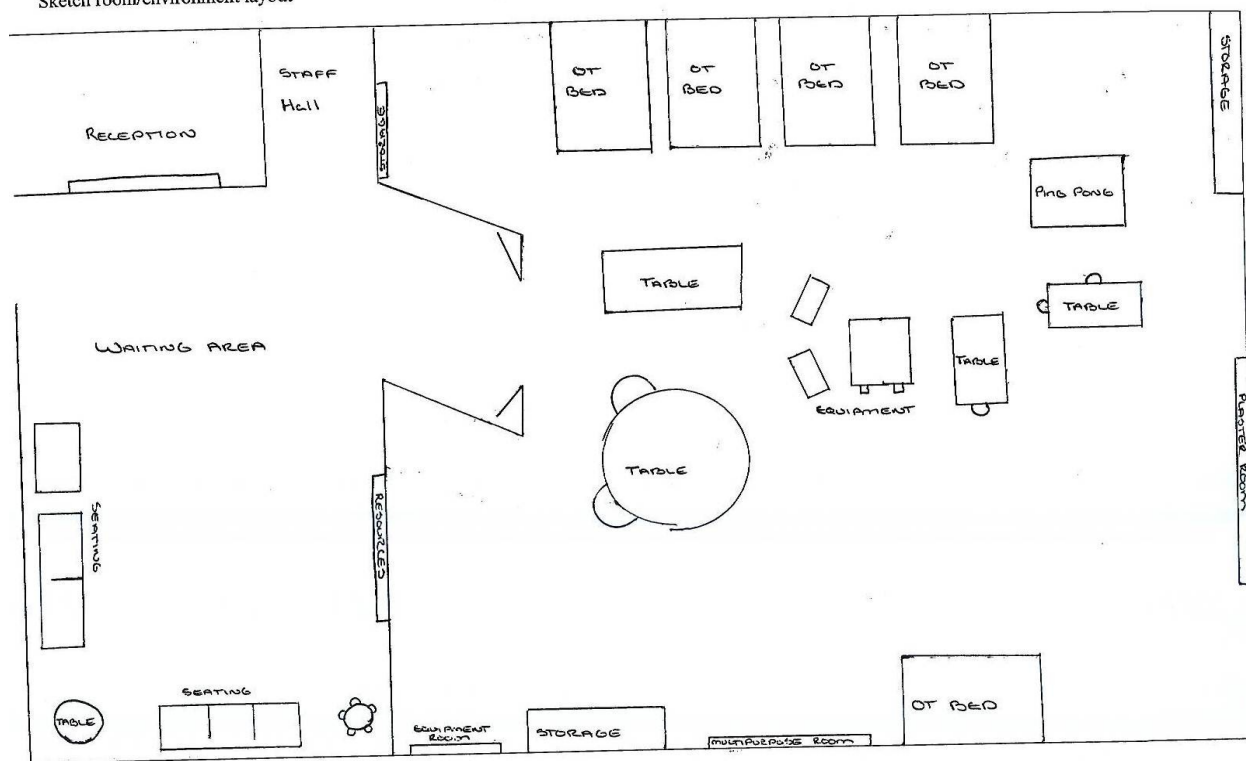


Figure 11. Sketch of the staff room.

My observations illuminated that the therapy areas are also not necessarily welcoming of family members. Within the occupational therapy space, the walls are decorated with photos of past patients with their therapists; family members are not included in any of the photos. At the time of my observations, each of the tables at which the therapists worked with the patients had two chairs available: one for the patient and one for the therapist. There was no seating available for family members in the therapy area, unless they were able to take a chair that was not being used at the time from one of the other workspaces. The occupational therapy waiting area does have general seating available for six people, but I noticed that it does not have a view of the therapy area. This space also had photos mounted on the walls; two of these photos included family members with past patients. On one wall of the waiting area, there were various resources

and reading materials available; however only one resource was geared to family members— a pamphlet for respite care. The physiotherapy area had even less seating available for family members. In two of the three main therapy spaces, there was no seating for family members; they had to stand or sit on the therapy beds or equipment. The third main therapy space, an open court space, had the only available seating; two benches and five chairs spread along the perimeter of the court where it seemed anyone could sit. The physiotherapy waiting area had general seating available for eight people and it had an obstructed view of the therapy area. This space had communication boards mounted on two of the walls with various resources and reading materials available. The same pamphlet for respite care that was available in the occupational therapy waiting area was also the only resource geared to family members in this waiting area. The recreation therapy, speech-language therapy, psychology, and social work areas consisted of private office spaces and small waiting areas. Social work was the only service that had resources visibly available for family members in the office spaces. I include below a sketch I made of these spaces in Figure 12 to illustrate their layout.

Sketch room/environment layout



Sketch room/environment layout

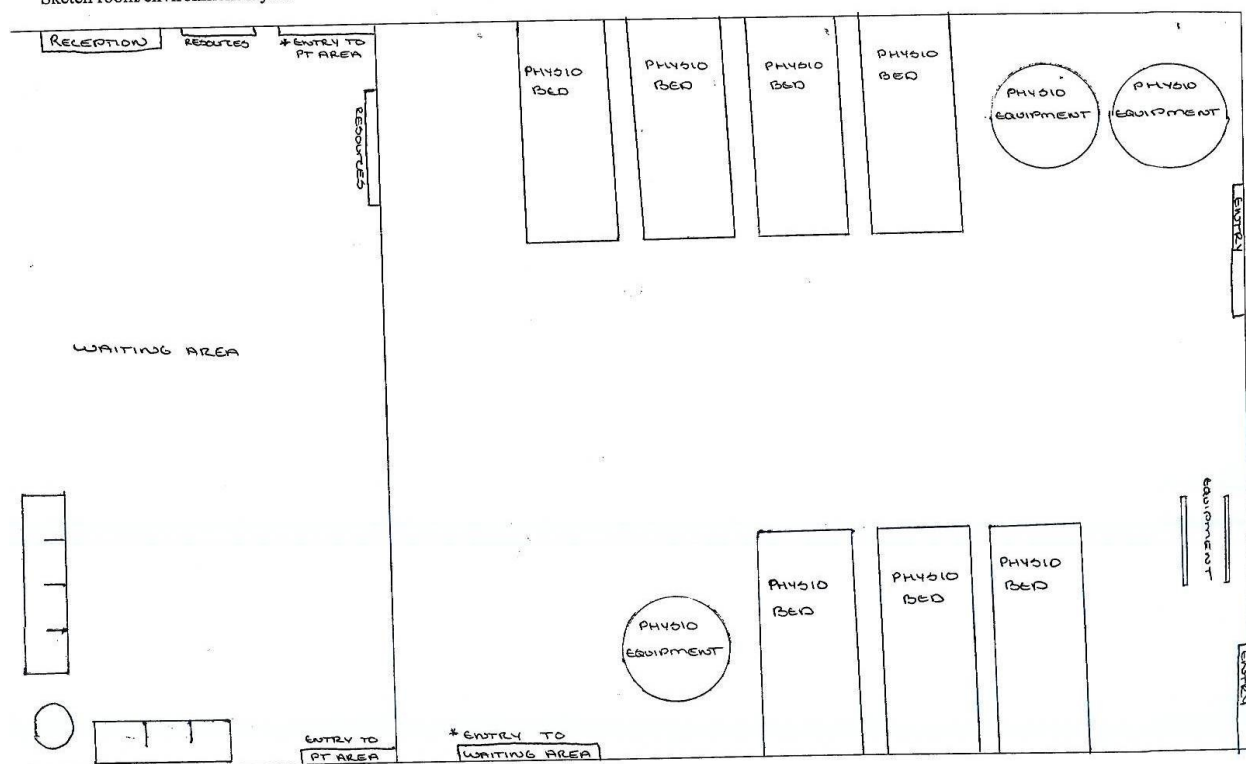


Figure 12. Sketch of main occupational therapy and physiotherapy areas.

Figure 13 below provides a general visual representation of the inpatient ABI ward as well as where I observed families to be present and involved. The spaces with no stars represent where I observed there to be no family presence or involvement. The spaces with one star represent where I observed there to be minimal family presence or involvement. Finally, the spaces with two stars represent where I observed there to be moderate family presence or involvement. I did not observe there to be significant family presence or involvement in any of the spaces.

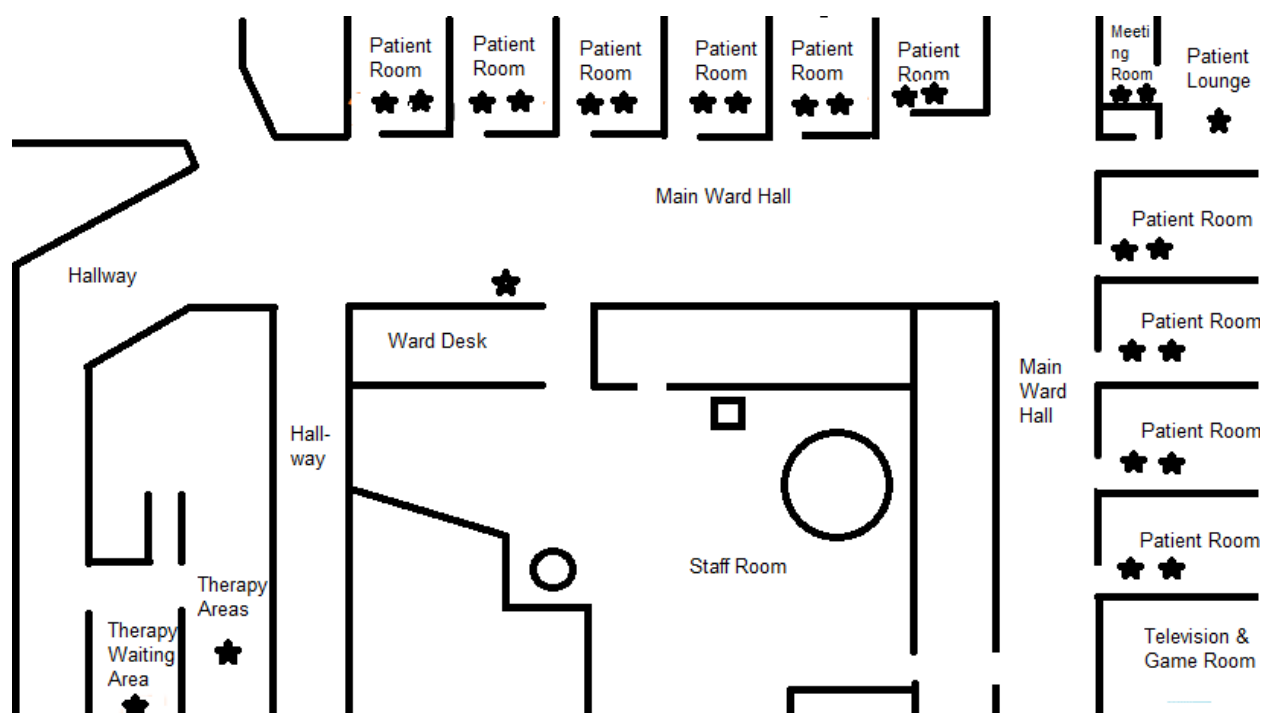


Figure 13. Visual representation of the findings for Phase 2, research question 3.

Chapter 6: Discussion, Contributions, Strengths and Limitations, Future Directions for Research, and Conclusion

Despite recommendations for increased family involvement in health services and in the rehabilitation process through the promotion of family-centred care— which states that patients, families, and healthcare professionals should be involved in healthcare processes to ensure quality care for patients (Foster et al., 2012; Rosenbaum et al., 1998), we know little about families' actual involvement in an important area of care, inpatient TBI rehabilitation. The findings from this study suggest that while patients, family members, and healthcare professionals similarly described the general activities in which family members were involved, the patients and family members had different understandings of family involvement than the healthcare professionals, specifically in relation to their perceptions about how these activities were enacted. In the sections below, I discuss the findings of this two-phased study in relation to the literature. I focus on the concrete ways in which family members were involved in adult inpatient TBI rehabilitation, explain several factors that potentially influenced this involvement, and suggest some areas for closing the gap between current practice, family members' perceived needs, and recommendations regarding involvement from the literature. In addition to this discussion of the key findings and the literature, I demonstrate how this study contributes to knowledge, rehabilitation practice, and methodology, discuss the study strengths and limitations, and finally, I discuss potential directions for future research.

Discussion of Findings and Literature

In the sections below, I integrate the findings of the present study with the literature to develop a better understanding of current family involvement in adult inpatient TBI rehabilitation. I first discuss the ways in which family members were involved in adult inpatient

TBI rehabilitation from the perceptions of patients, family members, and healthcare professionals and situate these key findings within the context of the knowledge base. I then discuss and situate within the literature patients', family members', and healthcare professionals' perceptions of family involvement in relation to how I observed this involvement in practice. In the final section, I discuss and situate within the literature the factors that potentially influenced the ways in which family members were involved in the inpatient rehabilitation process.

The ways family members were involved and differences in perceptions. Phase 1 of the present study elucidated, from the perspectives of patients, family members, and healthcare professionals, that family members were involved in adult inpatient TBI rehabilitation through the following activities: supporting the patient, information sharing, decision making, and care and therapy. More specifically, the patients and family members both described family involvement as family members being with and supporting the patients, informing other family members as well as the healthcare professionals and keeping themselves informed, helping the patients to make decisions, and participating in care and therapy. While the healthcare professionals similarly described family members being with and supporting the patients, they illustrated family members' involvement differently. They conceptualized it as family members providing information to and receiving information from the healthcare professionals as well as making decisions when required or deemed necessary by them, and learning care and therapy.

This difference in perceptions between the patients/family members and the healthcare professionals of the specific ways in which family members were involved in information sharing, decision making, and care and therapy is not entirely surprising. Shaw et al (1997) also previously revealed an important difference in perceptions between family members and healthcare professionals regarding family involvement in inpatient brain injury rehabilitation.

Their research showed that while family members and healthcare professionals generally agreed on the importance of family involvement, the healthcare professionals were hesitant about, for example, the appropriateness of families visiting as often as desired, families being fully informed in a consistent and timely manner, and family involvement in planning therapy (Shaw et al., 1997). These differences could be a reflection of the literature that shows that healthcare professionals have concerns about families being over involved or under involved, and perceive that family members may not have the skills necessary to contribute to decision making and thus, may be a barrier to progress (Lefebvre et al., 2005; Levack et al., 2009; Shaw & McMahon, 1990). While Shaw and colleagues' (1997) work had a different focus than the present study, it highlights, as did the present study, that family members and healthcare professionals have differences in perceptions and that researchers should explore these issues to understand how patients, family members, and healthcare professionals can effectively collaborate.

Research thus far has provided minimal insight into the specific ways in which family members are involved in adult inpatient TBI rehabilitation. The literature has allowed us, however, to anticipate some of the activities in which family members might be involved in this type of setting, such as information sharing, decision making, and therapy. The findings of the present study align with past research in demonstrating that family members were involved in supporting the patients, information sharing, decision making, and care and therapy. Specifically, the literature highlights that healthcare professionals believe that family members can and should be involved in information sharing, decision making, and care and therapy, (Degeneffe, 2001; DePompei & Williams, 1994; Sander, 2014). The literature also shows that family members identify involvement in all of the above activities as an important need and part of families'

rehabilitation experiences (Fleming et al., 2012; Ishikawa et al., 2011; Keenan & Joseph, 2010; Rotondi et al., 2007).

Moving beyond this general description of family involvement, the present study provides deeper insight into the concrete ways in which family members are involved in these general activities in the inpatient setting. With respect to supporting the patients, the findings indicate that family members spent time with the patients, brought food and personal items from home, including various forms of entertainment and items to decorate the patients' room, took care of their personal responsibilities outside of the rehabilitation setting, including their home, bills, and pets, and provided emotional support and encouragement throughout their recovery, including attending therapy to verbally encourage the patients. The healthcare professionals also described family members supporting the patients by maintaining their connections with friends and encouraging visits. These findings align with the premise that "optimal [patient] functioning occurs within a supportive family and community context" as presented in the family-centred literature (Law et al., 2003a, p.4). While the literature does identify family members as a key support for patients with TBI, it does not illustrate this support beyond the ideas of family members visiting with patients and providing emotional support (DePompei & Williams, 1994; Fleming et al., 2012; Gagnon et al., 2015; Keenan & Joseph, 2010). Therefore, the present study further illuminated how family members specifically provide support to patients with TBI during the inpatient rehabilitation phase of recovery. Understanding the ways in which family members support patients with TBI during inpatient rehabilitation is important, as it will allow us to better understand how to facilitate their efforts, especially considering that the patients, family members, and healthcare professionals in this study all described this support as instrumental in the patients' recovery process.

The patients and family members explained that, with regard to information sharing, family members kept other family members informed about the patients and their progress. They did so to keep them up to date, but also to facilitate their involvement in the patients' rehabilitation when they were with them (e.g., when visiting with them, spending time with them on weekend passes). There is also evidence that they acted as gatekeepers, facilitating interactions with friends who were supportive of therapy, while shielding patients from less helpful interactions. This is a new concept related to family involvement in adult inpatient TBI rehabilitation that researchers have not yet discussed in the literature. This finding is interesting when considering Bronfenbrenner's (1977) argument for the importance of considering an individual within their multiperson family system; an inclusive perspective with the recognition that multiple individuals can influence a person's recovery.

In addition to this, family members informed the healthcare professionals about things that they believed were important and relevant to the patients' recovery and well-being based on their knowledge of the patients' personality and history. The patients and family members explained that family members approached the healthcare professionals to help them get to know the patients and to express their thoughts about the patients' behaviors, challenges, abilities, and progress. These findings align with the family-centred care perspective that family members have the right to "have their opinions sought and to be listened to" and that healthcare providers have the responsibility of listening to family members (Law et al., 2003a, p.4). This finding is illustrative of that of Lefebvre et al (2005) who highlighted that family members believe that what they know and experience in inpatient TBI rehabilitation is important and that the healthcare team should recognize this. This finding is also partially in line with DePompei and William's (1994) assertion that family members can provide important information to the

healthcare team about the patients. It is, however, more of a reflection of Foster and colleagues (2012) recommendation that family members should have a voice in inpatient rehabilitation and that the healthcare team should actively listen to them and take their opinions seriously.

The literature shows that family members also want and need to be informed (Kuipers et al., 2014; Rotondi et al., 2007) and, acting on this need, family members seek information (Gagnon et al., 2016; Ishikawa et al., 2011). Kuipers and colleagues' (2014) and Gagnon and colleagues' (2016) recent studies showed that family members expressed a need to be informed about the patients' symptoms, their care, and their prognosis and seek out information and resources regarding TBI diagnosis, prognosis, functional implications, and relevant treatments, respectively. In the present study, patients and family members described family members being involved in a similar way. They expressed that family members wanted the healthcare professionals to inform them and sought out information about, for example, TBI, impairments, symptoms, therapy, therapist roles, test results, and rehabilitation goals. This reflects the family-centred literature that indicates that families have the right to "receive information that will enable them to make decisions about the care that will most effectively meet [the patient's] needs" and "have access to information regarding [the patient]" (Law et al., 2003a, p.4).

In the present study, family members sought out information by approaching the healthcare team, asking questions, asking for meetings, and researching online. Although Kuipers et al (2014) touch on this in their findings, briefly stating that some of their participants "complain[ed] that in many instances [information] had to be sourced out by [them]selves" (p. 477), the present study highlights concrete steps taken by family members in search of this information. The patients' and family members' descriptions of seeking information in the present study are much more in line with Gagnon and colleague's (2015) category "Researcher"

used to describe the somewhat independent role that family members take on in the community setting in supporting TBI survivors' reintegration and return to productivity. These findings are in contrast to the family-centred perspective that healthcare professionals have the responsibility of "informing, answering, and advising [family members]" and "sharing complete information about the [patients'] care on an ongoing basis" (Law et al., 2003a, p.4).

While the healthcare professionals also briefly spoke about family members approaching them to ask questions, they generally described family involvement in information sharing differently than the patients and family members. That is, they typically saw their role as providing information if and as they judged that the family required it or, indirectly, through the patient. In contrast, Sander (2014) recommends that neuropsychologists working with patients with TBI in rehabilitation settings should provide information to the family members regularly, mainly in the format of formal meetings, in order to meet their needs and thus reduce distress. While the findings of the present study do demonstrate that the healthcare professionals provided information directly to the family members, often in the forum of meetings, they did so for two main reasons; if the family members had Power of Attorney or if the healthcare team had identified that the family members were experiencing issues and thus felt they would benefit from information. In the present study, healthcare professionals stated that they did not meet with family members regularly, and in some cases, they did not meet with them at all.

In addition to this, the healthcare professionals also discussed that they provided information to the family members through the patients. That is, if they felt the patients were capable, then they communicated directly with the patients and the patients subsequently informed their family members. As suggested by DePompei and Williams (1994), the healthcare professionals in this study sought information related to the patients' care and therapy (e.g.,

weekend pass events, home environment) as well as about the patients from the family members. However, they did so only if they could not retrieve necessary information from the patients themselves or needed to verify the accuracy of information given to them by the patients.

In summary, the findings of the present study reveal a tendency of healthcare professionals to involve family members in information sharing only when they judged that it was required, which is in line with Lefebvre et al (2005) and Levack et al (2009) who showed that healthcare professionals tend to focus much more on the patients than the family members in the adult rehabilitation process. As mentioned above, these findings contradict the responsibility of healthcare professionals to consistently inform family members as brought forward in the family-centred literature (Law et al., 2003a). It is possible, however, that these findings could be a reflection of potential issues with information sharing in an adult healthcare setting, where the patient can dictate the type and amount of information to share with their family and the efforts of the healthcare professionals are typically focused on promoting patient independence (Allen & Petr, 1998; Levack et al., 2009). Therefore, it would be important to explore these issues in future research to understand how patients, family members, and healthcare professionals can effectively collaborate in the adult inpatient rehabilitation setting.

The patients' and family members' perceptions of family involvement in decision making also differed from those of the healthcare professionals. Similar to the perceptions expressed by TBI survivors and family members in Knox and colleagues' (2015) work in the community, the patients and family members in this study described decision making as a shared process. Specifically, they explained that family members helped the patients to make decisions and even when the patients were capable of making their own decisions, the patients wanted their family members involved in this process. In the same line, when family members had Power of

Attorney to make decisions for the patients, the family members involved the patients in decision making as much as possible and advocated for decisions they felt the patients would want.

The family-centred literature states that family members have the right to be decision makers (Law et al., 2003a). However, the healthcare professionals believed that family members were minimally involved in decision making. The healthcare professionals in this study explained that if the patients were capable, then they did not involve the family members in decision making. Instead, the family members were only involved if they had Power of Attorney, in which case the healthcare professionals sought their input on, for example, rehabilitation goals, personal and medical decisions, the purchasing of equipment, and renovations. These perceptions are in line with those in Lefebvre and colleagues' (2005) and Martone's (2001) work where they illustrated that family members are not included in decision making at all. They also reflect the findings of D'Cruz et al (2016) who showed that healthcare professionals dominate the decision making process related to goal setting in inpatient rehabilitation for brain injury and of Levack et al (2009) who revealed that healthcare professionals tend to not focus on the family members during the decision making process for goal setting. These findings are in opposition to the family-centred perspective that family members have the right to "define the priorities of intervention" and that healthcare professionals should "encourage [family member] decision making in partnership with other team members", including the patients (Law et al., 2003a, p.4). While recognizing that adult patients are typically their own decision makers, these perceptions are also in opposition to Foster and colleagues' (2012) recommendations to include family members in decision making immediately in the early stages of rehabilitation. In fact, they specify that, in the adult inpatient rehabilitation setting, family members should be included in

collaborative decision-making discussions about goals, rehabilitation duration, therapy planning, and discharge planning.

Confirming previous research by Keenan and Joseph (2010) and Rotondi et al (2007) who showed that family members expressed a desire and need to be involved in care and therapy, the present study showed that family members tried to be involved in care and therapy and that they wanted to be involved. Specifically, the patients and family members discussed how family members were involved in care by, for example, helping with personal care, giving medications, and accompanying to medical appointments and in therapy by observing sessions, encouraging the patients during sessions, encouraging activities outside of sessions, and supporting the rehabilitation strategies in place for the patients. In relation to involvement in care, these findings are consistent with those of Keenan and Joseph (2010) where family members briefly illustrated their involvement in helping with personal care (e.g., applying cream, wiping the mouth) to describe how they need to be involved in care. They also illustrate the finding of Ishikawa et al (2011) that family members provide care to the patients with TBI. With regard to involvement in therapy, the findings of the present study are in agreement with those of Gagnon and colleagues (2015) where they described how family members initiate and encourage the use of various therapeutic activities to help the patients with TBI prepare for their return to productivity in the community. They also described how family members support the patients' use of recommended strategies for their ADLs and motivate them to participate in these activities.

The healthcare professionals' perceptions of family involvement in care and therapy again differed from those of the patients and family members. They described family member involvement as learning care and therapy, and this mainly for the purpose of continuity after

inpatient rehabilitation. The healthcare professionals explained how they invited the family members to meet with them and attend therapy so that they could teach them what they needed to know immediately prior to weekend passes and discharge. This way of involving family members in care and therapy is in line with the literature focused on examining family members' role in facilitating treatment and carryover (Galvin et al., 2009; Harris et al., 2010; Maeshima et al., 2003; McKinlay & Hickox, 1988). DePompei and Williams (1994) have brought up this limited involvement as a tradition in rehabilitation settings, thus advocating for the active participation of family members in care in therapy with the purpose of recognizing their valuable perspectives. Foster and colleagues (2012) also recommend engaging family members in care and therapy early on and actively involving them throughout the entire rehabilitation process. That said, current evidence-based interventions typically focus on the adult with TBI and are individual in nature (i.e., the patient learns and applies the strategies), thus promoting the independent adult (Cicerone et al., 2006; Cicerone et al., 2010; Levack et al., 2009; Rees et al., 2007). This signals the need for research on family involvement in therapeutic interventions to build an evidence base to inform healthcare professionals' efforts in facilitating this type of involvement.

Perceptions versus practice. In Phase 2 of the present study, the findings again illuminated that family members were involved in adult inpatient TBI rehabilitation through the following activities: supporting the patient, information sharing, decision making, and care and therapy. However, the observations revealed that family members were specifically involved by being with and supporting the patient, providing information to and receiving information from the healthcare professionals as well as making decisions when required or deemed necessary by them, and participating in care and therapy.

Overall, the observation findings revealed a “traditional” approach to family involvement that aligns with practices prior to the adoption of family-centred philosophy in this setting, where family members were minimally involved and the focus remained on the patients (DePompei & Williams, 1994; Sohlberg et al., 2001). In fact, the observations revealed an approach that is much more in line with the healthcare professionals’ descriptions of family involvement in Phase 1 interviews. While the observation findings supported the patients’, family members’, and healthcare professionals’ perceptions that family members support the patients by being present and spending time with them, they highlighted the healthcare professional-led nature of the rehabilitation process in the inpatient setting in relation to information sharing, decision making, and care and therapy.

With regard to information sharing, I observed family members provide information to the healthcare professionals as the healthcare professionals had instructed them to. I also observed healthcare professionals request information from family members through the patient, as the patient could not directly provide this information. I observed healthcare professionals provide information to the family members when it was necessary, that is in preparation for a weekend pass or discharge. This one-way communication contrasts with DePompei and Williams’ (1994) recommendation that family members should not simply be the recipients of information from experts. In addition to being professional-centred, interactions between the family members and healthcare professionals were often brief and informal, most often taking place in the main hallway of the ward by the ward desk. Similar to Fleming and colleagues’ (2012) findings, the only formal forum through which family members and healthcare professionals interacted was family conferences. Additionally, these meetings did not take place for every patient and their family members and if one was scheduled, it was in the week prior to

discharge. This finding is interesting especially since Lefebvre et al (2005) demonstrated that healthcare professionals believe that a lack of information can negatively affect the family members' ability to adapt to their new situation.

During these same meetings, family members were asked to make decisions; decisions they were required to make when the patients were not able to fully participate in decision making or the decisions implicated the family members, including decisions about living arrangements, home renovations, supervision for weekend passes, and equipment purchases. Again, this healthcare professional-led approach reflects the findings of D'Cruz et al (2016) and Levack et al (2009) who showed that family members are limitedly involved in decision making. Decisions made without families included, for example, care and therapy plans, rehabilitation goals, therapeutic strategies, and discharge date options. They also shed light on the findings of Lefebvre et al (2005) and the comments of Martone (2001) who described little to no family involvement in decision making in inpatient TBI rehabilitation. In fact, Lefebvre and colleagues (2005) revealed that most healthcare professionals who participated in their study did not believe that family members had the skills necessary to participate in rehabilitation decisions. It is possible that the findings of the present study are illustrative of this lack of belief in family members' skills.

My observations of activities and interactions relating to care and therapy brought interesting findings. While I named the category "Participating in care and therapy" because what I had observed reflected the specific ways in which the family members had described their involvement in care and therapy, the dominance of the healthcare professionals still overshadowed this process. The observations revealed that the family members attended therapy with the patients, observed the sessions, interacted with the patient, and tried to interact with the

healthcare professionals. However, the healthcare professionals interacted minimally with the family members and remained focused on the patients during the entirety of the sessions. At times, the family members were even physically excluded from the interactions as the healthcare professionals and patients interacted turned away from the family members.

These findings confirm that, despite many years of advocating for family-centred care in adult brain injury rehabilitation, still today patient-healthcare professional dyads remain the typical form of service delivery (Sohlberg et al., 2001). The healthcare professionals had described family involvement in care and therapy by their invitation to meet with them and learn the patients' care and therapy. Although I did not observe any instances of this teaching (and therefore did not name the category "Learning care and therapy"), it appeared it was because the healthcare professionals had decided that none needed to take place at that time. I did observe, however, discussions between healthcare professionals about the need to invite certain family members for teaching in preparation for discharge. This again reflects an individual treatment, expert-led perspective rather than a collaborative approach with meaningful interactions between family members and healthcare professionals (DePompei & Williams, 1994; Foster et al., 2012; Levack et al., 2009; Sohlberg et al., 2001).

Factors that potentially influenced family involvement. During Phase 1 interviews and in Phase 2 observations, family involvement was described as and appeared to be limited. In fact, I found family involvement to reflect the Information and Consultation levels of involvement (nil to low) of the HCQ framework (2012; see Chapter 2, page 22). This is something that researchers have not yet directly stated in the literature up to this point. Participants explained that family members were rarely present on the ward and that their participation in care and therapeutic processes was minimal. I also observed family members to be rarely present on the

ward and I did not observe any other forms of communication occurring between the healthcare professionals and family members (e.g., phone calls, note writing). To put the idea of limited family involvement into perspective, the findings of the present study revealed the following factors that potentially influenced the ways in which families were involved: (a) families' presence, (b) patients' perceptions of family involvement, (c) healthcare professionals' level of engagement with family members, and (d) the suitability of the environment for family involvement.

The participants' descriptions and my observations of the ways in which families were involved in adult inpatient TBI rehabilitation illustrated how family involvement could often depend on family members' ability to be physically present on the ward and during formal rehabilitation hours. Formal rehabilitation occurred Monday to Friday between the hours of 9am and 4pm; the potential influence this could have on the ways in which families were involved in the process becomes evident. In the present study, participants discussed family members' difficulties with coming to the rehabilitation centre during the daytime and/or work week because of their distance from the centre, their work schedule, or their need to care for young children at home. Fleming et al (2012) touch on this same idea by briefly explaining that family members, who were unable to be physically present during formal rehabilitation hours (also due to work or distance from centre), reported that they had difficulty accessing the healthcare professionals and felt uninformed, resulting in them feeling unable to support the patients. Recognizing that the distance from family homes to the rehabilitation centre can often make it difficult for family members to be physically present on a regular basis, Foster and colleagues (2012) outline how their institution recently made efforts in this regard to facilitate family involvement. They specifically created support teams that help link family members to nearby

housing and assist with transportation and they have implemented a new fee system to help with costs. This brings to light the need for inpatient rehabilitation services to come up with creative and innovative ways to facilitate family involvement in adult inpatient TBI rehabilitation, rather than rely entirely on family members' ability to be physically present on the ward.

The participants in Phase 1 interviews also highlighted how patients' own perceptions of family involvement in their rehabilitation could potentially influence the involvement of their family members. The findings of the present study revealed that patients sometimes perceived their family members' involvement as a burden on the family member, and thus felt upset about their family members being involved or believed that they wanted a break from being involved. Some also expressed how patients believed that their family members' involvement was helpful but not necessary, or did not want their family members involved at all. Recognizing that the present study was interested in the adult population where the patients were most often capable of acting as their own decision makers, this finding brings out the complexity of family involvement in an adult healthcare setting and the conflicts that may arise. Given that the goal of TBI rehabilitation is to improve functioning and help the adult patient to become independent of others, interventions as well as their evidence base typically focus solely on the individual with the injury (Levack et al., 2009). Allen and Petr (1998) discussed these complexities in family involvement previously and they recognized that healthcare professionals will continue to be challenged by the balancing act in patient-family member-healthcare professional triads. It is important to recognize these complexities and by understanding the issues that may arise, such as a patient not wanting their family member involved, healthcare professionals can be better guided in their efforts to facilitate family involvement (Levack et al., 2009).

Engaging family members more effectively in adult inpatient TBI rehabilitation is an idea that has arisen numerous times in the literature (Fleming et al., 2012; Foster et al., 2012; Kuipers et al., 2014; Lefebvre et al., 2005). Considering that it is important for healthcare professionals to engage families in the rehabilitation process to facilitate their involvement, this topic was common in participants' discussions in the present study about the ways in which families were involved. Many of the patients and family members in this study expressed how families believed that healthcare professionals did little to engage them to be involved in the rehabilitation process. I also observed little family engagement from the healthcare professionals during my observations, observing very little interaction between the healthcare professionals and family members. Reflecting the findings of Fleming and colleagues (2012), Lefebvre and colleagues (2005), and Kuipers and colleagues (2014), the participants in this study explained that they did not feel engaged by the healthcare professionals with respect to being able to access them, receiving consistent and complete information from them, being involved in decision making, taking the family members' opinions and information seriously, being involved in meetings, and being involved in the patients' care and therapy. It is possible that these issues influenced some of the ways in which the patients and family members described involvement: family members seeking information, helping the patients to make decisions, and initiating participation in care and therapy.

These findings provide support for Levack and colleagues' (2009) statement that "rehabilitation services in Western countries do not in fact prioritize the involvement of families nor empower family members to become active partners in the rehabilitation team" (p. 193). The findings of the present study are important to consider in relation to the findings of Lefebvre et al (2005) who showed that information that is incomplete and provided inconsistently makes family

members feel uncertain, ill-prepares them to adapt to their new situation, and negatively affects their relationships with the healthcare team. They equally showed that family members' relationships with healthcare professionals are affected when family members are not engaged by the healthcare team to participate in decision making. In remembering that family-centred care emphasizes the role of families in health care and recognizes their mutually beneficial partnership with healthcare professionals (Johnson, 1990; Law et al., 2003a), the findings of the present study represent a more fragmented approach to rehabilitation. That is, an approach where the families work with the patients on one hand and the healthcare professionals work with the patients on the other hand.

Moreover, family-centred care advocates focusing on families “strengths and capabilities” (Allen & Petr, 1998, p.9). In the present study, family members conveyed not feeling trusted or taken seriously by the healthcare professionals when they approached them to inform them about something and the healthcare professionals expressed family members being a barrier at times and also having to attend to them when issues arised, which demonstrates more of a focus on weaknesses and inabilities. Importantly, the family-centred literature advocates that family members have the right to “feel welcome and supported in the level of participation they choose” and in supporting this, healthcare professionals have the responsibility to “provide an environment that encourages the participation of family members” and “believe and trust [family members]” (Law et al., 2003a, p.4). We must acknowledge the low engagement experienced by patients and family members and observed in this study given that families are often left to cope with the care and rehabilitation of the patient with TBI after inpatient rehabilitation (Martone, 2001). We should aim to understand how to foster collaborative relationships and facilitate the engagement and involvement of family members.

The setting in which the present study took place is one of many to implement the Better Together: Partnering with Families campaign to promote more patient- and family-centred care by adopting a family presence policy. This policy essentially means that there are no longer specified visiting hours and families are now supposed to be welcome to come to the rehabilitation centre at any time. However, the findings of this study indicate that there are other structural issues, in addition to visiting hours, that could be helpful in promoting family-centred care. Space was one such potential issue. Firstly, patient rooms provided very little space for family members to visit and spend time with the patients. These rooms were also shared with other patients, potentially having an impact on privacy while family members visited. Second, the designated common patient areas, including the patient lounge and the television and game room, were not well utilized. The patient lounge served multiple purposes and the small television and game room was located in an inconspicuous area of the ward. These areas did not appear overly welcoming to family members, which could have potentially contributed to their lack of use. Fleming et al (2012) also brought up the issue of the setting in their research as participants in their study had negative perceptions of the rehabilitation environment due to the lack of space for patients and their family members.

This apparent lack of space for family members also translated into the therapy areas of the rehabilitation centre. In fact, I observed there to be no available seating for family members in the therapy areas with the exception of the waiting areas. The family members who were present during my observations had to take a chair that was available for the patients and healthcare professionals or sit on the equipment. It is possible that the lack of seating discouraged family members from going into the therapy areas with the patients. Recognizing the impact that the rehabilitation environment can have on the involvement of family members,

Foster et al (2012) discuss the design of their new facility, which they described as a “home-like setting that encourages families to visit and be together (p. 1858).”

There were other indications to family members that their presence on the unit might be superfluous. While the setting in which the present study took place had some photos of patients with their family members on the walls, the majority were of patients with healthcare professionals. There were also very little resources visibly available for family members. With the exception of some additional resources available through the social work office, the rehabilitation centre and inpatient ABI ward had only one resource geared to family members; a pamphlet for respite care. There were no indications in the physical environment that families were an important part of the inpatient rehabilitation process.

The issues discussed related to the inpatient rehabilitation setting as well as the level of engagement from the healthcare professionals reflect an environment in need of proper structures to support partnerships between patients, families, and healthcare professionals. While organizations are adopting and promoting a family-centred philosophy, it is important that they consider the organizational structures and the educational training necessary to properly operationalize and uphold this philosophy through family-centred care (Lefebvre et al., 2005). In fact, adopting a family-centred philosophy requires a change in culture for healthcare organizations and the professionals working within them (Chassin, 2013; Clay & Parsh, 2014; Johnson, 1999). Solhberg and colleagues (2001) also address the issue of organizations lagging behind when it comes to supporting these partnerships between patients, families, and healthcare professionals, explaining that the healthcare professionals are often left to come up with creative ways to facilitate involvement within the constraints of their settings. Lewandowski and Tesler (2003) put forward a guide to family-centred care with the goal of helping healthcare

organizations implement family-centred care in their settings. They discuss specific recommendations for putting family-centred care into action. The recommendations are: (1) to obtain baseline information, (2) seek stakeholder motivation and commitment, (3) establish working groups with clear vision, goals, and an evaluation plan, (4) identify and use target outcomes, and (5) identify barriers and facilitators (Lewandowski & Tesler, 2003). The present study acted as a stepping-stone to accomplishing recommendations 1 and 2 at the study site. By obtaining baseline information about family involvement and gauging stakeholders' motivations and commitments to family involvement through the conduct of this study, we are better positioned to operationalize a family-centred philosophy in this unique environment.

Contributions to Knowledge, Practice, and Methodology

In recent years, we have seen family-centred philosophy adopted by an increasing number of adult healthcare organizations. Recognizing the impact that this philosophy has on patient and family outcomes, the quality of health care, and patient safety, researchers are now interested in applying this philosophy to healthcare delivery with the adult population through family-centred care. However, research efforts have neglected to explore the concrete ways in which family members are currently involved in inpatient rehabilitation processes for adult patients with TBI. It is important to understand this involvement to guide the provision of family-centred health and rehabilitation services. This study is the first to explore this concept with the adult population and, as such, with this study, I extend knowledge and understanding of family involvement in several ways.

Despite recommendations for increased family involvement in health care, we knew little about how family members were involved in inpatient rehabilitation for adult patients with TBI. The literature in this area had thus far remained primarily theoretical, and only a handful of

studies have empirically examined this topic area and thus, more research is necessary to move from theory to practice. The present study was the first to explore family involvement with this patient population in the inpatient rehabilitation setting. In fact, this study specifically explored how family members were involved at one point in time in an adult inpatient TBI rehabilitation setting. By doing so, the present study allowed for a better understanding of this phenomenon in adult rehabilitation, as both an intervention and context. The study site is a pioneer in trying to understand family involvement in their complex setting. As such, the present study makes an important contribution to the growing body of research on family involvement in health care and builds on the very limited body of empirical research on family involvement specifically in adult inpatient TBI rehabilitation.

Research in this area has neglected the perspectives of adult patients with TBI and their families. As such, the present study also added to the limited amount of literature looking at family member perceptions of family involvement in adult inpatient TBI rehabilitation and elucidated for the first time the perceptions of patients on this topic. Given that adult patients are important stakeholders in their own rehabilitation, it is imperative to include their perspectives of the phenomenon. This study also contributes to the literature as it clearly delineates the similarities and differences in patients', family members', and healthcare professionals' perceptions of family involvement and the specific ways in which family members were involved, something that was not well articulated prior. There is still much to understand about family involvement in adult inpatient TBI rehabilitation, therefore, the present study acts as a catalyst to future research in this area, with an overall goal of developing a comprehensive understanding of family involvement in this setting.

The conceptual framework that I developed prior to commencing this study (see Conceptual Framework section in Chapter 2) not only informed each step of this study, but also illustrated for the first time the concepts that contributed to the state of knowledge and understanding of family involvement in adult inpatient TBI rehabilitation. This conceptual framework illustrated the limited nature of our knowledge and understanding of this phenomenon and illuminated the important need for research in this area. With the findings from the present study, I have revised this conceptual framework (Figure 14) to include the new and emergent ideas that contribute to our current knowledge and understanding of family involvement in adult inpatient TBI rehabilitation. This revised conceptual framework will play an important role in guiding future research in this area.

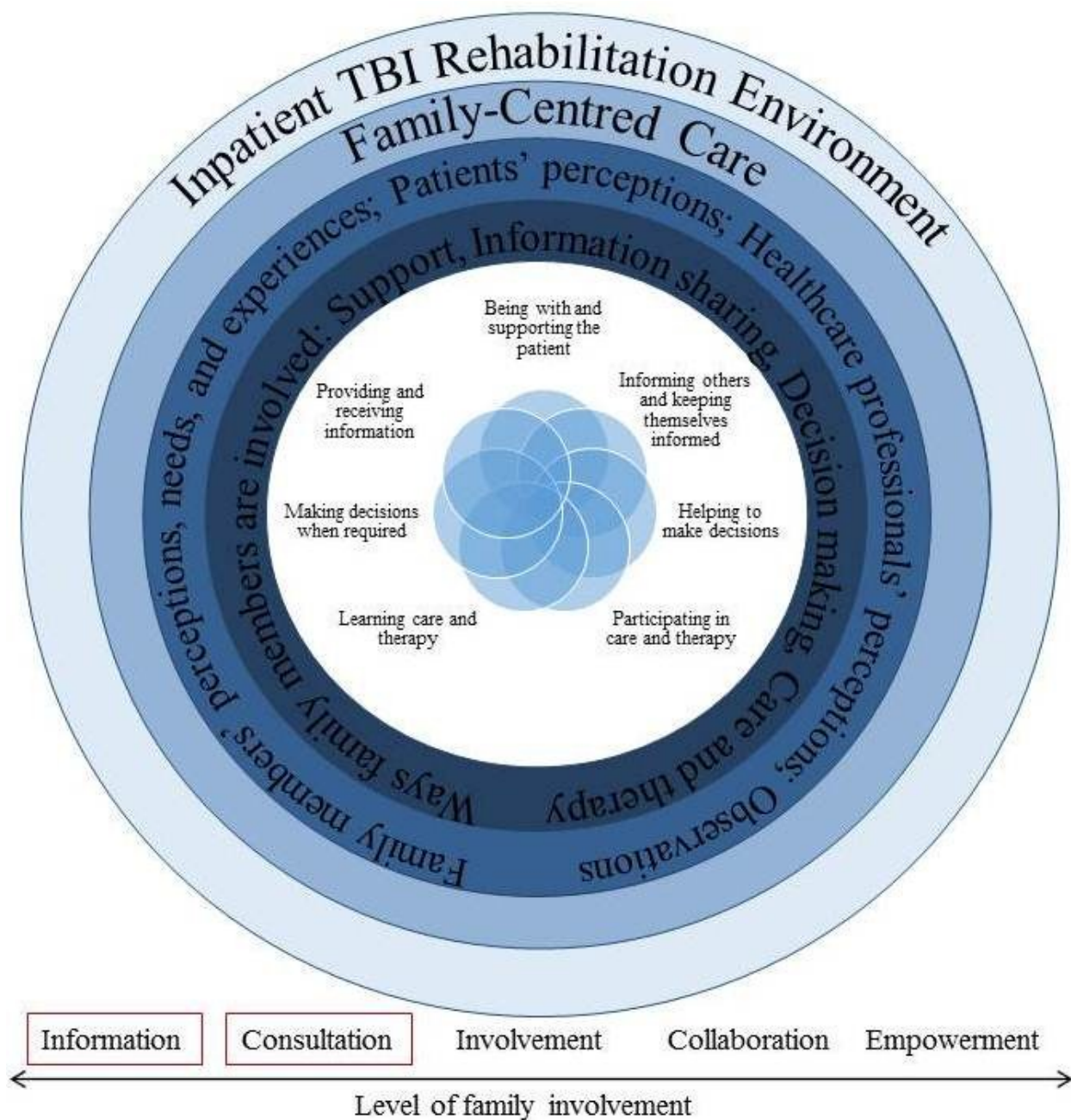


Figure 14. Visual diagram of the revised conceptual framework to inform future research.

The revised conceptual framework retains the concentric circles that were inspired by Bronfenbrenner's ecological model. These nested circles represent the various levels and factors of influence on family involvement, demonstrating the many interactions that occur between adult patients with TBI, their family, and the characteristics of the inpatient TBI environment.

Fittingly, the circular shapes also represent inclusivity as inspired and advocated by family-centred philosophy. The conceptual framework, which I believe will help further our understanding of family involvement, now consists of five primary components: (1) the ways family members were involved, (2) family perceptions, needs, and experiences, patient perceptions, healthcare professional perceptions, and observations (3) family-centred care, (4) the inpatient TBI rehabilitation environment, and (5) the level of family involvement. The outer layer of the framework represents the context in which these activities and interactions took place; inpatient TBI rehabilitation, and the environmental structures that potentially influenced family involvement; the setting and healthcare professional engagement. The second layer within the framework represents the approach to healthcare delivery that can facilitate family involvement; family-centred care. The middle layer of the framework represents the concepts in the literature as well as the findings of the present study that have contributed to our understanding thus far of family involvement in adult inpatient TBI rehabilitation; perceptions, needs, experiences, and direct observations. The interconnected circles represent the various ways family members were involved as presented in the theoretical and empirical literature and in the present study as well as the relationships between them. Finally, the double-headed arrow at the base of the circular diagram represents the level of family involvement evidenced in the present study.

The findings of the present study can also be used for professional development purposes and inform practice at the study site. Interestingly, it is possible that the simple occurrence of research can make an important contribution as stakeholders can sometimes make changes (e.g., in thinking, practice, structure) simply based on what was learned from the research process that took place in their setting. By improving our understanding of family involvement in the adult

inpatient TBI rehabilitation setting, this study also opens a dialogue about operationalizing a family-centred philosophy through family-centred care in this complex adult setting.

Importantly, with the findings from the present study as well as future research, the delivery of care and services can potentially be adapted in future, with the goal of improving the health and well-being of patients with TBI and their families.

The present study also contributes to methodology. Quantitative research remains the primary form of research conducted in the field of rehabilitation, but much like other areas in health care, qualitative research is becoming increasingly present as researchers begin to understand qualitative methods and recognize the benefits of this form of research (Parry, 2003). One area of research where researchers have utilized qualitative approaches pertains to family members and the rehabilitation of patients with brain injuries. So far, the few studies exploring the topic of families and brain injury rehabilitation have primarily drawn from a phenomenological approach (seeking to understand the complex meanings behind experiences), a grounded theory approach (seeking to develop a theory), or simply used qualitative interviews as a data collection method without an encompassing methodological approach (see Fleming et al., 2012; Foster et al., 2012; Ishikawa et al., 2011; Lefebvre et al., 2005; Levack et al., 2009). The present study was the first to use an interpretive qualitative approach to explore family involvement in this type of setting and provide a comprehensive description of it. This study was also the first to use observations as a data collection method to explore family involvement in this setting. I have shown, through the breadth of my findings, that an interpretive qualitative approach as well as an observational data collection method are feasible and beneficial in helping to understand the complex phenomenon of family involvement in inpatient TBI rehabilitation and advancing knowledge in this area of research and practice.

Strengths and Limitations of the Study

When considering the transferability of the present study's findings, one should note the study context, population of interest, and participants (see Research Context, Participants, and Participant characteristics sections of this thesis). It is equally important to consider the findings of this study within the context of its strengths and limitations. Specifically, the strengths and limitations of this study relate to recruitment and participant inclusion as well as data collection.

Recruitment and participant inclusion. This study explored family involvement in adult inpatient TBI rehabilitation. Therefore, patient recruitment in Phase 1 was limited to those with a primary diagnosis of TBI. While ABI is used as an “umbrella” term that encompasses many forms of brain injury and related causes, focusing solely on TBI allowed me to explore family involvement with a specific adult patient population. Specifically, TBI is most common among young and middle-aged adults (i.e., under the age of 60; CIHI, 2007); two age groups that allow for potential involvement from many different family members (e.g., parents, spouses, siblings, children, friends). Given the nature of the patients' injuries, the patients who participated in this study were limited to those who the rehabilitation team judged as capable of participating in an interview. It was important to establish this criterion for inclusion because, from an ethical standpoint, patients had to be capable and comfortable to participate in an interview. Unfortunately, however, this means that I excluded the perspectives of patients with more severe impairments.

The family members who participated in this study were also limited to those whose family member (i.e., the patient) had a primary diagnosis of TBI. As previously mentioned, this criterion allowed me to focus on family involvement with this specific patient population. The low number of family member participants in this study is a limitation. The site's admission rate

informed my recruitment and data collection. However, at the time of this study, the site experienced slow turnover, which affected the number of new admissions. Recruiting family members for the interviews was particularly challenging. While the healthcare professionals and patients were more easily accessible because of their regular presence on the ward, the family members were difficult to access. A healthcare professional within the circle-of-care had to first approach the family members. Once the healthcare professional was able to find the family members and obtain their verbal consent for me to approach them, I then had to find them on the ward or contact them if they had provided their contact information (i.e., phone number or e-mail). It was, however, difficult at times for the healthcare professional to find the family members if they were not present on the ward when the healthcare professional was present. It was also difficult for me to find the family members, as I rarely knew when they might be present on the ward. In addition, I was not always able to reach the family members via their contact information.

Difficulty recruiting family member participants could reflect several things. It is possible that family members were too busy to participate in the study given the circumstances, that family members were involved offsite, or that family members were involved onsite but around during later hours given the new 24-hour visiting policy. We should also consider that the study site often serves vulnerable individuals and therefore, family members may not have felt comfortable participating in an interview where I would ask them to share potentially negative details of their personal and care experiences. Unfortunately, language also became a limitation for recruitment in this study. Two patients and two family members decided not to participate in this study because they did not feel comfortable participating in an interview in English or in

French. Future studies could consider budgeting for an interpreter to ensure that all eligible patients and family members are included in the study.

While the number of family member participants is a limitation, the literature does not dictate a specific number of participants in qualitative studies. Patton (2015) stresses that qualitative research focuses on small samples in order to explore them in depth; sampling is purposeful rather than statistical. Varpio, Ajjawi, Monrouxe, O'Brien, and Rees (2017) further explain that qualitative research that is informed by theory and/or previous research, as the present study was, requires fewer participants than uninformed studies. Nevertheless, given the family focus of this study, I believe that my understanding of family involvement as well as the transferability of the study findings may have benefited from additional family members' perspectives.

Although I aimed to recruit, to the extent possible, healthcare professionals from varying disciplines, it was not possible to represent perspectives from all of the 11 healthcare disciplines present on the inpatient ABI team. However, the present study still provided the perspectives of healthcare professionals from seven different disciplines. Finally, it is important to note that the patients, family members, and healthcare professionals who participated in this study did so voluntarily by accepting my invitation to interview them. Therefore, it is difficult to know if those who participated had different perspectives from those who did not. It is possible that the participants in this study had a specific interest in this topic and thus, were more vocal and open about their perspectives and wanted to express them by participating in this study.

Data collection. For the present study, I collected data from one inpatient setting at an adult rehabilitation centre that is part of an academic hospital. It is possible that descriptions of family involvement will differ in other types and sizes of inpatient rehabilitation settings, such as

in-hospital rehabilitation units or independent rehabilitation institutions. I collected data using one-on-one semi-structured interviews and observations, each of which brings forth certain limitations.

The information that I gathered through interviews in Phase 1 of the study was based on participants' self-reports of their views on family involvement at one particular point in time. Nevertheless, the interviews allowed me to understand family involvement from the perspectives of those who had knowledge of and experience with family involvement. My presence in the interviews may have influenced participants' responses to the interview questions. For example, some may have changed their responses in order to present themselves or the centre in a more favorable way. My assurances, however, of the participants' anonymity hopefully encouraged them to answer openly and honestly during the interviews. The semi-structured nature of the interviews allowed me to focus the interviews with the aim of answering my research questions and thus, fulfill the aims of this study. However, it is possible that unstructured interviews could have elicited different and interesting information on the topic of family involvement. Further, the findings from participant interviews were based on my interpretation of the information gathered. Although I built in opportunity for participant verifications of the findings and interpretations, as mentioned in the Trustworthiness section of Phase 1, I did this in the preliminary stages of analysis and interpretation and not all participants agreed or were able to participate in the verification process. Even so, as recommended in qualitative research with a constructivist perspective, I positioned myself prior to commencing this study, acknowledging my prior experiences and positions. I continually reflected on what I was seeking to learn and what the data were telling me about it during analysis. I also regularly discussed my analysis and interpretation of the qualitative data with two research colleagues and obtained their feedback.

Similarly, the information I gathered through observations in Phase 2 of the study were based on my interpretation and understanding of the activities and interactions that I observed. Based on this interpretation and understanding, I decided what was relevant to record as field data. In the same line as the potential effect of my presence in the interviews, my presence during the activities and interactions that I observed may have influenced participants' behaviors. As such, during observation sessions, I adopted a *nonparticipant/observer as participant* relationship to prioritize my role as a researcher, remain unobtrusive, and maintain the quality of data recording (Creswell, 2013). This means that I remained an outsider to the participant group and recorded data from a distance. Although this distance benefited the quality of data recording, I recognize that it could have affected rapport with the participants I observed. We should also consider that the observations represent the activities and interactions that took place at one point in time and that I alone was able to observe. It is possible that I would have observed different things occurring at a different time. It is also possible that I missed activities and interactions related to family involvement when I was not present in the setting or in other spaces where I was not located during each observation session. I also did not observe activities outside of the rehabilitation centre where family involvement may have occurred with (e.g., monitoring patient on weekend passes) or without (e.g., managing patient's finances) the patient. However, I did ensure that I spent a prolonged period on the ward to account for this. That is, I spent approximately a month observing the setting.

Future Research

As the first step in a research program that is devoted to understanding family involvement in adult inpatient TBI rehabilitation, the present study elucidated how families were involved in this process. However, there remains much to understand about family involvement

in the rehabilitation of adult patients with TBI. Inpatient TBI rehabilitation is a unique and complex healthcare intervention and setting, and equally so is the involvement of family members in this process with the adult patient population, thus necessitating further research to fully understand this topic. The findings from the present study will contribute to the very limited body of empirical literature on this topic and thus, help form the foundation upon which to develop future studies in this area.

In 1989, Kreutzer and Marwitz brought forth the idea of family involvement in relation to family needs after TBI. Rotondi and colleagues (2007) and Keenan and Joseph (2010) later revisited this topic and identified involvement as an important factor in meeting family needs. However, these studies did not focus on exploring families' needs relative to their involvement in rehabilitation processes. As such, the literature on family involvement in adult inpatient TBI rehabilitation would benefit from further research in this area. Specifically, it would be important to understand if the types and levels of involvement illustrated in the present study meet family members' needs. It would also be interesting for us to understand how these types and levels of involvement meet or do not meet family members' needs. If we are not meeting families' needs, we should explore how we can better meet their needs and how we can improve family involvement in the adult inpatient TBI rehabilitation setting. I could ask, for example: (1) Do these types and levels of involvement meet family members' needs? (2) How do these types and levels of involvement meet or not meet family members' needs? (3) How can we better meet family members' needs? (4) How can we improve the involvement of family members? I could explore these potential research questions through quantitative and qualitative research methods. For example, I could answer the first question with a closed-ended survey of the extent to which needs are being met and the latter questions through qualitative exploration. Finally, recognizing

the critical role that healthcare professionals play in family involvement, we also need to understand the needs of healthcare professionals (e.g., organizational support, educational) to operationalize a family-centred philosophy and support family involvement in adult inpatient TBI rehabilitation. To explore this, I would design two two-phased sequential mixed-methods studies and ask, for example: (1) What are the needs of healthcare professionals to operationalize a family-centred philosophy into adult inpatient TBI rehabilitation? (2) What are the educational needs of healthcare professionals to operationalize a family-centred philosophy into adult inpatient TBI rehabilitation?

In conjunction with the exploration of needs in relation to family involvement in adult inpatient TBI rehabilitation, it would also be important to explore overall perceptions of family involvement. The findings of the present study demonstrated that patients/family members and healthcare professionals had differences in perceptions regarding the concrete ways in which families were involved. Previous work by Shaw et al (1997) also suggested differences in perceptions between family members and healthcare professionals about family involvement. Therefore, it would be important further explore perceptions of family involvement to better understand these differences and work towards a consensus on family involvement. Importantly, there are indications in the literature of factors that might impact how healthcare professionals involve families, including healthcare professionals' concerns about families being over involved (Shaw & McMahon, 1990) and their perceptions that families might lack the skills to contribute to decision making (Lefebvre et al., 2005). Further research in this area would allow us to add to the minimal amount of literature that currently exists by exploring patients', family members', and healthcare professionals' perceptions of appropriate and feasible family involvement; the factors that affect family involvement; and the barriers and facilitators to operationalizing a

family-centred philosophy through family-centred care. Research questions to explore these topics might include: (1) What are patients', family members', and healthcare professionals' perceptions of appropriate and feasible family involvement? (2) What are the factors that impact family involvement? (3) What are the barriers and facilitators to operationalizing a family-centred philosophy through family-centred care in adult inpatient TBI rehabilitation? Qualitative exploration would allow me to answer the first and second proposed research questions while a mixed-methods design would allow me to answer the third and fourth research question.

With an understanding of the types and levels of family involvement occurring in the adult inpatient TBI rehabilitation setting, as described in the present study, we can improve on previous research based entirely on theoretical literature, such as the development of measures of family involvement. In fact, the development of a tool to evaluate the level family involvement in this setting would be an important contribution. This evaluation tool would facilitate important research looking at the relationship between different types and levels of family involvement and patient and family outcomes. I might ask: What is the impact of different types and levels of family involvement on patient and family outcomes? As mentioned in the Discussion section, rehabilitation interventions for adult patients with TBI are typically individual in nature. Future research could then focus specifically on examining the impact of family involvement, of varying levels, in therapy on patient outcomes. A tool such as this would also allow us to compare the level of family involvement to healthcare professionals' level of family-centred care. More specifically, a future mixed-methods study could explore healthcare professionals' perceptions and understanding of family-centred care, measure their level of family-centred care using the MPOC-A (Bamm, Rosenbaum, & Stratford, 2010), and measure the level of family involvement in the setting.

Moving beyond the inpatient setting, future research should explore how family involvement evolves across the continuum of care for adult patients with TBI. Specifically, researchers can replicate the present study during the acute stage of recovery as well as during outpatient and community rehabilitation. This would allow us to gain an in-depth understanding of family involvement during the various stages of recovery after TBI and consider the ways in which family involvement might be similar or different during each stage. Also recognizing that rehabilitation is an important intervention for many physical illnesses and injuries (e.g., acquired brain injuries, spinal cord injuries, multiple sclerosis), it would be interesting to understand the ways in which family involvement in adult inpatient TBI rehabilitation is similar or different than that for adult patients with other physical illnesses or injuries. Researchers can explore similarities and differences in family involvement between this setting and other areas of health care where researchers have taken interest, such as cancer care.

Conclusion

Family-centred care extends across the age spectrum and through the process of care (Clay & Parsh, 2014). Research shows that family-centred care through the emphasis of active family involvement has a positive impact on patient and family outcomes. It also shows that healthcare professionals believe in family-centred care and family involvement. However, we still have much to understand about family involvement in adult inpatient TBI rehabilitation. This two-phased interpretive qualitative study elucidated for the first time how families were involved in the rehabilitation of adult patients with TBI, from the perspectives of patients, family members, and healthcare professionals. I used one-on-one interviews and observations to answer the following research questions: (1) In what ways are families involved in adult inpatient TBI rehabilitation? (2) What are the similarities and differences between patients', family members',

and healthcare professionals' perceptions of family involvement? and (3) What are the similarities and differences between patients', family members' and healthcare professionals' perceptions of family involvement and what is observed in practice?

In Phase 1 interviews, both the patients and family members described family members being with and supporting the patients, informing other family members as well as the healthcare professionals and keeping themselves informed, helping the patients to make decisions, and participating in care and therapy. The healthcare professionals similarly described family members being with and supporting the patients; however, they conversely illustrated family members' involvement as providing information to and receiving information from the healthcare professionals as well as making decisions when required or deemed necessary by them, and learning care and therapy. While the observation findings supported the patients', family members', and healthcare professionals' perceptions that family members support the patients by being present and spending time with them, they highlighted the healthcare professional-led nature of the rehabilitation process in the inpatient setting in relation to information sharing, decision making, and care and therapy. The findings of the present study also demonstrate that current family involvement in adult inpatient TBI rehabilitation is better categorized as moments of family involvement, rather than an integrated family-centred philosophy and approach to care (Poost-Foroosh, 2016).

I support the adoption of a family-centred philosophy in adult healthcare settings as I believe that family members can play an important role in health care, including the planning, delivery, and evaluation of healthcare services and the teaching and assessment of healthcare professionals. I also support the use of a family-centred approach to care in the adult inpatient rehabilitation setting for patients with TBI. This study revealed that patients and family members

had different understandings than healthcare professionals of the ways in which families were involved, and that overall family involvement was low. Recognizing that the adult population as well as the rehabilitation setting and process are unique and complex, I believe that family involvement in this setting could appropriately reach the Collaboration level of involvement of the HCQ framework (2012; see Chapter 2, page 22), where patients, family members, and healthcare professionals would work together in partnership. Involvement would be discussed and agreed upon by the patient, their family member(s), and healthcare professional(s) and would be unique to each family. Given the adoption of a family-centred philosophy, we need to understand how to operationalize it in this type of adult setting and close the gap between theory and practice. With this and future research, we will be better positioned to do so in this unique environment.

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Institute for Patient- and Family-Centered Care Framework

Core concepts	Description
Respect and dignity	Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
Information sharing	Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
Participation	Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
Collaboration	Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

Note. Adapted from “Patient- and family-centered care” by Institute for Patient- and Family-Centered Care, 2017a, retrieved from: <http://www.ipfcc.org/about/pfcc.html>

Premises, Principles, and Elements of Family-Centred Service

1 st Premise (basic assumption)		2 nd Premise (basic assumption)		3 rd Premise (basic assumption)	
Parents know their children best and want the best for their children.		Families are different and unique.		Optimal child functioning occurs within a supportive family and community context: The child is affected by the stress and coping of other family members.	
Guiding Principles ("should" statements)					
- Each family should have the opportunity to decide the level of involvement they wish in decision making for their child. - Parents should have ultimate responsibility for the care of their children.		Each family and family member should be treated with respect (as individuals).		- The needs of all family members should be considered. - The involvement of all family members should be supported and encouraged.	
Key Elements (rights and responsibilities)					
Expectations and Rights of Families	Service Provider Behaviours	Expectations and Rights of Families	Service Provider Behaviours	Expectations and Rights of Families	Service Provider Behaviours
- Be the ultimate decision makers. - Utilize their own resources. - Receive information which will enable them to make decisions about the care that will most effectively meet their needs. - Define the priorities of intervention. - Choose their level and type of involvement and the level of support they require. - Receive services with a minimum of hassle and in a timely manner. - Have access to information regarding their child and family.	- Encourage parent decision-making in partnership with other team members (to utilize family empowerment strategies.) - Assist families to identify their strengths and build their own resources. - Inform, answer, and advise parents (to encourage informed choices). - Work in partnership with parents and children and help them identify and prioritize their needs from their own perspective. - Collaborate with parents at all levels (care of the individual child; program development, implementation and evaluation; policy formation). - Provide accessible services that will not overwhelm families with paperwork and bureaucratic red tape. - Share complete information about the child's care on an ongoing basis.	- Maintain their dignity and integrity throughout the care-giving process - Be supported in the decisions that they make. - Have their opinions sought and to be listened to. - Receive individualized services.	- Respect the values, wishes and priorities of families. - Accept and support decisions made by families. - Listen. - Provide flexible and individualized services (and to respond to the changing needs of the family). - Be knowledgeable about and accept diversity among families (racial, ethnic, cultural and socio-economic). - Believe and trust parents. - Communicate in a language understandable by parents.	- Have their needs and concerns taken into account. - Feel welcome and supported in the level of participation they choose.	- Consider and be sensitive to the psychosocial needs of all family members. - Provide an environment that encourages the participation of all family members. - Respect the family's own style of coping without judging what is right and what is wrong. - Encourage family-to-family support and the use of natural community supports and resources. - Recognize and build on family and child strengths.

Note. From *FCS Sheet #01 – What is family-centred services?*, by M. Law et al., 2003b. Copyright 2003 by McMaster University: CanChild.

Patient English and French Interview Guides

PATIENT INTERVIEW GUIDE**Understanding family involvement in adult inpatient traumatic brain injury rehabilitation**

DATE: _____

TIME: _____

PARTICIPANT ID: _____

INTERVIEWER: _____

We recognize the important role that family members can play in traumatic brain injury rehabilitation. As such, with this interview, I want to understand how your family member(s) is/are involved in your rehabilitation.

To begin, I would like to ask you a few questions about yourself to provide some context for the interview.

Age: _____

Gender: _____

Household composition: _____

Employment status prior to injury: _____

1. Can you explain your injury to me?

Prompt: What type of injury do you have?

2. Can you explain to me why you are in rehabilitation?

Prompt: What rehabilitation services/therapies do you receive?

3. What healthcare professional(s) do you interact with most here at the Rehabilitation Centre?

Prompt: How often do you interact with this/these individual(s)?

4. Can you describe to me who your family is?

Prompt: Why do you consider these individuals to be your family?

5. What family member(s) is/are involved in your rehabilitation?

Prompt: Can you describe to me your relationship with [*the person(s) involved*]?

6. How has/have your family member(s) been involved in sharing information about you with your care team?

Prompt: Think about a time when your family member(s) was/were [*information sharing activity/interaction*]. What were they doing?

7. How has/have your family member(s) been involved in making decisions about your rehabilitation and care?

Prompt: Think about a time when your family member(s) was/were [*decision making activity/interaction*]. What were they doing?

8. How has/have your family member(s) been involved in setting goals for your rehabilitation?

Prompt: Think about a time when your family member(s) was/were [*goal setting activity/interaction*]. What were they doing?

9. How has/have your family member(s) been involved in planning your rehabilitation/therapy?

Prompt: Think about a time when your family member(s) was/were [*therapy planning activity/interaction*]. What were they doing?

10. How has/have your family member(s) been involved in your therapy?

Prompt: Think about a time when your family member(s) was/were [*therapy activity/interaction*]. What were they doing?

11. How has/have your family member(s) been involved in the planning of your discharge?

Prompt: Think about a time when your family member(s) was/were [*discharge planning activity/interaction*]. What were they doing?

12. How has/have your family member(s) been involved in meetings/conferences for your rehabilitation?

Prompt: Think about a time when your family member(s) was/were [*meeting activity/interaction*]. What were they doing?

13. How else has/have your family member(s) been involved in your rehabilitation?

Prompt: Think about a time when your family member(s) was/were [*other activity/interaction*]. What were they doing?

GUIDE D'ENTREVUE POUR LE PATIENT

L'engagement des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme crânio-cérébral

DATE: _____

HEURE: _____

NUMÉRO D'IDENTIFICATION: _____

INTERVIEWEUR: _____

Nous reconnaissons le rôle important que les membres de famille peuvent jouer dans la réadaptation pour les traumatismes crânio-cérébraux. À cet effet, avec cette entrevue, j'aimerais comprendre comment les membres de votre famille sont impliqués dans votre réadaptation.

Pour débiter, j'aimerais vous poser quelques questions sur vous-même afin de fournir une mise en situation pour l'entrevue.

Age: _____

Genre: _____

Composition du ménage: _____

Statut d'emploi avant l'accident: _____

1. Pouvez-vous m'expliquer votre blessure?

Indication: Quel genre de blessure avez-vous?

2. Pouvez-vous m'expliquer pourquoi vous êtes en réadaptation?

Indication: Quelles services/thérapies en réadaptation recevez-vous?

3. Avec quelle(s) professionnel(s) de la santé interagissez-vous le plus ici au centre de réadaptation?

Indication: Comment souvent interagissez-vous avec cet/ces individu(s)?

4. Pouvez-vous me décrire qui est votre famille?

Indication: Pourquoi vous considérez ces individus votre famille?

5. Quelle(s) membre(s) de votre famille est impliqué(s) dans votre réadaptation?

Indication: Pouvez-vous me décrire votre relation avec [*la personne impliquée*]?

6. De quelle façon est-ce que votre famille est impliquée dans le partage d'informations relatives à vous avec votre équipe de soins?

Indication: J'aimerais que vous réfléchissiez à un moment où votre famille était [*activité/interaction de partage d'informations*]. Que faisaient-ils?

7. De quelle façon est-ce que votre famille est impliquée dans la prise de décisions relatives à votre réadaptation et soins?

Indication: J'aimerais que vous réfléchissiez à un moment où votre famille était [*activité/interaction de prise de décisions*]. Que faisaient-ils?

8. De quelle façon est-ce que votre famille est impliquée dans l'établissement des objectifs relatifs à votre réadaptation?

Indication: J'aimerais que vous réfléchissiez à un moment où votre famille était [*activité/interaction d'établissement des objectifs*]. Que faisaient-ils?

9. De quelle façon est-ce que votre famille est impliquée dans la planification de votre réadaptation/thérapie?

Indication: J'aimerais que vous réfléchissiez à un moment où votre famille était [*activité/interaction de planification de thérapie*]. Que faisaient-ils?

10. De quelle façon est-ce que votre famille est impliquée dans votre thérapie?

Indication: J'aimerais que vous réfléchissiez à un moment où votre famille était [*activité/interaction de thérapie*]. Que faisaient-ils?

11. De quelle façon est-ce que votre famille est impliquée dans la planification de votre décharge?

Indication: J'aimerais que vous réfléchissiez à un moment où votre famille était [*activité/interaction de planification de décharge*]. Que faisaient-ils?

12. De quelle façon est-ce que votre famille est impliquée dans les rencontres/conférences relatives à votre réadaptation?

Indication: J'aimerais que vous réfléchissiez à un moment où votre famille était [*activité/interaction de rencontre*]. Que faisaient-ils?

13. Quelles autres façons est-ce que votre famille est impliquée dans votre réadaptation?

Indication: J'aimerais que vous réfléchissiez à un moment où votre famille était [*autre activité/interaction*]. Que faisaient-ils?

Family English and French Interview Guides

FAMILY INTERVIEW GUIDE**Understanding family involvement in adult inpatient traumatic brain injury rehabilitation**

DATE: _____

TIME: _____

PARTICIPANT ID: _____

INTERVIEWER: _____

We recognize the important role that family members can play in traumatic brain injury rehabilitation. As such, with this interview, I want to understand how you are involved in [*the patient's*] rehabilitation.

To begin, I would like to ask you a few questions about yourself to provide some context for the interview.

Age: _____

Gender: _____

Relationship to patient: _____

Household composition: _____

Employment status: _____

1. Can you explain [*the patient's*] injury to me?

Prompt: What type of injury does [*the patient*] have?

2. Can you explain to me why [*the patient*] is in rehabilitation?

Prompt: What rehabilitation services/therapies is [*the patient*] receiving?

3. What healthcare professional(s) do you interact with most here at the Rehabilitation Centre?

Prompt: How often do you interact with this/these individual(s)?

4. Can you describe to me who your family is?

Prompt: Why do you consider these individuals to be your family?

5. Can you describe to me your relationship with [*the patient*]?

6. Can you describe to me how you have been involved in sharing information about [*patient*]?

Prompt: I would like you to think about a time when you were involved in [*information sharing activity/interaction*]. What were you doing?

7. Can you describe to me how you have been involved in decision making for [*patient's*] rehabilitation and care?

Prompt: I would like you to think about a time when you were involved in [*decision making activity/interaction*]. What were you doing?

8. Can you describe to me how you have been involved in setting goals for [*patient's*] rehabilitation?

Prompt: I would like you to think about a time when you were involved in [*goal setting activity/interaction*]. What were you doing?

9. Can you describe to me how you have been involved in planning [*patient's*] rehabilitation/therapy?

Prompt: I would like you to think about a time when you were involved in [*therapy planning activity/interaction*]. What were you doing?

10. Can you describe to me how you have been involved in [*patient's*] therapy?

Prompt: I would like you to think about a time when you were involved in [*therapy activity/interaction*]. What were you doing?

11. Can you describe to me how you have been involved in the planning of [*patient's*] discharge?

Prompt: I would like you to think about a time when you were involved in [*discharge planning activity/interaction*]. What were you doing?

12. Can you describe to me how you have been involved in meetings/conferences for [*patient's*] rehabilitation?

Prompt: I would like you to think about a time when you were involved in [*meeting activity/interaction*]. What were you doing?

13. Can you describe to me other ways in which you have been involved in [*patient's*] rehabilitation?

Prompt: I would like you to think about a time when you were involved in [*other activity/interaction*]. What were you doing?

GUIDE D'ENTREVUE POUR LA FAMILLE

L'engagement des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral

DATE: _____

HEURE: _____

NUMÉRO D'IDENTIFICATION: _____

INTERVIEWEUR: _____

Nous reconnaissons le rôle important que les membres de famille peuvent jouer dans la réadaptation pour les traumatismes cranio-cérébraux. À cet effet, avec cette entrevue, j'aimerais comprendre comment vous êtes impliqué dans la réadaptation de [*le patient*].

Pour débiter, j'aimerais vous poser quelques questions sur vous-même afin de fournir une mise en situation pour l'entrevue.

Age: _____

Genre: _____

Relation avec le patient: _____

Composition du ménage: _____

Statut d'emploi: _____

1. Pouvez-vous m'expliquer la blessure de [*le patient*]?

Indication: Quel genre de blessure as-t-il [*le patient*]?

2. Pouvez-vous m'expliquer pourquoi [*le patient*] est en réadaptation?

Indication: Quelles services/thérapies en réadaptation reçoit-il [*le patient*]?

3. Avec quelle(s) professionnel(s) de la santé interagissez-vous le plus ici au centre de réadaptation?

Indication: Comment souvent interagissez-vous avec cet/ces individu(s)?

4. Pouvez-vous me décrire qui est votre famille?

Indication: Pourquoi vous considérez ces individus votre famille?

5. Pouvez-vous me décrire votre relation avec [*le patient*]?
6. Pouvez-vous me décrire la façon dont vous êtes impliqué dans le partage d'informations relatives à [*patient*]?

Indication: J'aimerais que vous réfléchissiez à un moment où vous étiez impliqué dans [*activité/interaction de partage d'informations*]. Que faisais-tu?

7. Pouvez-vous me décrire la façon dont vous êtes impliqué dans la prise de décisions relatives à la réadaptation et aux soins à [*patient*]?

Indication: J'aimerais que vous réfléchissiez à un moment où vous étiez impliqué dans [*activité/interaction de prise de décisions*]. Que faisais-tu?

8. Pouvez-vous me décrire la façon dont vous êtes impliqué dans l'établissement des objectifs relatifs à la réadaptation à [*patient*]?

Indication: J'aimerais que vous réfléchissiez à un moment où vous étiez impliqué dans [*activité/interaction d'établissement des objectifs*]. Que faisais-tu?

9. Pouvez-vous me décrire la façon dont vous êtes impliqué dans la planification de la réadaptation/thérapie à [*patient*]?

Indication: J'aimerais que vous réfléchissiez à un moment où vous étiez impliqué dans [*activité/interaction de planification de thérapie*]. Que faisais-tu?

10. Pouvez-vous me décrire la façon dont vous êtes impliqué dans la thérapie à [*patient*]?

Indication: J'aimerais que vous réfléchissiez à un moment où vous étiez impliqué dans [*activité/interaction de thérapie*]. Que faisais-tu?

11. Pouvez-vous me décrire la façon dont vous êtes impliqué dans la planification de la décharge à [*patient*]?

Indication: J'aimerais que vous réfléchissiez à un moment où vous étiez impliqué dans [*activité/interaction de planification de décharge*]. Que faisais-tu?

12. Pouvez-vous me décrire la façon dont vous êtes impliqué dans les rencontres/conférences pour la réadaptation à [*patient*]?

Indication: J'aimerais que vous réfléchissiez à un moment où vous étiez impliqué dans [*activité/interaction de rencontre*]. Que faisais-tu?

13. Pouvez-vous me décrire autres façons dont vous êtes impliqué dans la réadaptation à [*patient*]?

Indication: J'aimerais que vous réfléchissiez à un moment où vous étiez impliqué dans [*autre activité/interaction*]. Que faisais-tu?

Healthcare Professional English and French Interview Guides

HEALTHCARE PROFESSIONAL INTERVIEW GUIDE**Understanding family involvement in adult inpatient traumatic brain injury rehabilitation**

DATE: _____

TIME: _____

PARTICIPANT ID: _____

INTERVIEWER: _____

We recognize the important role that family members can play in traumatic brain injury rehabilitation. As such, with this interview, I want to understand how family members are involved in the patients' rehabilitation.

To begin, I would like to ask you a few questions about yourself to provide some context for the interview.

Age: _____

Gender: _____

Position at [rehabilitation centre]: _____

Amount of experience: _____

Length of time at [rehabilitation centre]: _____

Time allocated to ABI team: _____

1. Who do you interact with most on the rehabilitation team?

Prompt: How often do you interact with this/these individual(s)?

2. What family members are involved in rehabilitation for patients with TBI?

Prompt: Who is most often involved in rehabilitation for patients with TBI?

3. Can you describe to me how family members are involved in sharing information about the patients?

Prompt: I would like you to think about a time when family members were involved in [*information sharing activity/interaction*]. What were they doing?

4. Can you describe to me how family members have been involved in decision making for the patients' rehabilitation and care?

Prompt: I would like you to think about a time when family members were involved in [*decision making activity/interaction*]. What were they doing?

5. Can you describe to me how family members have been involved in setting goals for the patients' rehabilitation?

Prompt: I would like you to think about a time when family members were involved in [*goal setting activity/interaction*]. What were they doing?

6. Can you describe to me how family members have been involved in planning the patients' rehabilitation/therapy?

Prompt: I would like you to think about a time when family members were involved in [*therapy planning activity/interaction*]. What were they doing?

7. Can you describe to me how family members have been involved in the patients' therapy?

Prompt: I would like you to think about a time when family members were involved in [*therapy activity/interaction*]. What were they doing?

8. Can you describe to me how family members have been involved in planning the patients' discharge?

Prompt: I would like you to think about a time when family members were involved in [*discharge planning activity/interaction*]. What were they doing?

9. Can you describe to me how family members have been involved in meetings/conferences for the patients' rehabilitation?

Prompt: I would like you to think about a time when family members were involved in [*meeting activity/interaction*]. What were they doing?

10. Can you describe to me other ways in which family members have been involved in the patients' rehabilitation?

Prompt: I would like you to think about a time when family members were involved in [*other activity/interaction*]. What were they doing?

GUIDE D'ENTREVUE POUR LES PROFESSIONNELS DE LA SANTÉ

L'engagement des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral

DATE: _____

HEURE: _____

NUMÉRO D'IDENTIFICATION: _____

INTERVIEWEUR: _____

Nous reconnaissons le rôle important que les membres de la famille peuvent jouer dans la réadaptation pour les traumatismes cranio-cérébraux. À cet effet, avec cette entrevue, j'aimerais comprendre comment les membres de la famille sont impliqués dans la réadaptation des patients.

Pour débiter, j'aimerais vous poser quelques questions sur vous-même afin de fournir une mise en situation pour l'entrevue.

Age: _____

Genre: _____

Position au [centre de réadaptation]: _____

Montant d'expérience: _____

Longueur de temps au [centre de réadaptation]: _____

Temps alloué à l'équipe de LCA: _____

1. Avec qui interagissez-vous le plus souvent sur l'équipe de réadaptation?

Indication: Comment souvent interagissez-vous avec cet/ces individu(s)?

2. Quels membres de famille sont impliqués dans la réadaptation des patients avec TCC?

Indication: Qui est le plus souvent impliqué dans la réadaptation des patients avec TCC?

3. Pouvez-vous me décrire la façon dont les familles sont impliquées dans le partage d'informations relatives aux patients?

Indication: J'aimerais que vous réfléchissiez à un moment où des membres de famille étaient impliqués dans [*activité/interaction de partage d'informations*]. Que faisaient-ils?

4. Pouvez-vous me décrire la façon dont les familles sont impliquées dans la prise de décisions relatives à la réadaptation et aux soins des patients?

Indication: J'aimerais que vous réfléchissiez à un moment où des membres de famille étaient impliqués dans [*activité/interaction de prise de décisions*]. Que faisaient-ils?

5. Pouvez-vous me décrire la façon dont les familles sont impliquées dans l'établissement des objectifs relatifs à la réadaptation des patients?

Indication: J'aimerais que vous réfléchissiez à un moment où des membres de famille étaient impliqués dans [*activité/interaction d'établissement des objectifs*]. Que faisaient-ils?

6. Pouvez-vous me décrire la façon dont les familles sont impliquées dans la planification de la réadaptation/thérapie des patients?

Indication: J'aimerais que vous réfléchissiez à un moment où des membres de famille étaient impliqués dans [*activité/interaction de planification de thérapie*]. Que faisaient-ils?

7. Pouvez-vous me décrire la façon dont les familles sont impliquées dans la thérapie des patients?

Indication: J'aimerais que vous réfléchissiez à un moment où des membres de famille étaient impliqués dans [*activité/interaction de thérapie*]. Que faisaient-ils?

8. Pouvez-vous me décrire la façon dont les familles sont impliquées dans la planification de la décharge des patients?

Indication: J'aimerais que vous réfléchissiez à un moment où des membres de famille étaient impliqués dans [*activité/interaction de planification de décharge*]. Que faisaient-ils?

9. Pouvez-vous me décrire la façon dont les familles sont impliquées dans les rencontres/conférences pour la réadaptation des patients?

Indication: J'aimerais que vous réfléchissiez à un moment où des membres de famille étaient impliqués dans [*activité/interaction de rencontre*]. Que faisaient-ils?

10. Pouvez-vous me décrire autres façons dont les familles sont impliquées dans la réadaptation des patients?

Indication: J'aimerais que vous réfléchissiez à un moment où des membres de famille étaient impliqués dans [*autre activité/interaction*]. Que faisaient-ils?

English and French Scripts for First Contact

Script for First Contact

A PhD student in the Rehabilitation Sciences program at the University of Ottawa is doing a research study on traumatic brain injury rehabilitation. The goal of this study is to understand how families are involved in adult inpatient traumatic brain injury rehabilitation.

This study is voluntary. If you decide not to take part in the study, it will not have any effect on the health care or other services that you receive at this hospital or your employment at this hospital.

Would you be interested in meeting with the student to hear more about this study?

If YES,

Patient: May I give your name and room number to the student so she can set up a time to meet with you and give you more information on the study?

Family member: May I give your name and phone number to the student so she can set up a time to meet with you and give you more information on the study?

Healthcare professional: May I give your name and e-mail address to the student so she can set up a time to meet with you and give you more information on the study?

Lignes Directrices pour Premier Contact

Une étudiante au doctorat en sciences de réadaptation à l'université d'Ottawa fait une étude portant sur la réadaptation des adultes ayant subi un traumatisme cranio-cérébral. Le but de cette étude est de comprendre comment les familles sont impliquées dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral.

Cette étude est volontaire. Si vous décidez de ne pas participer dans l'étude, ceci n'aura aucun effet sur les services de santé ou autres services que vous recevez à cet hôpital ou votre statut d'emploi à cet hôpital.

Seriez-vous intéressé à rencontrer l'étudiante afin d'en savoir davantage sur ce projet?

Si OUI,

Patient: Puis-je donner votre nom et votre numéro de chambre à l'étudiante en question afin qu'elle puisse mettre en place un temps pour vous rencontrer et vous donner des informations supplémentaires sur l'étude?

Membre de famille: Puis-je donner votre nom et votre numéro de téléphone à l'étudiante en question afin qu'elle puisse mettre en place un temps pour vous rencontrer et vous donner des informations supplémentaires sur l'étude?

Professionnel de la santé: Puis-je donner votre nom et votre adresse courriel à l'étudiante en question afin qu'elle puisse mettre en place un temps pour vous rencontrer et vous donner des informations supplémentaires sur l'étude?

Patient English and French Consent Forms for Interview

PARTICIPANT INFORMED CONSENT FORM**Understanding family involvement in adult inpatient traumatic brain injury rehabilitation**

Local Site Principal Investigator (PI): [insert name and contact information]

Research Team:

Kaylee Eady, PhD(c), School of Rehabilitation Sciences, Faculty of Health Sciences, University of Ottawa

Mary Egan, PhD OT Reg. (Ont.), Supervisor, School of Rehabilitation Sciences, Faculty of Health Sciences, University of Ottawa

Funding: This study is not funded.

Please read this Participant Informed Consent Form carefully before you decide if you would like to participate. You may ask a member of the study team as many questions as you like.

Why am I being given this form?

You are being asked to participate in this study because you have a traumatic brain injury and you are in the Acquired Brain Injury program at [the rehabilitation centre]. We are interested in understanding how families are involved in adult inpatient traumatic brain injury rehabilitation.

Why is this study being done?

Families play an important role in adult inpatient traumatic brain injury rehabilitation, but we don't yet understand how families are involved. Findings from this study will help us better understand family involvement in adult inpatient traumatic brain injury rehabilitation.

How is the study designed?

The student will conduct interviews with patients, family members, and members of the healthcare team. The interviews will be conducted in a quiet and private room on the Acquired Brain Injury ward of [the rehabilitation centre]. The student will audio-record and type the interviews for analysis later on. At the end of this form, you will have the option to agree or disagree to being audio-recorded.

What is expected of me?

You will be asked to do one interview. During this interview, you will be asked to describe how your family is involved in your rehabilitation. The interview will be done about one week before your discharge from the Acquired Brain Injury ward of [the rehabilitation centre]. It will last

about 30 minutes. The interview will be done at a time that is most convenient for you. Depending on your preference, the interview can be done either in English or in French.

How long will I be involved in the study?

The entire study will last about 1 year. However, your participation in the study will last for the duration of the interview, about 30 minutes.

Your participation in the study may be stopped for any of the following reasons:

- The study team feels it is in your best interest.
- You have been unable to follow the study team's instructions.

What are the potential risks I may experience?

You may find the interview tiring. If you feel at all tired, you may ask that the interview be stopped at any time or rescheduled. You may tell the student if you do not want to answer a specific question or if you feel uncomfortable.

Can I expect to benefit from participating in this research study?

You will not receive any direct benefit from your participation in this study. However, this study will help us begin to understand family involvement in adult inpatient traumatic brain injury rehabilitation. This may help future patients and families.

Do I have to participate? What alternatives do I have? If I agree now, can I change my mind and withdraw later?

Your participation in this study is voluntary. The alternative is to not participate.

You may decide not to be in this study, or to be in the study now, and then change your mind later without affecting the health care or other services that you are receiving at this institution. If you withdraw your consent, the study team will no longer collect your personal identifying information for research purposes.

Will I be paid for my participation or will there be any additional costs to me?

You will not be paid to participate in this study. There will be no added costs by participating in this study.

How is my personal information being protected?

- All information collected during your participation in this study will be identified with a unique study number, and will not contain information that identifies you, such as your name, address, etc.

- The link between your unique study number and your name and contact information will be stored securely and separate from your study records, and will not leave this site.
- Any documents leaving [the rehabilitation centre] will contain only your unique study number. This includes publications or presentations resulting from this study.
- Information that identifies you will be released only if it is required by law.
- For audit purposes only, your original study records may be reviewed, under the supervision of [insert name of local site principal investigator], by representatives from:
 - the [academic hospital's] Research Ethics Board,
 - the [academic hospital's] Research Institute,
 - the [local university's] Research Ethics Board.
- Research records will be kept for 10 years, after this time they will be destroyed.

Who do I contact if I have any further questions?

If you have any questions about this study, or if you feel that you have experienced a study-related injury or illness, please contact [insert name and contact information of local site principal investigator]. You may also contact Kaylee Eady, the PhD student, at [insert contact information].

The [academic hospital's] Research Ethics Board has reviewed this protocol. The Board considers the ethical aspects of all research studies involving human participants at [the academic hospital]. If you have any questions about your rights as a study participant, you may contact the Chairperson at [insert contact information].

Understanding family involvement in adult inpatient traumatic brain injury rehabilitation

Consent to Participate in Research

- I understand that I am being asked to participate in a research study about family involvement in adult inpatient traumatic brain injury rehabilitation
- This study was explained to me by _____.
- I have read, or have had it read to me, each page of this Participant Informed Consent Form.
- All of my questions have been answered to my satisfaction.
- If I decide later that I would like to withdraw my participation and/or consent from the study, I can do so at any time.
- I voluntarily agree to participate in this study.
- I will be given a copy of this signed Participant Informed Consent Form.

I agree to be audio-recorded. Yes ☐ No ☐ Initials ____

Participant's Printed Name

Participant's Signature

Date

Investigator or Delegate Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Investigator/Delegate's Printed Name

Investigator/Delegate's Signature

Date

Assistance Declaration

Was the participant assisted during the consent process? ☐ Yes ☐ No

☐ The consent form was read to the participant/substitute decision-maker, and the person signing below attests that the study was accurately explained to, and apparently understood by, and consent was freely given by the participant/substitute decision-maker.

☐ The person signing below acted as a translator for the participant/substitute decision-maker during the consent process. He/she attests that they have accurately translated the information for the participant/substitute decision-maker, and believe that the participant/substitute decision-maker has understood the information translated.

Printed Name of Person Assisting

Signature

Date

FORMULAIRE DE CONSENTEMENT

L'engagement des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral

Chercheur principal: [Insérer le nom et les coordonnées]

Équipe de recherche:

Kaylee Eady, PhD(c), École des Sciences de la Réadaptation, Faculté des Sciences de la Santé, Université d'Ottawa

Mary Egan, PhD OT Reg. (Ont.), Superviseure, École des Sciences de la Réadaptation, Faculté des Sciences de la Santé, Université d'Ottawa

Financement: Cette étude n'est pas financée.

Veillez s'il vous plaît lire ce formulaire de consentement attentivement avant de confirmer votre participation. Vous pouvez demander à un membre de l'équipe de recherche autant de questions que vous le souhaitez.

Pourquoi suis-je donnée ce formulaire?

Vous êtes invité à participer à cette étude puisque vous avez subi un traumatisme cranio-cérébral et vous êtes dans le programme pour lésions cérébrales acquises au [centre de réadaptation]. Nous sommes intéressé à comprendre comment les familles sont impliquées dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral.

Pourquoi cette étude est-elle menée?

Les familles jouent un rôle important dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral, mais nous ne comprenons pas comment les familles sont impliquées. Les résultats de cette étude nous aideront à mieux comprendre l'implication des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral.

Comment l'étude est-elle conçue?

L'étudiante mènera une entrevue avec les patients, les membres de la famille, et les membres de l'équipe de soins. Les entrevues se dérouleront dans un endroit calme et privé sur le pavillon pour lésions cérébrales acquises au [centre de réadaptation]. L'étudiante enregistrera et transcrira les entrevues pour l'analyse plus tard. À la fin de ce formulaire, vous aurez l'option d'accepter ou ne pas d'être enregistré.

Qu'attend-on de moi?

Vous seriez invité à faire une entrevue. Durant cette entrevue, vous seriez demandé de décrire comment votre famille est impliquée dans votre réadaptation. Cette entrevue aura lieu environ une semaine avant votre décharge du pavillon pour lésions cérébrales acquises au [centre de réadaptation]. Celle-ci durera environ 30 minutes. L'entrevue sera menée à un moment qui vous convient le mieux. Selon vos préférences, l'entrevue peut être dirigée soit en anglais ou en français.

Combien de temps vais-je être impliqué dans l'étude?

L'étude complète étendra sur une durée d'environ 1 an. Cependant, votre participation à l'étude durera le temps de l'entrevue, environ 30 minutes.

Votre participation à cette étude peut être arrêtée pour une des raisons suivantes :

- L'équipe de recherche croît qu'il est dans votre meilleur intérêt.
- Vous avez été incapable de suivre les instructions de l'équipe de recherche.

Quels sont les risques potentiels que je peux rencontrer?

Vous trouverez peut-être l'entrevue fatigante. Si vous vous sentez fatigué, vous pouvez demander que l'entrevue soit arrêtée à n'importe quel moment ou reporter. Vous pouvez aviser l'étudiante si vous ne souhaitez pas répondre à une question spécifique ou si vous vous sentez mal à l'aise.

Puis-je espérer bénéficier de participer à cette étude?

Vous ne recevrez aucun avantage direct de votre participation à cette étude. Cependant, cette étude nous aidera à comprendre l'implication des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral. Cela pourra aider de futurs patients et familles.

Dois-je participer? Quelles sont les alternatives? Si je suis d'accord maintenant, est-ce que je peux changer d'avis et me retirer plus tard?

Votre participation à cette étude est volontaire. L'option alternative serait de ne pas y participer.

Vous pouvez décider de ne pas participer à cette étude, ou d'y participer maintenant, et changer votre avis plus tard sans impact sur les services de santé ou autres services que vous recevez à cette institution. Si vous retirez votre consentement, l'équipe de recherche ne recueillera plus vos informations d'identification personnelle pour fins de recherche.

Serai-je payé pour ma participation ou est-ce qu'il y aura des coûts supplémentaire pour moi?

Vous ne serez pas payé pour participer à cette étude. Il n'y aura aucun coût supplémentaire en participant à cette étude.

Comment mes renseignements personnels sont-ils protégés?

- Toutes informations recueillis durant votre participation à cette étude seront identifiées avec un numéro d'étude unique, et ne contiendra aucune information qui vous identifie, tel que votre nom, adresse, etc.
- Le lien entre votre numéro d'étude unique et votre nom et vos coordonnées sera gardé en toute sécurité et séparé de vos données, et ne quittera pas ce site.
- Tous les documents qui quittent le [centre de réadaptation] contiendront seulement votre numéro d'étude unique. Ceci inclus les publications ou présentations résultant de cette étude.
- L'information qui vous identifie ne sera libérée que si elle est requise par la loi.
- À des fins de vérification, vos documents de recherche originaux peuvent être examinés, sous la supervision du personnel à [insérer le nom du chercheur principal], par des représentants du:
 - comité d'éthique en recherche de [l'hôpital universitaire],
 - Institut de recherche de [l'hôpital universitaire],
 - comité d'éthique en recherche de [l'université].
- Les documents de recherche seront conservés pendant 10 ans, à la fin de cette période ils seront détruits.

Qui dois-je contacter si j'ai d'autres questions?

Si vous avez des questions supplémentaires au sujet de cette étude, ou si vous croyez que vous avez subi une blessure ou une maladie en lien avec l'étude, veuillez communiquer avec [insérer le nom et les coordonnées du chercheur principal]. Vous pouvez également communiquer avec Kaylee Eady, l'étudiante au doctorat, au [insérer les coordonnées].

Le Comité d'éthique en recherche de [l'hôpital universitaire] a examiné ce protocole. Le comité considère les aspects éthiques de toutes les études en recherche impliquant des participants humains à [l'hôpital universitaire]. Si vous avez des questions concernant vos droits en tant que participant à l'étude, vous pouvez contacter le président, au [insérer les coordonnées].

L'engagement des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral

Consentement de participation dans la recherche

- Je comprends qu'on me demande de participer à une étude de recherche portant sur l'implication des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral.
- Cette étude m'a été expliquée par _____.
- J'ai lu, ou on m'a lu, chaque page du formulaire de consentement.
- Toutes mes questions ont été répondues à ma satisfaction.
- Si je décide plus tard que je voudrais retirer ma participation et/ou le consentement de l'étude, je peux le faire à tout moment.
- Je suis d'accord de participer volontairement à cette étude.
- Je recevrai une copie de ce formulaire de consentement éclairé.

J'accepte d'être enregistré. Oui ☐ Non ☐ Initiales ____

Nom imprimé du participant

Signature du participant

Date

Déclaration du chercheur ou du délégué

J'ai expliqué attentivement l'étude au participant de l'étude. Selon mes connaissances, le participant comprend la nature, les exigences, les risques ainsi que les avantages découlant de la participation à cette étude.

Nom imprimé du chercheur/délégué

Signature du chercheur/délégué

Date

Déclaration d'assistance

Est-ce que le participant a été assisté durant le processus de consentement? ☐ Oui ☐ Non

☐ Le formulaire de consentement a été lu au participant/mandataire, et la personne signant ci-dessous atteste que l'étude a été expliqué avec précision au, et apparemment compris par, et le consentement a été volontairement donné par le participant/mandataire.

☐ La personne signant ci-dessous a agi comme traducteur pour le participant/mandataire durant le processus de consentement. Il/elle atteste qu'il/elle a traduit avec précision l'information pour le participant/mandataire, et croit que le participant/mandataire a compris l'information traduit.

Nom imprimé de la personne qui assiste

Signature

Date

Family English and French Consent Forms for Interview

PARTICIPANT INFORMED CONSENT FORM

Understanding family involvement in adult inpatient traumatic brain injury rehabilitation

Local Site Principal Investigator (PI): [insert name and contact information]

Research Team:

Kaylee Eady, PhD(c), School of Rehabilitation Sciences, Faculty of Health Sciences, University of Ottawa

Mary Egan, PhD OT Reg. (Ont.), Supervisor, School of Rehabilitation Sciences, Faculty of Health Sciences, University of Ottawa

Funding: This study is not funded.

Please read this Participant Informed Consent Form carefully before you decide if you would like to participate. You may ask a member of the study team as many questions as you like.

Why am I being given this form?

You are being asked to participate in this study because you have a family member who has a traumatic brain injury and is in the Acquired Brain Injury program at [the rehabilitation centre]. We are interested in understanding how families are involved in adult inpatient traumatic brain injury rehabilitation.

Why is this study being done?

Families play an important role in adult inpatient traumatic brain injury rehabilitation, but we don't yet understand how families are involved. Findings from this study will help us better understand family involvement in adult inpatient traumatic brain injury rehabilitation.

How is the study designed?

The student will conduct one-on-one semi-structured interviews with patients, family members, and members of the healthcare team. The interviews will be conducted in a quiet and private room on the inpatient Acquired Brain Injury ward of [the rehabilitation centre]. The student will audio-record and type the interviews for analysis later on. At the end of this form, you will have the option to agree or disagree to being audio-recorded.

What is expected of me?

You will be asked to do one interview. During this interview, you will be asked to describe how you are involved in the patient's rehabilitation. The interview will be done about one week

before the patient's discharge from the inpatient Acquired Brain Injury ward of [the rehabilitation centre]. It will last about 60 minutes. The interview will be done at a time that is most convenient for you. Depending on your preference, the interview can be done either in English or in French.

How long will I be involved in the study?

The entire study will last about 1 year. However, your participation in the study will last for the duration of the interview, about 60 minutes.

Your participation in the study may be stopped for any of the following reasons:

- The study team feels it is in your best interest.

What are the potential risks I may experience?

You may find the interview tiring. If you feel at all tired, you may ask that the interview be stopped at any time or rescheduled. You may tell the student if you do not want to answer a specific question or if you feel uncomfortable.

Can I expect to benefit from participating in this research study?

You will not receive any direct benefit from your participation in this study. However, this study will help us begin to understand family involvement in adult inpatient traumatic brain injury rehabilitation. This may help future patients and families.

Do I have to participate? What alternatives do I have? If I agree now, can I change my mind and withdraw later?

Your participation in this study is voluntary. The alternative is to not participate.

You may decide not to be in this study, or to be in the study now, and then change your mind later without affecting the health care or other services that you are receiving at this institution.

If you withdraw your consent, the study team will no longer collect your personal identifying information for research purposes.

Will I be paid for my participation or will there be any additional costs to me?

You will not be paid to participate in this study. There will be no added costs by participating in this study.

How is my personal information being protected?

- All information collected during your participation in this study will be identified with a unique study number, and will not contain information that identifies you, such as your name, address, etc.
- The link between your unique study number and your name and contact information will be stored securely and separate from your study records, and will not leave this site.
- Any documents leaving [the rehabilitation centre] will contain only your unique study number. This includes publications or presentations resulting from this study.
- Information that identifies you will be released only if it is required by law.
- For audit purposes only, your original study records may be reviewed, under the supervision of [insert name of local site principal investigator], by representatives from:
 - the [academic hospital's] Research Ethics Board,
 - the [academic hospital's] Research Institute,
 - the [local university's] Research Ethics Board.
- Research records will be kept for 10 years, after this time they will be destroyed.

Who do I contact if I have any further questions?

If you have any questions about this study, or if you feel that you have experienced a study-related injury or illness, please contact [insert name and contact information of local site principal investigator]. You may also contact Kaylee Eady, the PhD student, at [insert contact information].

The [academic hospital's] Research Ethics Board has reviewed this protocol. The Board considers the ethical aspects of all research studies involving human participants at [the academic hospital]. If you have any questions about your rights as a study participant, you may contact the Chairperson at [insert contact information].

Understanding family involvement in adult inpatient traumatic brain injury rehabilitation

Consent to Participate in Research

- I understand that I am being asked to participate in a research study about family involvement in adult inpatient traumatic brain injury rehabilitation
- This study was explained to me by _____.
- I have read, or have had it read to me, each page of this Participant Informed Consent Form.
- All of my questions have been answered to my satisfaction.
- If I decide later that I would like to withdraw my participation and/or consent from the study, I can do so at any time.
- I voluntarily agree to participate in this study.
- I will be given a copy of this signed Participant Informed Consent Form.

I agree to be audio-recorded. Yes ☐ No ☐ Initials _____

Participant's Printed Name

Participant's Signature

Date

Investigator or Delegate Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Investigator/Delegate's Printed Name

Investigator/Delegate's Signature

Date

Assistance Declaration

Was the participant assisted during the consent process? ☐ Yes ☐ No

☐ The consent form was read to the participant/substitute decision-maker, and the person signing below attests that the study was accurately explained to, and apparently understood by, and consent was freely given by the participant/substitute decision-maker.

☐ The person signing below acted as a translator for the participant/substitute decision-maker during the consent process. He/she attests that they have accurately translated the information for the participant/substitute decision-maker, and believe that the participant/substitute decision-maker has understood the information translated.

Printed Name of Person Assisting

Signature

Date

FORMULAIRE DE CONSENTEMENT

L'engagement des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral

Chercheur principal: [Insérer le nom et les coordonnées]

Équipe de recherche:

Kaylee Eady, PhD(c), École des Sciences de la Réadaptation, Faculté des Sciences de la Santé, Université d'Ottawa

Mary Egan, PhD OT Reg. (Ont.), Superviseure, École des Sciences de la Réadaptation, Faculté des Sciences de la Santé, Université d'Ottawa

Financement: Cette étude n'est pas financée.

Veillez s'il vous plaît lire ce formulaire de consentement attentivement avant de confirmer votre participation. Vous pouvez demander à un membre de l'équipe de recherche autant de questions que vous le souhaitez.

Pourquoi suis-je donnée ce formulaire?

Vous êtes invité à participer à cette étude puisque vous avez un membre de la famille qui a subi un traumatisme cranio-cérébral et est dans le programme pour lésions cérébrales acquises au [centre de réadaptation]. Nous sommes intéressé à comprendre comment les familles sont impliquées dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral.

Pourquoi cette étude est-elle menée?

Les familles jouent un rôle important dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral, mais nous ne comprenons pas comment les familles sont impliquées. Les résultats de cette étude nous aideront à mieux comprendre l'implication des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral.

Comment l'étude est-elle conçue?

L'étudiante mènera une entrevue semi-dirigée de type un-à-un avec les patients, les membres de la famille, et les membres de l'équipe de soins. Les entrevues se dérouleront dans un endroit calme et privé sur le pavillon pour lésions cérébrales acquises au [centre de réadaptation]. L'étudiante enregistrera et transcrira toutes les entrevues pour l'analyse plus tard. À la fin de ce formulaire, vous aurez l'option d'accepter ou ne pas d'être enregistré.

Qu'attend-on de moi?

Vous seriez invité à faire une entrevue. Durant cette entrevue, vous seriez demandé de décrire comment vous êtes impliquée dans la réadaptation du patient. Cette entrevue aura lieu environ une semaine avant la décharge du patient du pavillon pour lésions cérébrales acquises au [centre de réadaptation]. Celle-ci durera environ 60 minutes. L'entrevue sera menée à un moment qui vous convient le mieux. Selon vos préférences, l'entrevue peut être dirigée soit en anglais ou en français.

Combien de temps vais-je être impliqué dans l'étude?

L'étude complète étendra sur une durée d'environ 1 an. Cependant, votre participation à l'étude durera le temps de l'entrevue, environ 60 minutes.

Votre participation à cette étude peut être arrêtée pour une des raisons suivantes :

- L'équipe de recherche croit qu'il est dans votre meilleur intérêt.

Quels sont les risques potentiels que je peux rencontrer?

Vous trouverez peut-être l'entrevue fatigante. Si vous vous sentez fatigué, vous pouvez demander que l'entrevue soit arrêtée à n'importe quel moment ou reporter. Vous pouvez aviser l'étudiante si vous ne souhaitez pas répondre à une question spécifique ou si vous vous sentez mal à l'aise.

Puis-je espérer bénéficier de participer à cette étude?

Vous ne recevrez aucun avantage direct de votre participation à cette étude. Cependant, cette étude nous aidera à comprendre l'implication des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral. Cela pourra aider de futurs patients et familles.

Dois-je participer? Quelles sont les alternatives? Si je suis d'accord maintenant, est-ce que je peux changer d'avis et me retirer plus tard?

Votre participation à cette étude est volontaire. L'option alternative serait de ne pas y participer. Vous pouvez décider de ne pas participer à cette étude, ou d'y participer maintenant, et changer votre avis plus tard sans impact sur les services de santé ou autres services que vous recevez à cette institution. Si vous retirez votre consentement, l'équipe de recherche ne recueillera plus vos informations d'identification personnelle pour fins de recherche.

Serai-je payé pour ma participation ou est-ce qu'il y aura des coûts supplémentaire pour moi?

Vous ne serez pas payé pour participer à cette étude. Il n'y aura aucun coût supplémentaire en participant à cette étude.

Comment mes renseignements personnels sont-ils protégés?

- Toutes informations recueillies durant votre participation à cette étude seront identifiées avec un numéro d'étude unique, et ne contiendra aucune information qui vous identifie, tel que votre nom, adresse, etc.
- Le lien entre votre numéro d'étude unique et votre nom et vos coordonnées sera gardé en toute sécurité et séparé de vos données, et ne quittera pas ce site.
- Tous les documents qui quittent le [centre de réadaptation] contiendront seulement votre numéro d'étude unique. Ceci inclus les publications ou présentations résultant de cette étude.
- L'information qui vous identifie ne sera libérée que si elle est requise par la loi.
- À des fins de vérification, vos documents de recherche originaux peuvent être examinés, sous la supervision du personnel à [insérer le nom du chercheur principal], par des représentants du:
 - comité d'éthique en recherche de [l'hôpital universitaire],
 - Institut de recherche de [l'hôpital universitaire],
 - comité d'éthique en recherche de [l'université].
- Les documents de recherche seront conservés pendant 10 ans, à la fin de cette période ils seront détruits.

Qui dois-je contacter si j'ai d'autres questions?

Si vous avez des questions supplémentaires au sujet de cette étude, ou si vous croyez que vous avez subi une blessure ou une maladie en lien avec l'étude, veuillez communiquer avec [insérer le nom et les coordonnées du chercheur principal]. Vous pouvez également communiquer avec Kaylee Eady, l'étudiante au doctorat, au [insérer les coordonnées].

Le Comité d'éthique en recherche de [l'hôpital universitaire] a examiné ce protocole. Le comité considère les aspects éthiques de toutes les études en recherche impliquant des participants humains à [l'hôpital universitaire]. Si vous avez des questions concernant vos droits en tant que participant à l'étude, vous pouvez contacter le président, au [insérer les coordonnées].

L'engagement des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral

Consentement de participation dans la recherche

- Je comprends qu'on me demande de participer à une étude de recherche portant sur l'implication des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral.
- Cette étude m'a été expliquée par _____.
- J'ai lu, ou on m'a lu, chaque page du formulaire de consentement.
- Toutes mes questions ont été répondues à ma satisfaction.
- Si je décide plus tard que je voudrais retirer ma participation et/ou le consentement de l'étude, je peux le faire à tout moment.
- Je suis d'accord de participer volontairement à cette étude.
- Je recevrai une copie de ce formulaire de consentement éclairé.

J'accepte d'être enregistré. Oui ☐ Non ☐ Initiales ____

Nom imprimé du participant

Signature du participant

Date

Déclaration du chercheur ou du délégué

J'ai expliqué attentivement l'étude au participant de l'étude. Selon mes connaissances, le participant comprend la nature, les exigences, les risques ainsi que les avantages découlant de la participation à cette étude.

Nom imprimé du chercheur/délégué

Signature du chercheur/délégué

Date

Déclaration d'assistance

Est-ce que le participant a été assisté durant le processus de consentement? ☐ Oui ☐ Non

☐ Le formulaire de consentement a été lu au participant/mandataire, et la personne signant ci-dessous atteste que l'étude a été expliqué avec précision au, et apparemment compris par, et le consentement a été volontairement donné par le participant/mandataire.

☐ La personne signant ci-dessous a agi comme traducteur pour le participant/mandataire durant le processus de consentement. Il/elle atteste qu'il/elle a traduit avec précision l'information pour le participant/mandataire, et croit que le participant/mandataire a compris l'information traduit.

Nom imprimé de la personne qui assiste

Signature

Date

Healthcare Professional English and French Consent Forms for Interview

PARTICIPANT INFORMED CONSENT FORM

Understanding family involvement in adult inpatient traumatic brain injury rehabilitation

Local Site Principal Investigator (PI): [Insert name and contact information]

Research Team:

Kaylee Eady, PhD(c), School of Rehabilitation Sciences, Faculty of Health Sciences, University of Ottawa

Mary Egan, PhD OT Reg. (Ont.), Supervisor, School of Rehabilitation Sciences, Faculty of Health Sciences, University of Ottawa

Funding: This study is not funded.

Please read this Participant Informed Consent Form carefully before you decide if you would like to participate. You may ask a member of the study team as many questions as you like.

Why am I being given this form?

You are being asked to participate in this study because you work with patients who have a traumatic brain injury and are in the Acquired Brain Injury program at [the rehabilitation centre]. We are interested in understanding how families are involved in adult inpatient traumatic brain injury rehabilitation.

Why is this study being done?

Families play an important role in adult inpatient traumatic brain injury rehabilitation, but we don't yet understand how families are involved. Findings from this study will help us better understand family involvement in adult inpatient traumatic brain injury rehabilitation.

How is the study designed?

The student will conduct one-on-one semi-structured interviews with patients, family members, and members of the healthcare team. The interviews will be conducted in a quiet and private room on the inpatient Acquired Brain Injury ward at [the rehabilitation centre]. The student will audio-record and type the interviews for analysis later on. At the end of this form, you will have the option to agree or disagree to being audio-recorded.

What is expected of me?

You will be asked to do one interview. During this interview, you will be asked to describe how families are involved in rehabilitation. The interview will be done at a time that is most

convenient for you. The interview will last about 60 minutes. Depending on your preference, the interview can be done either in English or in French.

How long will I be involved in the study?

The entire study will last about 1 year. However, your participation in the study will last for the duration of the interview, about 60 minutes.

What are the potential risks I may experience?

You may find the interview tiring. If you feel at all tired, you may ask that the interview be stopped at any time or rescheduled. You may tell the student if you do not want to answer a specific question or if you feel uncomfortable.

Can I expect to benefit from participating in this research study?

You will not receive any direct benefit from your participation in this study. However, this study will help us begin to understand family involvement in adult inpatient traumatic brain injury rehabilitation. This may help future patients and families.

Do I have to participate? What alternatives do I have? If I agree now, can I change my mind and withdraw later?

Your participation in this study is voluntary. The alternative is to not participate.

You may decide not to be in this study, or to be in the study now, and then change your mind later without affecting the employment or other services that you are receiving at this institution. If you withdraw your consent, the study team will no longer collect your personal identifying information for research purposes.

Will I be paid for my participation or will there be any additional costs to me?

You will not be paid to participate in this study. There will be no added costs by participating in this study.

How is my personal information being protected?

- All information collected during your participation in this study will be identified with a unique study number, and will not contain information that identifies you, such as your name, address, etc.
- The link between your unique study number and your name and contact information will be stored securely and separate from your study records, and will not leave this site.
- Any documents leaving [the rehabilitation centre] will contain only your unique study number. This includes publications or presentations resulting from this study.
- Information that identifies you will be released only if it is required by law.

- For audit purposes only, your original study records may be reviewed, under the supervision of [insert name of local site principal investigator], by representatives from:
 - the [academic hospital's] Research Ethics Board,
 - the [academic hospital's] Research Institute,
 - the [local university's] Research Ethics Board.
- Research records will be kept for 10 years, after this time they will be destroyed.

Who do I contact if I have any further questions?

If you have any questions about this study, or if you feel that you have experienced a study-related injury or illness, please contact [insert name and contact information of local site principal investigator]. You may also contact Kaylee Eady, the PhD student, at [insert contact information].

The [academic hospital's] Research Ethics Board has reviewed this protocol. The Board considers the ethical aspects of all research studies involving human participants at [the academic hospital]. If you have any questions about your rights as a study participant, you may contact the Chairperson at [insert contact information].

Understanding family involvement in adult inpatient traumatic brain injury rehabilitation
Consent to Participate in Research

- I understand that I am being asked to participate in a research study about family involvement in adult inpatient traumatic brain injury rehabilitation
- This study was explained to me by _____.
- I have read, or have had it read to me, each page of this Participant Informed Consent Form.
- All of my questions have been answered to my satisfaction.
- If I decide later that I would like to withdraw my participation and/or consent from the study, I can do so at any time.
- I voluntarily agree to participate in this study.
- I will be given a copy of this signed Participant Informed Consent Form.

I agree to be audio taped. Yes ☐ No ☐ Initials _____

Participant's Printed Name

Participant's Signature

Date

Investigator or Delegate Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Investigator/Delegate's Printed Name

Investigator/Delegate's Signature

Date

FORMULAIRE DE CONSENTEMENT

L'engagement des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral

Chercheur principal: [Insérer le nom et les coordonnées]

Équipe de recherche:

Kaylee Eady, PhD(c), École des Sciences de la Réadaptation, Faculté des Sciences de la Santé, Université d'Ottawa

Mary Egan, PhD OT Reg. (Ont.), Superviseure, École des Sciences de la Réadaptation, Faculté des Sciences de la Santé, Université d'Ottawa

Financement: Cette étude n'est pas financée.

Veillez s'il vous plaît lire ce formulaire de consentement attentivement avant de confirmer votre participation. Vous pouvez demander à un membre de l'équipe de recherche autant de questions que vous le souhaitez.

Pourquoi suis-je donnée ce formulaire?

Vous êtes invité à participer à cette étude puisque vous travaillez avec les patients qui ont subi un traumatisme cranio-cérébral et qui sont dans le programme pour lésions cérébrales acquises au [centre de réadaptation]. Nous sommes intéressé à comprendre comment les familles sont impliquées dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral.

Pourquoi cette étude est-elle menée?

Les familles jouent un rôle important dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral, mais nous ne comprenons pas comment les familles sont impliquées. Les résultats de cette étude nous aideront à mieux comprendre l'implication des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral.

Comment l'étude est-elle conçue?

L'étudiante mènera une entrevue semi-dirigée de type un-à-un avec les patients, les membres de la famille, et les membres de l'équipe de soins. Les entrevues se dérouleront dans un endroit calme et privé sur le pavillon pour lésions cérébrales acquises au [centre de réadaptation]. L'étudiante enregistrera et transcrira toutes les entrevues pour l'analyse plus tard. À la fin de ce formulaire, vous aurez l'option d'accepter ou ne pas d'être enregistré.

Qu'attend-on de moi?

Vous seriez invité à faire une entrevue. Durant cette entrevue, vous seriez demandé de décrire comment les familles sont impliquées dans la réadaptation. Cette entrevue sera menée à un moment qui vous convient le mieux. Cette entrevue durera environ 60 minutes. Selon vos préférences, l'entrevue peut être dirigée soit en anglais ou en français.

Combien de temps vais-je être impliqué dans l'étude?

L'étude complète étendra sur une durée d'environ 1 an. Cependant, votre participation à l'étude durera le temps de l'entrevue, environ 60 minutes.

Quels sont les risques potentiels que je peux rencontrer?

Vous trouverez peut-être l'entrevue fatigante. Si vous vous sentez fatigué, vous pouvez demander que l'entrevue soit arrêtée à n'importe quel moment ou reporter. Vous pouvez aviser l'étudiante si vous ne souhaitez pas répondre à une question spécifique ou si vous vous sentez mal à l'aise.

Puis-je espérer bénéficier de participer à cette étude?

Vous ne recevrez aucun avantage direct de votre participation à cette étude. Cependant, cette étude nous aidera à comprendre l'implication des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral. Cela pourra aider de futurs patients et familles.

Dois-je participer? Quelles sont les alternatives? Si je suis d'accord maintenant, est-ce que je peux changer d'avis et me retirer plus tard?

Votre participation à cette étude est volontaire. L'option alternative serait de ne pas y participer.

Vous pouvez décider de ne pas participer à cette étude, ou d'y participer maintenant, et changer votre avis plus tard sans impact sur les services de santé ou autres services que vous recevez à cette institution. Si vous retirez votre consentement, l'équipe de recherche ne recueillera plus vos informations d'identification personnelle pour fins de recherche.

Serai-je payé pour ma participation ou est-ce qu'il y aura des coûts supplémentaire pour moi?

Vous ne serez pas payé pour participer à cette étude. Il n'y aura aucun coût supplémentaire en participant à cette étude.

Comment mes renseignements personnels sont-ils protégés?

- Toutes informations recueillies durant votre participation à cette étude seront identifiées avec un numéro d'étude unique, et ne contiendra aucune information qui vous identifie, tel que votre nom, adresse, etc.
- Le lien entre votre numéro d'étude unique et votre nom et vos coordonnées sera gardé en toute sécurité et séparé de vos données, et ne quittera pas ce site.
- Tous les documents qui quittent le [centre de réadaptation] contiendront seulement votre numéro d'étude unique. Ceci inclus les publications ou présentations résultant de cette étude.
- L'information qui vous identifie ne sera libérée que si elle est requise par la loi.
- À des fins de vérification, vos documents de recherche originaux peuvent être examinés, sous la supervision du personnel à [insérer le nom du chercheur principal], par des représentants du:
 - comité d'éthique en recherche de [l'hôpital universitaire],
 - Institut de recherche de [l'hôpital universitaire],
 - comité d'éthique en recherche de [l'université].
- Les documents de recherche seront conservés pendant 10 ans, à la fin de cette période ils seront détruits.

Qui dois-je contacter si j'ai d'autres questions?

Si vous avez des questions supplémentaires au sujet de cette étude, ou si vous croyez que vous avez subi une blessure ou une maladie en lien avec l'étude, veuillez communiquer avec [insérer le nom et les coordonnées du chercheur principal]. Vous pouvez également communiquer avec Kaylee Eady, l'étudiante au doctorat, au [insérer les coordonnées].

Le Comité d'éthique en recherche de [l'hôpital universitaire] a examiné ce protocole. Le comité considère les aspects éthiques de toutes les études en recherche impliquant des participants humains à [l'hôpital universitaire]. Si vous avez des questions concernant vos droits en tant que participant à l'étude, vous pouvez contacter le président, au [insérer les coordonnées].

L'engagement des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral

Consentement de participation dans la recherche

- Je comprends qu'on me demande de participer à une étude de recherche portant sur l'implication des familles dans la réadaptation en milieu hospitalier des adultes ayant subi un traumatisme cranio-cérébral.
- Cette étude m'a été expliquée par _____.
- J'ai lu, ou on m'a lu, chaque page du formulaire de consentement.
- Toutes mes questions ont été répondues à ma satisfaction.
- Si je décide plus tard que je voudrais retirer ma participation et/ou le consentement de l'étude, je peux le faire à tout moment.
- Je suis d'accord de participer volontairement à cette étude.
- Je recevrai une copie de ce formulaire de consentement éclairé.

J'accepte d'être enregistré. Oui ☐ Non ☐ Initiales ____

Nom imprimé du participant

Signature du participant

Date

Déclaration du chercheur ou du délégué

J'ai expliqué attentivement l'étude au participant de l'étude. Selon mes connaissances, le participant comprend la nature, les exigences, les risques ainsi que les avantages découlant de la participation à cette étude.

Nom imprimé du chercheur/délégué

Signature du chercheur/délégué

Date

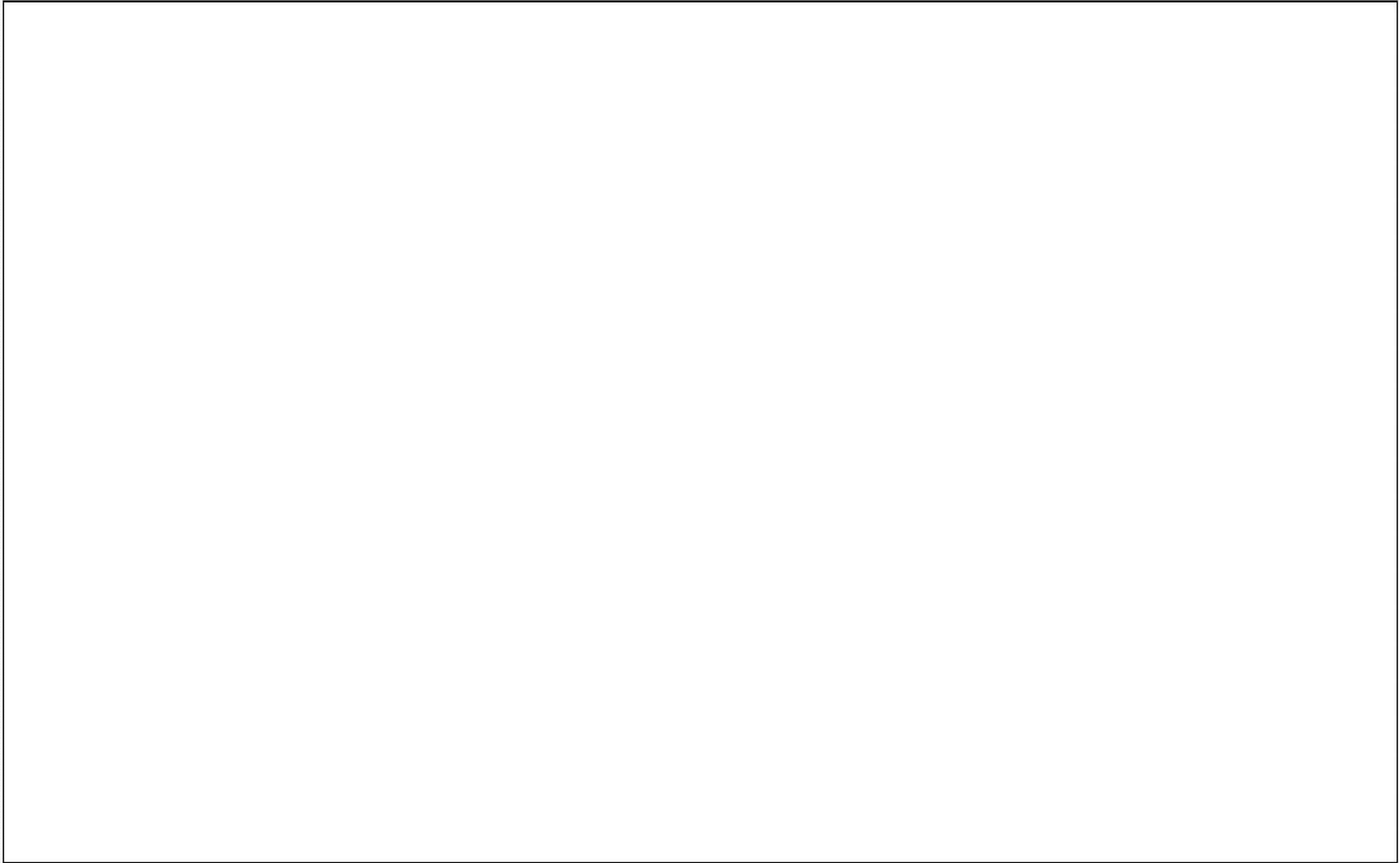
Observational Field Guide

Family Involvement: Observational Field Guide

Date: MM/DD/YY **Day of week:** Weekday/Weekend **Time of day:** Morning/Afternoon/Evening **Observation completed by:** _____

Participants observed in interaction (Specify number if > one)	Location and Context	Descriptive Notes Directly observable behaviors, duration, body language, tone, conversation topics...	Reflective Notes
☐ Patient ☐ Family ☐ Nurse ☐ Social Worker ☐ Occupational Therapist ☐ Physiotherapist ☐ Speech-language Pathologist ☐ Recreational Therapist ☐ Rehabilitation Therapist ☐ Psychiatrist ☐ Resident ☐ Psychologist ☐ Dietician ☐ Pharmacist ☐ Other (specify)	☐ Bedside ☐ Ward Hallway ☐ Group Room ☐ Dining Room ☐ Kitchen ☐ OT Therapy Room ☐ PT Therapy Room ☐ SLP Therapy Room ☐ Rec Therapy Room ☐ Meeting Room ☐ Office ☐ Other (specify)		
	☐ Bedside Rounding ☐ Rehabilitation Session ☐ Education Session ☐ Group Session ☐ Formal Meeting ☐ Inpatient Management ☐ Family Conference ☐ Formal Interview ☐ Informal Meeting ☐ Shift Change Meeting ☐ Visitation ☐ Other (specify)		

Sketch room/environment layout



Tri-Council Policy Statement, Chapter 10, Qualitative Research, Article 10.3

*Chapter 10 – Qualitative Research***Observational Studies**

In qualitative research, observation is used to study behaviour in a natural environment. It often takes place in living, natural and complex communities or settings, in physical environments, or in virtual settings. Observational studies may be undertaken in publicly accessible spaces (e.g., a stadium, library, museum, planetarium, beach, park), in virtual settings (e.g., Internet chat rooms), or in private or controlled spaces (e.g., private clubs or organizations).

Observational research is of two kinds: “non-participant” where the researcher observes, but is not a participant in, the action (also known as “naturalistic observation”); and “participant” where the researcher engages in, and observes, the action.

Participant observation is often identified with ethnographic research, in which the researcher’s role is to gain a holistic overview of the studied context through engagement in, and observation of, the setting to describe its social environments, processes and relationships. Participant observation may or may not require permission to observe and participate in activities of the setting studied. In some situations, researchers will identify themselves and seek consent from individuals in that setting; in others, researchers will engage in covert non-participant or participant observation and not seek consent.

A matter that is publicly accessible may, nevertheless, be considered private in a prospective participant’s culture. There may be a reasonable expectation of privacy by some groups, or for some activities. For example, individuals involved in religious services or practices, or chat rooms on the Internet, may assume that participants and observers will accord the proceedings some degree of privacy. Observing sacred ceremonies without approval from the appropriate individuals or groups (e.g., Elders or traditional knowledge holders in Aboriginal research) and without engaging them about the subsequent use or interpretation of the data may have unintended negative implications (see Articles 9.5, 9.6 and 9.8). Considerations of the nature of the research, its aims and its potential to invade sensitive interests may help researchers improve the design and conduct of such research.

Observational studies in public places where there is no expectation of privacy are exempt from REB review (see Article 2.3).

Article 10.3 In research involving observation in natural environments or virtual settings where people have a reasonable or limited expectation of privacy, the researcher shall explain the need for an exception to the general requirement for consent. The REB may approve research without requiring that the researcher obtain consent from individuals being observed on the basis of the justification provided by the researcher and appropriate privacy protection.

Application Observational studies raise concerns for the privacy of those being observed. In observational research, breaches of privacy may arise from identification of individuals, groups or communities in the publication or dissemination of research results.

Observational research that does not allow for the identification of the participants in the dissemination of results, that is not staged by the researcher, and is non-intrusive should normally be regarded as being of minimal risk.

REBs and researchers need to consider the methodological requirements of the proposed research project and the ethical implications associated with observational approaches, such as the possible infringement of privacy. They should pay close attention to the ethical implications of such factors as the nature of the activities to be observed, the environment in which the activities are to be observed, whether the activities are staged for the purpose of the research, the expectations of privacy that prospective participants might have, the means of recording the observations, whether the research records or published reports involve identification of the participants, and any means by which those participants may give permission to be identified. REBs shall ensure that the proposal contains measures to protect the privacy of the individual in accordance with the law.

Researchers and REBs should consult Chapters 3 and 5 for additional details and considerations regarding consent, and privacy and confidentiality.

For observational research in which consent is not sought, researchers shall demonstrate to the REB that necessary precautions and measures have been taken to address privacy and confidentiality issues.

Because the knowledge that one is being observed can be expected to influence behaviour, research involving non-participant or covert observation generally requires that the participants not know that they are being observed for research purposes. Typically the researcher has no direct interaction with the individuals being observed and therefore their consent is not sought. Covert observation of queuing behaviours in shopping malls is one example of a study where the research could not be completed if shoppers knew that they were being observed. Some forms of qualitative research seek to observe and study criminal behaviours, violent groups, or groups with restricted membership or access using covert participant observation. For example, some social science research that critically probes the inner workings of criminal organizations might never be conducted if the participants know in advance that they are being observed. Other observational studies may be anonymous but involve intervention by the researcher (e.g., studying the propensity of bystanders to help in an emergency normally requires a staged emergency). These methodological approaches may require the researcher seeking an exception to the requirement to seek prior consent.

Where no personal information is collected, consent is not required. Where personal information will be collected, researchers must explain whether the need for such

Chapter 10 Qualitative Research

covert research justifies an exception to the requirement to seek prior consent, and REBs should exercise their judgment taking into consideration the methodological requirements (see Article 3.7A). Researchers and REBs shall take the necessary steps to ensure that the privacy of the individual is protected in accordance with the law in the absence of consent. Where no consent is sought, researchers and REBs may also consider whether debriefing is possible, practicable and appropriate (see Article 3.7B). Chapter 5 on privacy and confidentiality provides additional information.

Researchers and REBs should also be aware that, in some jurisdictions, publication of identifying information – for example, a photograph taken in a public place, but focused on a private individual who was not expecting this action – may be interpreted in a civil suit as an invasion of privacy.

Privacy and Confidentiality in the Dissemination of Research Results

Article 10.4 In some research contexts, the researcher may plan to disclose the identity of participants. In such projects, researchers shall discuss with prospective participants or participants whether they wish to have their identity disclosed in publications or other means of dissemination. Where participants consent to have their identity disclosed, researchers shall record each participant's consent.

Application In some types of qualitative research (e.g., oral history, a biographical study or a study involving specific personalities) respect for the participant's contribution is shown by identifying the individual in research publications, or other means of dissemination of the results from the research. For instance, in an interview study with visual artists concerning some aspect of the way they work, it might be appropriate and respectful to identify the respondents. If failing to identify participants would be unethical because of any disrespect it would represent, or if informed participants assert their desire to be named, then researchers should do so, according to the practices of their discipline. For example, social historians seek to document and archive the lives of individuals, or highlight the contributions that ordinary people make in social and political life. In oral history, anonymity is the exception. Researchers make the option for anonymity known to participants as part of the discussion around the nature and conditions of their consent.

In some types of critical inquiry, anonymity would result in individuals in positions of power not being held accountable for their actions, and for how their exercise of power has implications for others. The safeguards for those in the public arena are through public debate and discourse, and through action in the courts for libel.

In much other social science and some humanities research, it is primarily the harm that can result from violations of confidentiality that REBs and researchers need to address. This can pose a particular challenge in qualitative research because of the depth, detail, sensitivity and uniqueness of information obtained. The default approach is to maintain confidentiality of the research data. In some instances,

Note. Canadian Institutes of Health Research, Natural Sciences and engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada. (2014). Qualitative Research. In *Tri-council policy statement: Ethical conduct for research involving humans* (pp. 145-147). Retrieved from <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default/>

Example Observation Encounter

Session # 12, encounter # 4

Family Involvement: Observational Field Guide

Date: 06/06/16 Day of week: Weekday Weekend Time of day: Morning/Afternoon/Evening Observation completed by: KE

Participants observed in interaction (Specify number if > one)	Location and Context	Descriptive Notes Directly observable behaviors, duration, body language, tone, conversation topics...	Reflective Notes
☒ Patient ☒ Family x 2 ☐ Nurse ☐ Social Worker ☒ Occupational Therapist ☐ Physiotherapist ☐ Speech-language Pathologist ☐ Recreational Therapist ☐ Rehabilitation Therapist ☐ Psychiatrist ☐ Resident ☐ Psychologist ☐ Dietician ☐ Pharmacist ☒ Other (specify) OT recep	☐ Bedside ☐ Ward Hallway ☐ Group Room ☐ Dining Room ☐ Kitchen ☐ OT Therapy Room ☐ PT Therapy Room ☐ SLP Therapy Room ☐ Rec Therapy Room ☐ Meeting Room ☐ Office ☒ Other (specify) OT waiting area ☐ Bedside Rounding ☒ Rehabilitation Session ☐ Education Session ☐ Group Session ☐ Formal Meeting ☐ Inpatient Management ☐ Family Conference ☐ Formal Interview ☐ Informal Meeting ☐ Shift Change Meeting ☐ Visitation ☐ Other (specify)	2 FMs waited w/ pt. in waiting area. OT collected pt, did not interact w/ FMs. FMs stayed in waiting area all session. Chatted among one another. Spoke w/ receptionist briefly about weather. OT brought pt back to waiting area after, again no interaction w/ FMs. Said bye to pt. FMs accompanied pt to room. Asked how session went.	I saw little interactions between the HCP + FMs, except a brief nod. I wonder why the FMs stayed in the waiting area? They were clearly interested in therapy as they asked how it went after. I wonder why they didn't ask the HCP? The HCP also didn't engage. FMs were not asked to join or offered info. I also think the fact they stayed in waiting area shows interest as they could have gone elsewhere (TV room).

Note. FM = family member; Pt = patient; OT = occupational therapist/therapy; HCP = healthcare professional.