BALANCING RISK-TAKING AND SAFETY AMONG PATIENTS, FAMILIES, AND CLINICIANS DURING TRANSITIONS IN CARE FROM BRAIN INJURY REHABILITATION

by

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This study examines the factors that influence how patients, families, and clinicians make decisions about risk-taking and safety in brain injury rehabilitation. Despite the importance of these decisions, particularly during transitions in care, there is scant literature to help guide these care partners in ethical and clinical decision-making related to risk-taking and safety. This study suggests that there are tensions between rehabilitation and patient safety efforts. Risk-taking lies at the core of brain injury rehabilitation; however, decisions about risk-taking are also influenced by conflicting values, system pressures, and patient abilities. A relational approach to autonomy that addresses patients’ decisional and functional abilities within their social contexts is more nuanced than a liberal individualist approach to autonomy, and provides a better framework for understanding decision-making. Relational autonomy may help clinicians make better decisions that balance risk-taking and safety, decisions that are committed to the principles of respecting autonomy and advancing safety.
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Chapter 1: Introduction

Choose topics that ignite your passion. Do something that makes a difference in the world. Then enter the phenomenon and open yourself to the research experience. Face the inevitable ambiguities. Flow with the existential dislocation of bewilderment. Bring passion, curiosity, and care to your work. In the end, you will transform our images of studied life, and your research journey will transform you. (Charmaz, 2004, p. 991)

Neither ethics nor rehabilitation can afford to continue ignoring each other. (Scofield, 1993, p. 341)

Despite the recent spotlight on the safety of transitions in care, transitions remain a vulnerable time for patients and families (Coleman & Fox, 2004; Forster, Murff & Peterson, 2003; Perry, 2004). Transitions in care challenge how patients, families, and clinicians balance the importance of patient risk-taking and safety; however, the transition from rehabilitation to home poses unique challenges that are different from acute care and not well understood (Macchiocci & Stringer, 2001). While there is a rich body of safety and ethics literature focusing on transitions from acute care settings (Herbison, 1998; Meire & Purtilo, 2001; Mukherjee & McDonough, 2006), less has been written about the intersection of these issues in a rehabilitation context (but see Meire & Purtilo, 1994; Stiggelbout & Molewijk, 2004), and even less from the perspectives of patients and families (Leathem, Heath & Woolley, 1996; Perlesz, Kinsella & Crowe, 1999; Rotondi, Sinkule, Balzer, Harris & Moldovan, 2007). Patient safety issues in rehabilitation differ from those in acute care, and reflect the complexities of living with a chronic disability, the multifacted interactions between patients, families, and clinicians, and the challenges of balancing risk-related behaviours within a goal-oriented model of care (Kirschner, Stocking, Wagner, Foye & Siegler, 2001; Wolosin, Verlcer & Matthews, 2006). Many would agree that the aim of
rehabilitation is to help patients achieve their maximum level of physical, cognitive and behavioural function, in order to reintegrate back into their lives (Cardol, de Jong, van den Bos, Beelen & de Haan, 2002a). Despite rehabilitation’s unique contribution to enhancing community integration, the tension between promoting patient safety and respecting the choice to live at risk is not well understood.

Respect for patient autonomy is a core ethical principle that guides us to honour the right of patients to determine their day-to-day lives, based on the psychological capacity to make decisions that reflect their own goals (Beauchamp & Childress, 2008; Meier & Purtilo, 2001). However, no decision is made in a vacuum. Patient autonomy should also be grounded in an understanding of relationships with care providers, family members and others (Agich, 2003; Sherwin, 1998). Despite this, little progress has been made in engaging patients and families in a discussion of these ethical and clinical issues, particularly as they prepare to leave the hospital environment (Ponte, Connor, CeMarco & Price, 2004). Clinicians are regularly required to determine if a person with a brain injury can walk independently, manage finances, return to work, or perform activities of daily living (ADLs) (Leathem et al., 1996; McGrath, 2007).

The purpose of this study is to explore how patients, families, and clinicians balance risk-taking and safety during decision-making in brain injury rehabilitation. It also seeks to identify social and systems factors, characteristic of this population that can further influence ethical and clinical decision-making and safe transitions in care. By understanding some of these conflicts and proposed solutions, clinicians may be better equipped to address the tensions inherent in respecting patient autonomy and advancing safety as they help prepare patients and families for life beyond institutional care.
Background and Rationale

To address the lack of safety research in rehabilitation, we conducted twelve focus groups within Toronto Rehab from October 2007 to February 2008 as part of an externally funded research study (Tardif & Baker, 2008). These focus groups involved two distinct groups: Former inpatients of the Toronto Rehabilitation Institute (n = 57); and family members of former inpatients (n = 49) from each of the hospital’s six clinical programs, including cardiac, geriatric, musculoskeletal, neuro and spinal cord rehab, and complex continuing care (CCC). The aim of this research was to better understand the nature of patient risk-taking and safety during the inpatient rehabilitation process. The results offer broad preliminary insight into three areas that are important to understanding autonomy at the inpatient level: (1) reinserting the changed self following significant bodily changes, (2) prioritizing inpatient emotional support and care, and (3) identifying factors in the human and physical hospital environment that can threaten or enhance safety. The Tardif and Baker study is a first step in understanding these ethical and clinical issues; however, it is also has important limitations. First, the twelve focus groups focused on the inpatient perspectives of patients and families; the transition to home was less emphasized. Second, while the researchers sought to understand the role of the clinician in preparing patients and families for discharge, the perspectives of the clinicians themselves were not solicited. Finally, respect for patient autonomy was raised across all participant groups as a key component to patient safety; however, it was the brain injury participants who identified issues that were

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1 This research project was conducted in partnership with the Toronto Rehabilitation Institute and University of Toronto, and co-funded by the Canadian Patient Safety Institute and the Toronto Rehabilitation Institute. The co-principal investigators of the study were Dr. Gaétan Tardif and Dr. G. Ross Baker.
particularly challenging and the least understood. These issues reflected the complex triad of
cognitive, behavioural, and physical impairments typical of this population, longer length of
stays compared to other rehabilitation programs, and the often suddenness and chronicity of
brain injury.

My study builds on this research, but differs in three distinct ways: It explores in rich
detail issues related to patient autonomy and patient safety specific to brain injury
rehabilitation; it considers clinicians as critical to conceptualizing patient autonomy, and has
expanded to include this group; and it aims to understand factors that influence patient risk-
taking and safety in the context of the transition from inpatient rehabilitation to home.

Overview of Thesis Chapters

This thesis is presented in five chapters which provide a logical roadmap of the
context, problem, and proposed solutions of this qualitative inquiry. In Chapter 2, I examine
the literature relevant to understanding three key areas of this study. The first section offers a
brief review of brain injury and the role of rehabilitation in maximizing recovery. The second
section considers some of the ethical and clinical issues important to respecting autonomy for
patients with complex care needs. It also introduces the concepts of relational autonomy and
World Health Organization (WHO)’s *International Classification of Functioning Disability
and Health*. The final section examines the ethical and clinical implications of safe
transitions in care following rehabilitation.

In Chapter 3, I present a methodological review of the research procedures for this
study. This chapter discusses the assumptions and logic that justify my “methodological
moves” based on my interpretive epistemology and constructivist approach to grounded
theory. I also outline specific criteria for judging the soundness of qualitative research, and
reflexive considerations important to conducting 16 semi-structured, focused interviews with patients, families, and clinicians during the transition from brain injury rehabilitation to home.

The results of this research are offered in Chapter 4, which provides a descriptive as well as an interpretive analysis of key themes and concepts of this study. This chapter explores five tensions that influence how patients, families, and clinicians make decisions about risk-taking and safety during transitions in care. These tensions emphasize how values about risk-taking and safety are often in conflict among providers, patients, and families; how social and systems factors are critical to balancing risk-taking and safety; how the realities of clinical practice challenge the ideal of patient-centered care; how home supports can threaten or enhance both autonomy and on-going recovery; and how access to community services and systems of care are also linked to a patient’s decisional and functional abilities.

Finally, in Chapter 5, I reflect critically on the results of the study and discuss the study’s limitations. My research proposes that there are tensions between rehabilitation and patient safety efforts. Healthcare providers are frequently required to make decisions that attempt to balance risk-taking and safety\(^2\); however, they struggle with conflicting values,\

\(^2\) I have chosen to use the term *balance* to frame how stakeholders in this study make decisions that, all things considered, give precedence to either take taking or safety. In the same way that Grisso and Appelbaum (1998) describe, “*balancing autonomy and protection*”, I am using this term to describe how patients, families and clinicians balance decision-making about risk-taking and safety in the context of rehabilitation. In Grisso and Appelbaum’s “competence balance scale” they examine the outcome when autonomy and protection are balanced against each other. Suspended at one arm of the scale is an “autonomy cup”, and at the other end a “protection cup”. The balancing judgment depends, “on the balance of (1) the patient’s abilities in the face of decisional demands, weighed against (2) the probable gain-risk of the patient’s treatment choice, (3) when the fulcrum is set to favor autonomy,” (p. 139). As the weight of the cups increases with information such as patient abilities, clinician values, and social contexts, it tips the scale in favour of either risk-taking or safety. This understanding of the term *balance* is not arbitrary or fixed; it is sufficiently nuanced in that it takes into account context, values, and individual and team decision-making. It also acknowledges the difficult process of making decisions about patient risk-taking and safety in brain injury rehab, and the deliberation and negotiation that takes place in how clinicians evaluate the anticipated costs, risks and benefits of these decisions.
social issues, and system pressures. A relational approach to autonomy emphasizes that patient autonomy is socially situated and contextualized within interdependent health, familial, and community relationships. This approach offers a framework for understanding ethical and clinical decision-making, and may provide clinicians with the guidance they need to make better decisions about patient risking-taking and safety during brain injury rehabilitation. The implications of this research for both clinical practice and future inquiry are also discussed.

**Definition of Terms**

Throughout this document, I use the term "patient" to identify a person who has sustained a brain injury and has received rehabilitative care. The term "client" may be preferred over "patient" particularly by certain health care professionals. This term acknowledges that individuals are consumers of health care services and, as such, have a set of rights related to free choice and determination. While I respect the use of this language, I have chosen to identify people who have sustained a brain injury as “patients”. My approach to this term is not one of the “passive sufferer”, but as an active collaborator and participator in care (D'Amour & Oandasan, 2004). The term “family” is more straightforward, and I have used it interchangeably with the term “loved one” or “family caregiver”. In all cases these family members live in the same household or are the primary caregivers of the patients in this study. Finally, the term “clinician” includes the wide range of healthcare professionals who provide rehabilitative care to the patients and families in this study.
Chapter 2: Literature Review

Introduction

The purpose of this chapter is to provide the reader with a concise review of the literature about three concepts important to this research: Brain injury rehabilitation, respect for patient autonomy, and safe transitions in care. I also identify some of the gaps in this literature with the goal to situate my own research within these gaps. First, I provide a brief review of acquired brain injury (ABI) in a Canadian context, and discuss some of the assumptions that guide our understanding of rehabilitation and recovery. Second, I examine bioethical issues characteristic of brain injury rehabilitation, including some of the debates and paradoxes within the autonomy literature. Next, I introduce two concepts that form the sensitizing context for this study. The first is a relational approach to autonomy. This approach offers a more nuanced interpretation of autonomy than a liberal individualist approach, and considers patients’ decisional and functional abilities within social and contextual factors. The second is the WHO’s International Classification of Functioning (ICF) that considers disability in terms of three health-related domains: Impairments, activity limitations and participation restrictions. I then discuss issues important for safe transitions in care and the emergence of qualitative literature in the area of rehabilitation and patient safety. I conclude by presenting the purpose of this study in response to these ethical and clinical issues.
Acquired Brain Injury: A Brief Primer

Neurotrauma is a critical public health problem that deserves the attention of the world's health community (WHO, 2009). Estimates of ABI incidence indicate that these injuries can cause enormous losses to individuals, families, and communities. They result in a large number of deaths and are a leading cause of serious, long term disability among adults under the age of 40 (Pickett, Ardern & Brison, 2001). While ABI definitions vary in the literature, reflecting policy, legislative, and administrative contexts, the Ontario Neurotrauma Foundation (2005) offers a definition that is widely used and consistent with other established definitions such as by the Pediatric Acquired Brain Injury Advisory Committee:

An acquired brain injury is damage to the brain which occurs seven days after birth. The damage may be caused:

- traumatically (e.g. from an external force such as motor vehicle collision, fall, assault, shaken baby syndrome, work-related injury, or sports injury); or
- through a medical problem or disease process which causes damage to the brain (e.g. brain tumour or stroke).

In Canada, approximately 55,000 people sustain a traumatic brain injury (TBI) each year (Canadian Institute for Health Information [CIHI], 2007; Zygun, Laupland, Hader, Kortbeek & Findlay, 2005). Of these hospitalizations, approximately 18,000 are in Ontario. Toronto alone treats 4,200 TBI annually; this number more than doubles when expanded to include ABI (Toronto ABI Network, 2006). In TBI, there is an overall male bias and a peak incidence in those aged 15-24 years. Brain injury incidence increases again in elderly adults, largely as a result of falls and strokes (Kraus & Chu, 2005).

The range of motor, behavioural, and cognitive impairment associated with ABI is extensive and well discussed in the literature (Campbell, 2000; Rosenberg, Simantov & Patel, 2007). Many people who survive brain injury experience persisting cognitive and behavioural impairments that lead to longer-term disability (Rao & Lyketsos, 2000). Such
impairments can also impact the degree to which individuals appreciate the extent of their impairments and the risks they take in their day-to-day lives. This in turn, can interfere with their ability to participate in social and familial roles, and reintegrate back into meaningful activities, such as returning to work and driving directly (Whyte, Hart, Laborde & Rosenthal, 1998). As a result, people with cognitive and behavioural impairments secondary to brain injury are at a significant disadvantage when it comes to benefiting from and appreciating the consequences of inpatient rehabilitation (Lannoo, Colardyns, Jannes & De Soete, 2001).

Complicating the picture is the possibility that different parts of the brain are competing with each other during recovery. Early findings suggest that there is only finite brain space to support recovery; the more cognitive recovery there is, the less motor recovery there may be, and vice versa (Till, Colella, Verwegen & Green, 2008).

A key determinant of a patient’s therapy needs, prognosis, and outcome is how he or she presents neurologically in acute care, which is generally classified as mild, moderate or severe (Kraus, 1999; Oyesiku, 2005). The majority of research on predicting long term outcome following brain injury has focused on three primary measures: The Glasgow Coma Scale, post-traumatic amnesia, and loss of consciousness (Green, Colella, Christensen, Johns, Frasca et al., 2008). For a summary of the factors used to determine brain injury severity see Table 1.

Table 1. Determining the Severity of Traumatic Brain Injury (Rosenthal, Griffith, Bond & Miller, 1990)

<table>
<thead>
<tr>
<th></th>
<th>Initial Glasgow Coma Scale</th>
<th>Duration of Post-Traumatic Amnesia</th>
<th>Loss of Consciousness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>12 -15</td>
<td>Less than 24 hours</td>
<td>Less than 30 minutes</td>
</tr>
<tr>
<td>Moderate</td>
<td>9-11</td>
<td>1-7 days</td>
<td>30 minutes – 24 hours</td>
</tr>
<tr>
<td>Severe</td>
<td>3-8</td>
<td>1-4 weeks</td>
<td>More than 24 hours</td>
</tr>
</tbody>
</table>
The social burden of brain injury is significant. Due to improved medical technology, many patients who would have died due to their injuries are now surviving with greater levels of disability, require more supports, and experience greater economic pressures (National Rehabilitation Institute of Ontario [NRIO] Outcome Study, 2006). In Canada, the direct and indirect medical costs of ABI are an estimated three billion dollars a year (CIHI, 2007). The expenditures associated with a life-time of disability are also high. The average lifespan of a person living with brain injury, injured before the age of 30, is 79 years (National Institute of Health [NIH], 2000). While there is a paucity of literature investigating the individual costs of brain injury, two seminal studies estimate that the life-time costs for people with non-TBI and TBI range from $228,000 to $1,875,000 respectively (Dorset, 1998; Taylor, Davis, Torner, Holmes, Meyer et al, 1996). These figures likely grossly underestimate the economic burden of brain injury to families and society as they do not include lost earnings, costs to social services systems, and the value of the time and foregone income of family caregivers (NIH Consensus Statement, 1998).

Clinical Issues in Brain Injury Rehabilitation

People living with brain injury are surviving longer with multiple disabilities and complex medical issues. The need for brain injury rehabilitation is steadily increasing, as well as the scope and complexity of its interventions (NRIO Outcome Study, 2006). The goals of brain injury rehabilitation are extremely broad due to variations in injury severity, differences in the nature and location of the neuropathology, and the constellation of co-morbidities that often accompany brain injury (Rosenberg et al., 2007). Although the outcome of ABI is reasonably well characterized over the first few years of injury, very little is known about the long term consequences of aging with a moderate to severe ABI (CIHI,
In particular, there is growing acknowledgement that mental health and substance abuse issues can have a significant impact on prognosis and outcome (Douglas & Spellacy, 2000). An individual’s social context also shapes his or her rehabilitation needs. Those with few social supports must often reach higher levels of independence to live outside of institutional care than those with well-developed social networks and financial resources (Campbell, 2000; Gan, Campbell, Gemeinhardt & McFadden, 2006). Further, while access to rehabilitation is broadly available in Canada, there are no national standards of care for brain injury rehab (Cullen, 2007). This creates a disparity in services between wealthier and poorer provinces; urban centers and community hospitals; and patients with third party or private funding, and those who rely solely on the public system for their healthcare (Toronto ABI Network, 2006).

There is a growing but incomplete understanding of the mechanisms underlying long term brain injury recovery. The time course of ABI is lifelong and involves complex but interrelated impairments that are active at different times during recovery. Consequently, specific interventions such as intensive rehabilitation need to be well timed in order to maximize effectiveness (Kraus & Chu, 2005; Rosenberg et al., 2007). The duration of rehabilitation is also highly variable (Whyte et al., 1998). Those with relatively mild injuries may require a brief rehabilitation stay and then return essentially to their pre-injury level of function. Others with moderate to severe injuries experience lifelong deficits that require a shift from a medical treatment model to a patient-centered support model that recognizes psychosocial and environmental needs, particularly as patients and families transition from rehabilitation to home (Whyte, Laborde & DiPasquale, 1999).
One of the tenets of rehabilitation is a collaborative approach to patient-centered care (Caplan, 1987). Rehabilitation relies on the efforts of a large interprofessional therapy team, often over long periods of time. A single ABI patient may be treated by up to 15 different healthcare professionals, many of whom have specific expertise in behaviour management and rehabilitative care (Rosenberg et al., 2007). Patient-centered care is a practice orientation that assumes that health care professionals work together with their patients towards specific patient goals (Reeves, Zwarenstein, Goldman, Barr, Freeth, et al, 2008). Many argue that this collaborative framework forms one of the cornerstones of rehabilitation and involves the, “continuous interaction of two or more professions, organized into a common effort, to solve or explore common issues with the best possible participation of the patient,” (D’Amour & Oandasan, 2004, p. 1). The patient's care and willingness to participate in the process is also critical. This coordinated interprofessional approach involves – in an ideal environment – the shared responsibility of clinician and ethical decisions across a diverse range of healthcare professionals that has few equivalents in other areas of healthcare (Caplan, 1987).

One of the assumptions of brain injury rehabilitation is that patients will continue to improve over time (Dikmen, 2003). However, Canadian researchers have recently challenged this assumption, and argue that while some people continue to improve after they leave rehabilitation, others do not, regardless of the severity of their injury or the extent of their impairments (Green et al., 2008; Till et al., 2008). The reasons for this are unclear, but early findings suggest that this decline likely reflects the sudden drop off of therapeutic supports once patients leave rehabilitation, particularly for those without third party coverage. The consequence is twofold: The first is that that the ability of clinicians to predict recovery is
modest, despite much research in this area (Dikmen, Machamer, Temkin & McLean, 1990; Lannoo et al., 2001; Sherer, Stouter & Hart, 2006); and the second is that an understanding of the relationship between on-going access to therapy and the prevention of decline is clearly needed (Till et al., 2008).

Several conclusions from this review are possible. While there is some agreement around the outcomes of moderate and severe brain injury (Green et al., 2008), there is far less consensus about how to focus treatment and service efforts (Gan et al., 2006; Whyte et al., 1999). Part of the problem is that there is limited literature that examines the clinical and ethical factors that influence ABI care. Thus, when an intervention is effective, we learn only that it is useful, but not how it might be improved or augmented. Despite, or perhaps because of the heterogeneity in brain injury treatment and recovery, there is a need for research that asks questions beyond whether (or not) an intervention is successful, but to describe and engage in the macro, meso and micro level implications of these ethical and clinical issues (Haggstrom & Lund, 2008; Wendell, 2001).

**Ethical Issues in Inpatient Brain Injury Rehabilitation**

It has been said that rehabilitation is a medical specialty lacking an age, organ, technology or appendage to define it. (Caplan, 1987, p. 3)

Bioethical issues have been debated since at least Hippocrates; however, the modern field of bioethics has only emerged as an academic discipline in the 1960s. Over the past 50 years bioethics has heightened professional awareness of the moral issues that are relevant to healthcare research, and suggested strategies for addressing and resolving them (Herbison, 1998). Bioethics invites patients, families, and clinicians to use a framework to deliberate
thoughtfully and carefully about what ought to be done in the light of what can be done (Scofield, 1993). By forming a bridge between moral theory and clinical practice, bioethics can make a powerful contribution to clinical judgment, and promote a, “philosophy of responsibility” that may help rehabilitation clinicians provide optimal care (Meier & Purtilo, 1994, p. 366).

Similar to bioethics, the field of rehabilitation is also relatively new. Rehabilitation medicine as a recognized specialty rose to prominence only during World War II when pioneer physicians Howard Rusk and Henry Kessler demonstrated the efficacy of rehabilitation in returning soldiers to active duty, rather than to on-going disability (O’Brien, 2001). Until recently, the bioethical issues in the area of rehabilitation medicine have received relatively little attention (Wendell, 2001). This lack of emphasis may be in part due to the fact that rehabilitation is a relatively young specialty; however, Caplan (1987) suggests that, “the newness of the field is not an entirely satisfactory explanation for such analytical neglect,” (p. 3). Despite the potential to make a powerful contribution to rehabilitation, bioethics as a field has been largely devoted to the ethical problems of acute care medicine (Herbison, 1998; McGrath, 2007). The ethical challenges specific to the care of people with chronic and complex disabilities have received far less attention (Davies, Laker & Ellis, 1997; Wendell, 2001).

Bioethics in rehabilitation attracts relatively little attention for several reasons. The first is raised by Scofield (1995) who argues that the realities of rehabilitation do not fit into the “relatively pristine” (p. 78) and tidy world of acute care medicine, or into decision-making frameworks that are often applied across care settings. While there is certainly a connection between rehabilitation and acute care, Scofield suggests that the values that
underpin traditional bioethics, and the attitudes and circumstances that affect our beliefs about how these values should be applied, need to shift in the context of complex disabilities. While the ethical dilemmas in acute care are challenging, they are relatively well defined – life versus death, physician versus patient, paternalism versus self-determination (Scofield, 1993, p. 341). Rehabilitation, however, takes a different approach. In this setting, ethical perspectives are less adversarial and more nuanced. The focus instead is, “not on cure, but on care; not on a specific pathology, but on the whole patient; and treatment is neither oriented nor driven by crisis,” (Scofield, 1993, p. 342).

Second, rehabilitation is often regarded as the “distant cousin” of acute care medicine (Haas, 1993, p. 231). Rehabilitation lacks the visibility and appeal of the high tech dramas played out in acute care settings (Ells, 2001; Scofield, 1995). This may reflect the belief that the ethics of rehabilitation, like rehabilitation itself, is less interesting or important than acute care medicine, where critical decisions involving life or death are made every day (Wendell, 2001). Acute care focuses on restoring patients, on reversing the course of disease – essentially, on curing patients. In contrast, brain injury rehabilitation focuses on patients whose injuries are typically life-changing and irreversible (Huby, Stewart, Tierney & Rogers, 2004). Haas goes so far as to say that rehabilitation is regarded as a second-class field, where some (my emphasis) type of medicine is practiced, but it is not like the real medicine that is delivered in acute care. However, as Hass further argues, rehabilitation in concerned not only with survival, but with enhancing function and maximizing quality of life. Its greatest challenge, then, is, “not adding years to life, but adding life to years” (p. 342).

The third reason that rehabilitation ethics attracts relatively little attention is because what accounts for “success” in acute care and rehabilitation is often quite different (Cardol,
de Jong & Ward, 2002b, p. 971). Despite the mainstreaming of disability and society’s increasingly responsive attitudes to people with chronic disease, there is a still a widespread lack of understanding about what rehabilitation can offer to patients whom others believe have reached the end of their functional potential. As Scofield (1995) succinctly writes:

It is not uncommon to hear family members of patients undergoing rehabilitation to marvel at the progress they make, partly because someone else previously led them to believe that their loved one would probably never be able to do much of anything again (p. 79).

In rehabilitation, however, patients and families are not passive recipients of care. A rehabilitation stay that is meaningful and effective depends on patients who are engaged and invested in their care. This calls for a different relationship between patients and providers, one that is collaborative and defined by patients’ goals and their commitment to be more independent (Huby et al., 2004).

Over fifteen years ago Scofield (1993) cautioned that, “neither ethics nor rehabilitation can afford to continue ignoring each other,” (p. 341). With an aging population and medicine’s success at combating death, a growing proportion of patients are living for longer periods of time with increasing levels of disability (Wendell, 2001). As a result, patients, families, and rehabilitation professionals are facing difficult questions around maintaining quality of life as patients progress along the continuum of care (Grant, Glandon, Elliott, Giger & Weaver, 2006).

*Autonomy in the Liberal Individualist Tradition*

Although there is a wide variation in the uses of the term *autonomy* in public discourse and philosophical discussion, the core meaning of autonomy is related to its literal translation “self-rule” (Christman, 1988). However, as Beauchamp and Childress (2001)
point out, autonomy is rich in paraphrase and loose in definition (p.58). To be autonomous means to be capable of self-determination in terms of decision-making or action. Further, an autonomous person is often characterized in Western liberal individualist cultures by ideas that include independence, but also self-reliance and the unrestrained ability to choose, as well as reflect on these choices (Agich, 2003). In the gerontological bioethics literature, Thomasma (1984) suggested five different meanings for freedom, which he equates with autonomy. Two decades later, Sandman (2004) summarized much of the thinking about autonomy into four elements, including self-determination, freedom, desire fulfillment, and independence. These features collectively describe autonomy as it is understood in the liberal individualist tradition (Agich, 2003). In this approach, autonomy is primarily defined by individual belief, choice, and action (Beckel, 1996). This view of autonomy has provided an important foundation for human rights and freedoms, such as the right to privacy and protection from the interference of others, but it has important limitations. Agich (1993) argues that while the abstract liberal concept of autonomy has its place legal and political spheres, it has no place in healthcare where a fuller conception is required, one that acknowledges the, “essential social nature of human development.” (p. 8). Another feature of most discussions about autonomy in the liberal individualist tradition is their exclusive focus on the individual (Secker, 1999; Sherwin, 1998). This feature mirrors the medical model that locates illness and disease within the patient, separated from the social contexts that contribute to health and disease (WHO, 2002). Moreover, it encourages patients to see their own healthcare decisions in isolation, thereby increasing their sense of vulnerability and dependence on their healthcare team.
Approaches to Autonomy in Rehabilitation

Agich (2003) suggests an alternative to the mainstream liberal individualist view of autonomy as it is applied to chronic disability. He proposes a more nuanced approach that is better suited to the reality of rehabilitative care – one that rethinks and reconsider the ethics of disability. Such a “refurbished concept” (p. 9) offers important advantages for understanding the ethical complexities of brain injury rehabilitation. A liberal individualistic approach to autonomy suggests that patients make independent decisions based solely on their own needs and values. Relational autonomy challenges this thinking, and suggests instead that patients seek meaningful self-direction within a network of dependent and interdependent relationships (Donchin, 1995; Sherwin, 1998). Predominant in feminist ethics, this approach to autonomy shifts the focus away from the lone individual, to thinking about people as interdependent beings who make decisions in the context of their social and physical environments. Bergum and Dossetor (2005) describe relational autonomy as a normative ethical approach grounded in the importance of relationships. In the context of healthcare, this includes the relationships between clinicians and patients, between patients and their families, between clinicians themselves, and even between healthcare teams and systems of care. They suggest that it is the relationships themselves that support and inform ethical reflection and decision-making, and that choice involves responsibility and connectedness to others, as well as being attentive and responsive to different life circumstances. Thus, relational autonomy requires us to consider who else may be involved in the decisions we make, who might be affected, and who may also wish to participate in the discussion (Oberle & Bouchal, 2009). In essence, this more robust understanding of autonomy moves away from the sole focus on individual rights and freedoms, to thinking
about the choices that patients and families make in the context of their healthcare and home communities (McDonald, 2002).

With acknowledgement of this “conceptual plasticity” (Agich, 2003, p. 10), I have begun to understand autonomy from the perspectives of three pivotal ethical thinkers, all of whom have a relational understanding of autonomy. The first is Collopy (1988) who defines autonomy as, “a notional field, a loose system of inter-related concepts that are characterized by ideas of self-determination, freedom, independence, liberty of choice and action,” (p. 10). He also points out that in this definition, the autonomous person does not make healthcare decisions in isolation; instead such decisions are made within a network of social relationships that can intern influence these decisions. The second is Agich (2003) who reminds us that in the context of disability, autonomy is not only a philosophical concept, but also an important cultural ideal that emphasizes dependence and interdependence, as well as the historical and social nature of patients and families. And the third is Sherwin (1998) who advocates that to respect autonomy is to treat patients as adults, to expect them to act responsibly, and to acknowledge and support their capacity for self-determination by recognizing a relational approach to autonomy that is socially and contextually dependent. Sherwin further emphasizes that in relational autonomy, social factors play a key role in whether or not an individual is able to make decisions or function autonomously.

The Intersection of Ethical and Clinical Issues: The Paradox of Autonomy in Brain Injury

The ethical and clinical issues that arise in the course of treating patients with chronic and complex care needs are multifaceted, and tend not to fit neatly into dominant models of decision-making (Wendell, 2001). Compounding these challenges is that discussions of patient autonomy in the rehabilitation literature in general, and brain injury in particular, are
scarce (Cardol et al, 2002b; Proot, ter Meulen, Abu-Saad & Crebolder, 2007). I have drawn instead from the learnings and deliberations on autonomy that are raised in the substantive long term care (LTC) literature. Thinking about ABI-related autonomy from the perspective of LTC is more helpful than acute care because it examines autonomy in the context of chronic disability. As well, LTC addresses the cognitive and behavioural impairments that differentiate people receiving brain injury rehab from patients receiving care from other rehabilitation settings – settings which focus almost exclusively on physical impairments (such as rehab following hip replacement).

Despite the dearth of ethical and clinical discussions in brain injury rehabilitation, respect for autonomy in this care setting raises complex and multidimensional issues. One of these issues is the tension between maximizing patient autonomy (or freedom of choice or self-determination), and ensuring that patients are adequately protected from harm (Wong, Clare, Gunn & Holland, 1999). In their thoughtful and provocative article, Cardol et al (2002b) suggest that growing social and political pressure has encouraged healthcare practitioners to move away from a predominantly medical model, to one in which the patient takes centre stage. In shifting from interest in the disease to interest in the person, they argue that autonomy is a fundamental prerequisite for participation in rehabilitation, and that it is a key concept in patient-centered care. Chan (2002) builds on these concepts of autonomy in the context of rehabilitation, and suggests that patient-centered practice is a cultural ideal that is based on active patient and family participation, as well as and shared decision-making between patients, families, and providers. However, Saadah (2002) responds to Cardol arguing that autonomy is not as straightforward in clinical practice as it is in theory. Instead, he maintains, there are important distinctions that are often in tension with each other,
including a) the ability to make decisions versus the ability to implement decisions, b) the challenges associated with decision-making capacity in people with cognitive impairments, and c) issues of negative and positive autonomy.

**Decisional Autonomy versus Functional Autonomy**

Decisional autonomy (the ability and freedom to make decisions) and functional or executional autonomy (the ability to implement these decisions) (Agich, 2009) are often in conflict in brain injury rehabilitation. In an ideal clinical environment decisional and functional autonomy³ are equal; however, given the complexities of rehabilitative practice and the heterogeneity of brain injury, this ideal is not always achieved (Collopy, 1988). Although many people with brain injury are dependent on others for care, they are often able to decide many things on their own. For example, patients who are unable to walk might nonetheless be fully capable to decide where they want to go, what they want to do, and with whom they want to spend their time. Even people who have cognitive impairments that diminish decisional autonomy are able to function independently in many ways (Agich, 2003). Collopy (1988) emphasizes, then, that if autonomy is defined principally in terms of execution, patients with complex disabilities – but who have decision-making capacity – may be erroneously “relegated to non-autonomous status” (p. 11). Cardol et al. (2002b) further argue that physical conditions often impede autonomy of function, even when systems of care are well resourced. For example, although accessible transportation is available within many urban centers in Ontario, patients consistently report that the system is so rigid that they are unable to flexibly respond to their environment.

³ *Functional autonomy* and *executional autonomy* are used interchangeably in the literature. While Collopy (and others) emphasize the latter, I have chosen to use functional autonomy in the same way that (Montuclard et al. (2000) (among others) have, because of its direct reference to physical, cognitive and behavioural function.
The distinction between decisional and functional autonomy is critical in brain injury rehab because as physical and cognitive impairments increase, the, “inner decisional core becomes a last and therefore most crucial preserve of self-determination,” (Collopy, 1988, p. 12). Making this distinction raises three important ethical, clinical, and policy gaps within the current literature: First, within the dynamic of rehabilitative care, to what extent do clinicians interpret the potential for physical dependence as a sign of decisional dependency? Second, can loss of autonomy be presumptively extended from levels of execution to levels of decision-making? And third, are there specific areas of autonomy in which this loss is most likely to occur - areas such as autonomy in ADLs, autonomy in regard to finances, and autonomy in transitions in care (Collopy, 1988; Proot, Meulen, Abu-Saad & Crebolder, 2007)? Supporting decisional autonomy, then, is fundamental to respect for autonomy in brain injury. However, it requires more than being simply open-minded: Specific supports must be in place to recognize and respond to the decision-making needs of those whose autonomy is defined beyond their ability to execute a task.

**Capable and Incapacitated Autonomy**

Capable autonomy is highly valued and widely debated in the context of chronic and complex disability. Capable autonomy refers to patient choices or behaviours that are informed, appreciate the consequences, and are made without coercion (Wong et al., 1999). In contrast, incapacitated autonomy involves patient choices that are uninformed, fail to

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4 This debate acknowledges that some understandings of autonomy involve the capacity to understand, appreciate, and execute informed choices, and thus would not have a notion of “incapable autonomy”. According to Dworkin (1988), critical reflection on desires is the key to autonomy. Therefore, as long as a person’s brain injury does not affect the capacity to reflect, it does not threaten autonomy (unlike some less rigorous accounts that might understand autonomy as mere free choice, and not require that the person have decision-making capacity). I have chosen to draw from the term that Agich (1993) uses, with an understanding that it is not autonomy, per se, that is capable/incapable or autonomous/non-autonomous, but most certainly, the patient.
appreciate the consequences, and/or are manipulated or coerced (Collopy, 1988). This brings us back to the earlier tension between respect for patient autonomy while ensuring that patients are also protected from harm. The principal ethical challenge for the clinician assessing decision-making capacity is to determine when this capacity is sufficiently lacking such that decisions need to be made on behalf of a patient. In other words, determining when a patient is so incapacitated that others must justifiably intervene in order to promote the principle of beneficence (Beauchamp & Childress, 2009; Lush, 2001). Collopy (1988) complicates matters further when he questions whether informed consent requires the ability of the patient to make insightful, unmanipulated, and independent decisions and if so, how useful the concept of self-determination is for patients whose injury has impacted the very skills associated with good judgment.

One way to help clinicians determine a patient’s required level of capacity is a sliding-scale approach to risk (Buchanan & Brock, 1998). Buchanan and Brock (1998) are advocates of a risk-related standard of capacity; this standard suggests that the degree of risk a patient is willing to take is proportional to how much capacity he or she requires. In other words, in a risk-related standard of capacity, a patient who wishes to take greater risks requires greater decision-making capacity. Thus, a the patient who wishes to return to independent living rather than reside in LTC requires greater capacity in order to balance the risks and benefits associated with his or her decision (Schermer, 2004). This approach assumes that the greater the cognitive challenge posed by high risk activities, the more the elevated required standard of capacity (see Beauchamp & Childress, 2001; Wicclair, 1991a, b). It also implies that a lower standard of capacity should be used when a patient is asked to choose among lower risk, or more standard approaches to care. A risk-related standard may
be useful in brain injury because it recognizes the context-specific nature of capacity and the fact that patients’ choices reflect how they perceive themselves within their relationships, communities, and society at large (Oberle & Bouchal, 2009; Sherwin, 1998).

Another challenge concerning the assessment of capacity in rehabilitation is that the informed consent standard has emerged from acute care where there is a narrower view of the relationship between doctors and patients (Collopy, Dubler & Zuckerman, 1990). Further, many of the issues surrounding consent and capacity have surfaced through lawsuits, and it is through a legalistic prism that many clinicians understand their obligation to respect patient autonomy (Halpern, 2001). Therefore, the relevance of these issues to the practical decisions of patients with chronic and complex disability may be limited (Moody, 1988).

Finally, capacity is not static. Since physical and cognitive abilities can change over time, capacity, too, can change (Mukherjee & McDonough, 2006). If we accept that capacity means that a person has the ability to perform a certain task or direct someone to perform that task on his or her behalf, then capacity is always activity-related: A patient may be capable of performing certain tasks (or making decisions regarding that task), but may not be capable of performing or making decisions about all tasks (Collopy et al., 1990; Lush, 2001). For example, a person may be able to buy his own groceries, but not be able to handle his own finances. However, this understanding of capacity also assumes that decision-making itself is an activity, and grants that sometimes the action itself may be to not act (Beauchamp and Childress, 2008). As a result, several factors need to be considered when assessing capacity in brain injury. These include the patient’s physical, cognitive and behavioural abilities, comprehension of the situation (both in general terms and the patient’s part in it), cultural
background, network of relationships, as well as the risks associated with the decision (Lush, 2001).5

In conclusion, there are two inherent risks for clinicians when determining the capacity of a person with an ABI. The first is there is no simple agreed-upon algorithm for quick assessment of a patient’s decision-making capacity (Lush, 2001). This raises questions about the difficulty and complexity of capacity assessments, and the possibility that the assessment may be wrong. The second is the decisions that these patients make are often in conflict with clinical goals, professional expectations, and societal norms (Collopy, 1988). As a result of these perhaps questionable decisions, clinicians may, rightly or wrongly, challenge patient capacity.

Negative and Positive Autonomy

The third tension related to patient autonomy and brain injury arises from the well developed philosophical discussion of rights and liberty (Collopy, 1988). Such discussion distinguishes between the current medical norm of non-interference or negative autonomy on one hand, and empowerment or positive autonomy, on the other (Agich, 1993; Beauchamp & Childress, 2008). Negative autonomy in healthcare involves leaving patients alone to make decisions without interference from the medical community. Although this norm of autonomy has greatly influenced current clinical practice, it is a relatively recent ideal,

5 For an in-depth discussion on important factors to consider when assessing capacity in brain injury see Lush, 2001, p. 93 – 95.)
emerging from the biomedical ethics movement over the past forty years. In her seminal work, “From Detached Concern to Empathy” (2001), Jodi Halpern calls for a paradigm shift in how bioethics understands autonomy. She suggests that we need to look beyond the current emphasis on negative autonomy as non-interference, towards a more positive view of autonomy—that emphasizes the capacity of a person to act in a way that is guided by free and flexible reasoning, and not simply by a person’s liberty to do whatever he or she wants. Halpern advocates that viewing autonomy as freedom from interference frequently translates into leaving patients alone, often without supports, to make difficult clinical and ethical decisions. She argues against this legalistic conception and supports a more positive approach that aims to empower, support, and enhance decision-making. Agich (1990) agrees, proposing an interpretation of autonomy that views individuals concretely, and understands choice as a, “problem of providing options that are meaningful rather than as an issue of removing obstacles to choice or impediments to action,” (p.12). This approach encourages clinicians to step forward, not back, and provide resources, offer assistance, and advocate for choices. The paradox nonetheless remains: The traditional liberal individualistic view of autonomy supports the concept of patients who are self-sufficient, articulate and able to make decisions about the course of their lives on their own (Sherwin, 1998). However, this is not the reality for many ABI patients who are often vulnerable and dependent for many aspects of their care (Agich, 1993).

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6 Few other cultures prioritize respect for autonomy and truth-telling as a dominant paradigm of the medical community. See Agich, 2003; Glick, 1997; and Good, 1991 for a thorough review.
Thus, a shift from detached non-interference to empathic engagement of patients and families moves clinicians away from a more liberal individualist view of autonomy, to a more socially situated or contextualized approach (Sherwin, 1998). This positive approach is relevant to ABI patients who must often decide among discharge options that may not reflect their own wishes (such as considering institutional care). However, Collopy (1988) cautions that while negative notions of autonomy can be used to justify care that is non-involved and “minimally custodial” (p.17), positive notions of autonomy are also ethically problematic. One concern is that families (or clinicians) who adopt a purely positive approach to autonomy may assume an unjustified paternalistic stance to patient decision-making. In other words, they interfere with a patient’s choices and behaviours allegedly in the name of respect for autonomy. Therefore, developing a more balanced interplay between positive and negative notions of autonomy is critical – one that ultimately moves beyond simply protecting the primacy of non-interference – to recognizing clinicians’ obligations to enhance autonomous choice and function among those within their care (VHA Bioethics Committee, 1999).

International Classification of Functioning, Disability and Health

Another concept that guides my thinking about disability and function is the WHO’s International Classification of Functioning Disability and Health (ICF). This model also recognizes the influence of social factors on disability and health, and offers clinicians, policy-makers and researchers a framework for discussing these issues (Ustün, Chatterji, Bickenbach, Kostansek, & Schneider, 2003; WHO, 2002). The ICF considers disability in terms of three health-related domains: Impairments, activity limitations and participation restrictions. Impairments are defined as problems in body function and structure, such as
significant deviation or loss. *Activity limitations* are characterized by difficulties experienced by an individual in executing an activity. *Participation restrictions* are problems experienced at the level of the community. For a representation of the model of disability that is the basis for ICF see Figure 1. Within the ICF, function and disability are understood in the context of the individual, institutional and societal levels, making it a valuable tool to understanding health-related questions involving clinical, research, and policy issues (Australian Institute of Health and Welfare, 2003; WHO, 2002).

The general principles that underpin the ICF are closely linked to the biopsychological model of disability (Eadie, 2003). This model understands disability as a complex phenomenon that is mediated by personal, environmental and social factors (WHO, 2002). A biopsychological approach sees disability as an interaction between features of the person and features of the environment in which the person lives. For example, a person in a wheelchair may be unable to return to work due to the combination of her physical impairments, as well the fact that her office has no assessable bathroom.

Figure 1: One Representation of the Model of Disability that Forms the Basis for the ICF. The disability versions of the central constructs are shown in italics (WHO, 2002)
Critics of the ICF argue that although the domains within the model relate to quality of life, quality of life itself is not considered (Wade & Harrigan, 2003). They also highlight that the framework does not separate out or acknowledge possible differences between the perspective of the individual and the perspective of external observers (Post, de Witte & Schrijvers, 1999). Third, it does not take into account issues of time, such as a person’s stage of life or illness (Wade & Harrigan, 2003).

Despite these limitations, the ICF is an important international tool for identifying and measuring the effectiveness of rehabilitation services, grounded in an integrated biopsychosocial model of human functioning and disability (Ustun et al., 2003; WHO, 2002). The framework is a radical shift from emphasizing an individual’s disabilities, to focusing on his or her level of health. A significant part of this shift is that it helps articulate the complex and dynamic social factors that determine health and health outcomes (Imms, 2006).

**The ICF in the Context of Acquired Brain Injury**

ABI-related disability has enormous economic and social consequences across a patient’s lifespan (Whyte et al., 1999); however, rarely are the consequences limited to one set of symptoms, clearly delineated impairments, or one aspect of life. Rather, the impact of ABI influences function along a continuum, from altered physiological function of cells, to physical, cognitive and behavioural impairments, to medical issues that affect the individual, family, and greater society (NIH Consensus Statement, 1998). Table 2 gives some examples of ABI-related impairment associated with the three ICF levels of function.
Table 2: Examples of Disabilities Associated with the Three Levels of ICF Function in the context of ABI

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Nature of Impairment</th>
<th>Activity Limitation</th>
<th>Participation Restriction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor</td>
<td>Unilateral weakness of the upper and lower limbs</td>
<td>Unable to use public transportation independently</td>
<td>Lack of accessible transportation leads to reduced participation in community activities</td>
</tr>
<tr>
<td>Sensory</td>
<td>Loss of sensation in dominant hand</td>
<td>Difficulty performing fine motor tasks</td>
<td>Unable to eat independently in public</td>
</tr>
<tr>
<td>Visual</td>
<td>Bilateral double vision</td>
<td>Difficulty focusing on an object in space</td>
<td>Change in family role as unable to drive</td>
</tr>
<tr>
<td>Communication</td>
<td>Difficulty in producing meaningful spoken or written language</td>
<td>Unable to communicate with friends on the telephone or computer</td>
<td>Decreased ability to communicate leads to “fading away” of relationships</td>
</tr>
<tr>
<td>Cognitive</td>
<td>Short term memory and attention deficits</td>
<td>Challenges in concentrating and multi-tasking; difficulty in remembering new information</td>
<td>Denied employment because of employer’s lack of understanding and ability to accommodate</td>
</tr>
<tr>
<td>Behavioural</td>
<td>Feelings of depression and apathy</td>
<td>General disinterest and lack of initiation in day-to-day activities</td>
<td>Reduced participation in rehabilitation and other activities aimed at recovering function</td>
</tr>
</tbody>
</table>

Patient Safety and Transitions in Care

Involving Patients in Patient Safety

Over the past decade there has been a shift in the role of patients from receivers of care, to active and responsible partners in their care (Consumers Advancing Patient Safety, 2008). International, national, and local initiatives have all echoed this change (WHO World Alliance for Patient Safety, 2009; Hatlie, 2006; Ontario Hospital Association [OHA], 2006). In their 2006 media campaign, the OHA launched Your Health Care: Be Involved, which
aimed at empowering patients and families to take a more active role in their healthcare and promoting better health outcomes by improving information exchange between patients and providers. Although the centrality of patients and families seems like a basic tenet of rehabilitation, little is known about engaging them as active participants in their care (Ponte et al., 2004). It seems reasonable to assume that when healthcare teams expand to include patients and families, they become more proactive in their decision-making, more aware of issues around risk-taking and safety, and more effective in working together to achieve their rehab goals. However, the evolution of highly effective interprofessional teams has been challenging, particularly given the hierarchical, outcome-oriented, and medically-driven hospital environment (Ponte, Conlin, Conway, Grant & Medeiros, 2003). In such an environment, patients and families often feel intimidated to share their perspectives on challenging and sensitive issues such as risk-taking and safety (Grant, Glandon, Elliott, Giger & Weaver, 2006).

Despite the acknowledged importance, there is limited evidence to support including patients and families in clinical and ethical decision-making in rehabilitation (Zipperer, Berendsen & Watson, 2006). Research suggests that patients want advice about risk-taking and safety, and wish to be told be informed about the risks and potential harms associated with their decisions and actions (Gallagher, Waterman, Ebers, Fraser & Levinson, 2003). Yet the views of patients are only slowly being integrated into efforts to improve safety (Edgman-Levitan, 2004). Amidst this debate is growing political and social pressure that clinicians have a responsibility to disclose adverse events to patients (Entwistle, Mello & Brennan, 2005; Gallagher et al., 2003). In response, Ontario has recently adopted legislation that makes it easier for healthcare professionals and organizations to apologize in the event of
The underlying aim of this legislative framework is to improve systems and processes to reduce the chance of the harm occurring again. Despite heightened awareness on the part of patients, families, and clinicians of the importance of involving patients in their care, little is known about engaging these stakeholders in safety and ethical issues important to them as they transition beyond acute care (Cardol et al., 2002b; Leathem et al., 1996).

**Transitions in Care**

Patients with complex care needs frequently require care in multiple care settings and are particularly vulnerable to poorly executed transitions in care (Coleman, 2004; Levine, 1998). Despite the recent spotlight on transitions from one care setting to the next, clinical and policy discussions about enhancing the safety of transitions in healthcare remain disjointed (Forster et al., 2003; Perry, 2004; Perry, Wears & Emily, 2008). Transitions or “handoffs” in care represent a highly vulnerable time for errors. For example, over 40 percent of older adults transferred from acute care experience at least one medication discrepancy (Coleman, 2003). Significant resources have focused on examining this critical period in care delivery; however, in the absence of adequate preparation, communication and understanding, poorly executed care transitions can confound an institution’s best attempts to keep patients and families safe after they leave their care setting (Henriksen, Oppenheimer, Leape, Hamilton & Bates et al., 2008).

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7 Following the lead of British Columbia and other provinces, Ontario has freed healthcare providers to apologize without admission of liability in civil proceedings. Under the *Apology Act, 2009*, "words or actions indicating contrition or commiseration" no longer constitute admission of fault. The legislative framework is based on the idea that apologizing not only helps the healing process of patients by acknowledging that a harm has been done, it also promotes an atmosphere of accountability and open communication between patients, families, and their healthcare team (Health Insurance Reciprocal of Canada, 2009). A full reading of the Act is available at: [http://www.e-laws.gov.on.ca/Download?dID=462378](http://www.e-laws.gov.on.ca/Download?dID=462378)
Call for improvements to safe transitions in care often cite enhancing communication between clinicians, patients, and families, implementing electronic health records that include standardized medication reconciliation elements, and developing better performance measures (National Transitions in Care Coalition, 2008). While these are important considerations, transitions in care have largely focused on acute care settings and from the perspective of the healthcare provider, often in a highly mechanistic way (Moore, Wisnevesky & Williams, 2003; Philibert & Leach, 2005). Little emphasis is placed on transitions beyond acute care and from the perspective of patients and families. However, the transition from rehabilitation to home poses safety issues that are different from acute care and not well understood (Macchiocci & Stringer, 2001).

The Emergence of Qualitative Research in Patient Safety and Rehabilitation

One of the issues that confounds our understanding of safe transitions in care is the issue of empirical measurement. Implementing safety initiatives within hospitals involves multi-component interventions interacting within complex and adaptive social systems (Berwick, 2008). In his bold and somewhat controversial commentary, Don Berwick (2008) of the Institute for Healthcare Improvement maintains that solely relying on randomized control trials is an “impoverished” (p. 1183) way of measuring the effectiveness of healthcare systems that are influenced by complex factors such as organizational culture, changing leadership, and dynamic care environments. This epistemological incongruency is echoed by others who argue that other richer – and equally as rigorous – ways of understanding multidimensional phenomena, are needed (Wolosin et al., 2006). Physician and researcher Eric Coleman is a key contributor in the area of qualitative research and transitions in care. He suggests that qualitative inquiry can play an important role in understanding the factors
that are important to making care transitions safer, how, and in what context (Coleman & Fox, 2004; Coleman, Smith, Frank, Min, Parry et al., 2004). A growing number of qualitative studies support this claim. They consistently demonstrate that patients and families are often unprepared for their next care setting and identify critical areas where patients and families are vulnerable to error because of disjointed transitional care processes. For example, patients often receive conflicting advice regarding the management of their condition, are unable to reach an appropriate member of their care team who has access to their care plan, and have minimal input into their discharge goals (Grimmer, Moss & Gill, 2000; Harrison & Verhoef, 2002; vom Elgen, Walker, Edgman-Levitan, Cleary & Delbanco, 1999; Levine, 1998).

Qualitative study in rehabilitation is a rapidly developing field. Over the past two decades the area has reached a level of maturity and sophistication that has expanded beyond rapidly moving clinical trials, to more interpretive work that has made valuable contributions to understanding complex phenomenon in rehabilitation (Cardol et al., 2002a; Haas, 1994; McGrath, 2007). However, despite an emerging body of qualitative work, as well as healthcare’s recent emphasis on transitions in care, there is a paucity of literature that seeks to better understand transitions in care in the context of rehabilitation. Recent research conducted within Toronto Rehabilitation Institute, a large adult rehabilitation and CCC facility in Toronto, has explored patient safety issues from the perspective of staff members (Fancott, Velji, Aimone & Sinclair, 2006). Issues of risk-taking and safety related to patient autonomy were raised consistently by staff as areas of concern, particularly as they influence discharge planning and safe transitions in care. Absent from these discussions, however, were the views of patients and families, and their perspectives of risk-taking and safety
during the rehabilitation process. There is a compelling argument that for transitions in care to be as safe as they can be, they need to be understood from the perspective of patients, families, and clinicians, and the issues involved in balancing patient risk-taking and safety during rehabilitation.

**Summary**

Acquired brain injury is a significant and growing health concern in Canada, and is the leading cause of serious disability among adults. It is complex, life-long, and has significant social, healthcare and human costs. As people live longer and with greater degrees of disability, the importance of brain injury rehabilitation as an important first step in recovery is clear. However, less clear are the factors that are important to recovery and safety as patients and families transition from rehabilitation to home.

Critical to ethical and clinical decision-making in brain injury rehabilitation is an understanding of some of the debates about how patient autonomy is conceptualized in the literature. Emerging from these discussions is a strong argument that a liberal individualistic view of autonomy is inadequate for brain injury care, and the recognition of the paradoxical nature of autonomy in the context of complex and chronic illness. These paradoxes challenge widespread values and assumptions about the concepts of patient autonomy, both within and outside the healthcare system. Specifically, brain injury rehabilitation brings into question our understanding of the nature of the provider-patient relationship, ethical principles and standards governing healthcare decision-making, and conventional expectations about the caregiving duties of the family.

While there is extensive literature on patient autonomy, as well as a growing discussion on transitions in care, there has been little exploration of the issues that influence
ethical and clinical decision-making related to autonomy during transitions in care. Research in these areas has focused largely on acute care and the patient-provider relationship; the challenges of patients and families transitioning beyond rehabilitation have received comparatively little attention. Qualitative inquiry is a rapidly developing field in rehabilitation and has played a key role in understanding patient risk-taking and safety in fuller and more meaningful ways; however, there are few studies that guide clinicians regarding the factors that are important to understanding these issues during brain injury rehabilitation. Further, there is limited evidence exploring risk-taking and safety from the perspectives of patients, families, and clinicians who play critical roles in the ethical analysis of transitions in care.

**Purpose and Research Questions**

This study examines the challenge of balancing risk-taking and safety among patients, families, and clinicians during decision-making in the transition from brain injury rehabilitation to home. The goal of this grounded theory research is to explore the ethical and clinical issues that influence such decisions related to both respecting patient autonomy and advancing patient safety in the area of rehabilitation. Specifically, this study asks the following research questions:

1. a) What ethical and clinical challenges do clinicians experience in deciding how to balance patient risk-taking and patient safety during inpatient brain injury rehabilitation?

   b) To what extent do these clinicians’ decisions conflict with those of the patients and families in their care, as well as with those of other members of their healthcare team?

   c) How do these potential conflicts influence decision-making related to patient risk-taking and safety, which may have an impact on patient autonomy?
d) What are the implications of these potential conflicts on clinical practice?

2. a) What are the social and systems factors both within and outside healthcare that can also influence ethical and clinical decision-making related to patient risk-taking and safety?

   b) What influence do these factors have on safe transitions in care from inpatient rehabilitation?

3. a) Might a relational (vs. individualistic) approach to autonomy provide better guidance to clinicians in deciding how to balance patient risk-taking and safety in brain injury rehabilitation?

   b) What are the ethical and clinical implications of a relational approach to autonomy that is committed to both the principles of respecting patient autonomy and advancing patient safety?
Chapter 3: Research Procedures

The aim of this study is to explore the ethical and clinical factors that influence how patients, families, and clinicians make decisions about risk-taking and safety. Despite its acknowledged importance, there is scant literature to guide these stakeholders in decision-making related to risk-taking and safety during brain injury rehabilitation. By understanding some of the factors that can influence such decisions, rehabilitation clinicians may be better equipped to address the tensions inherent in respecting autonomy and advancing safety as they help prepare patients and families to transition beyond their care. To explore these issues I used in-depth interviews with former patients of the ABI service at the Toronto Rehabilitation Institute (Toronto Rehab), their family caregivers, and key members of their inpatient clinical team. The following section describes the assumptions and logic that guide my research methodology and methods. I begin by discussing my interpretivist orientation as the epistemological foundation to my research. Next, I define my approach to grounded theory, an approach that combines symbolic interactionism with constructivist methodology. I then outline specific methodological considerations, including the use of in-depth interviews as my primary method of data collection. Finally, I reflect on my approach to reflexivity, grounded in the context of my interpretivist and constructivist leanings, including a discussion on criteria for judging soundness in qualitative inquiry. I conclude by introducing the participants of the study, as well as the ABI unit at Toronto Rehab.
An Interpretivist View of the World

My research explicitly assumes that any theoretical rendering offers an interpretivist portrayal of the world, not an exact picture of it. Interpretivism is a response against the notion that postpositivism and empiricism are the only means of doing good science (Charmaz, 2003). This philosophy proposes that we cannot come to know how the world really is, and rejects the search for generalizable truths and laws about human behaviour as the sole source of science. Interpretivism reacts against the idea that the same research methods and paradigms apply to both the social sciences and the natural sciences. Instead, interpretivists believe that we also need to concentrate on a more local understanding of the world (Willis, 2007). Understanding is a fundamental tenet of an interpretivist world view. It assumes that the meaning of human action is inherent in what is studied, and that the task of the inquirer is to unearth that meaning (Schwandt, 2007). Perhaps most importantly, interpretivism strives to understand in context, and acknowledges that “understanding” a phenomenon (an interpretivist ideal) is much different than “knowing” it, (a postpositivist claim). This desire to understand rather than to know forms the ideological orientation to my research, and directly informs my philosophical approaches to grounded theory.

Towards Symbolic Interactionism and Constructivism in Grounded Theory

In addition to an interpretivist’s view of reality, my approach to grounded theory methodology also draws from constructivism and symbolic interactionism. Since its “discovery” in the late 1960s, grounded theory has taken on two different forms: Constructivism and objectivism (Charmaz, 2003). Constructivists assert that reality is socially constructed and can be understood only in context. They assume that knowledge is mutually created by the researcher and participant, and strive towards a more interpretive
understanding of meaning (Charmaz, 2003; 2006). In contrast, objectivists propose that all data are derived from the observable facts of reality, and that this reality is awaiting discovery from the unbiased observer who records facts about it. Theory grounded in objectivism or postpositivism believes that the careful application of one’s methods will generate theoretical knowledge. The researcher then becomes more of a conduit for the research process than the creator of it (Charmaz, 2002). Constructivist grounded theory distinguishes between the real and the true. It does not seek universal and singular truths; instead, it understands that reality is multidimensional and explicitly offers an interpreted portrayal of the world (Denzin & Lincoln, 1995). Take for example, the experience of returning home following a TBI from a constructivist view. The researcher would perceive very differently the man who is adjusting to life in a wheelchair, the wife who must now provide full time care, and the therapist who recommends difficult discharge options. The implications of constructivism to healthcare research is that it attempts to bridge philosophy and practice, and understands that context is critical to how patients and families experience life after sudden disease, illness or trauma (Corbin & Strauss, 2008).

While constructivism informs the methodological basis of my approach to grounded theory, symbolic interactionism, as first described by Mead (1969) and Blumer (1969) and later by Denzin & Lincoln (2005), provides the theoretical foundation. Symbolic interactionism is rooted in sociology and social psychology, and is based on the belief that people behave and interact based on how they give meaning to specific symbols in their lives (Creswell, 2007). Creswell proposes that people construct their own realities from the symbols around them and through interaction with others. In this way, humans are active participants in creating meaning. In the context of healthcare, symbolic interaction studies
relationships between clinical stakeholders, and emphasizes that this interaction is not based solely on the way health-related experiences “really” are, but on how we interpret them (Locke, 2001). Therefore, it is symbolic meaning rather than concrete meaning that is most important in symbolic interaction studies (Denzin & Lincoln, 2005; Schwandt, 2007).

My approach to grounded theory builds upon a symbolic interactionist theoretical perspective combined with constructivist methodology. A constructivist approach to grounded theory complements symbolic interactionism because they both emphasize how action and meaning are constructed. They also both recognize that theory is an interpretation that depends on the researcher’s view; it does not and cannot stand outside of it (Charmaz, 2006). Thus, the aim of the researcher is to understand the meanings of participants’ experiences and build a conceptual analysis of them (Schwandt, 1998). In summary, two characteristics lie at the heart of my interpretive epistemology: The search for contextual understanding instead of universal laws and truths, and an emergent approach that seeks to understand human behaviour in context.

Data Collection

Semi-Structured Interviews

For the purpose of this study I conducted 16 intensive, active, and in-depth interviews. Specifically, this research involves three groups: Former inpatients of the adult ABI program at Toronto Rehab, who had been discharged home within the last four months; a family caregiver of these former inpatients; and a key member their healthcare team. Clinicians were selected because of their involvement in the discharge planning process, and included a physician, a physiotherapist, two occupational therapists, a rehabilitation therapist and a social worker. In total six clinicians, five patients, and five family members were
invited to participate in one-on-one, semi-structured interviews to identify issues of patient autonomy, risk-taking, and safety following discharge from brain injury rehabilitation. Interviews were 60 – 90 minutes in length and conducted at a location of convenience for participants, including at their home, at work, or at Toronto Rehab.

These interviews were based on a grounded theory approach that offers three advantages to this research. First, grounded theory interviewing proposes fresh ways of exploring ideas through a combination of control and flexibility (Kvale, 1996). In this approach, the interviewer assumes a controlled stance over the construction and analysis of data. Grounded theory interviewing differs from other in-depth interviewing because the researcher narrows the range of interview topics in order to gather specific data for developing a concept and gain more analytic control (Charmaz, 2006). I explored issues of respect for patient autonomy and clinical decision-making related to risk-taking and safety among participants who were selected based on their substantial experience and insight. Interviewing is also a flexible and emergent technique; as ideas and issues emerged during the interview, I immediately pursued these leads. I used a semi-structured interview (see Interview Guides in Appendix A and B) which allowed participants enough flexibility to share their perspectives, but was narrow enough for me to explore their specific clinical experiences (Kvale, 1996; Loftland & Loftland, 1995). I also asked open-ended questions related to participant’s views on risk-taking and safety during the rehabilitation process; how these views may be congruent or in conflict with others; and the social, environmental, clinical, and policy factors that are also critical to safe transitions in care.

Second, I took several steps to make the patient interview experience as positive and valuable as possible. Initially, I piloted the interview questions to ensure that they were
workable and feasible. Piloting also helped me to evaluate the sequencing and phrasing of the questions, as well as to further develop my interviewing skills. As suggested by Bowers (1995), I also tried to select my questions economically and ask those with the highest priority first, to reduce patient fatigue and agitation. Prior to our interview, I held a short preliminary meeting with all patient and family participants, as outlined by Paterson and Scott-Findlay (2002). This provided an opportunity for participants to acquaint themselves with me, to ask questions related to the consent and research process, and to begin developing rapport. As well, it allowed discussion about the best location and timing for the interview, taking into consideration tolerance of stimuli and patterns of fatigue for patients.

Third, interviews with participants were guided by the principles of the Active Interview (Gubrium & Holstein, 2002). In this method, the passive responder is rejected in favour of the active participant who is engaged in the co-construction of meaning. Throughout the data collection phase I modified the interview questions to reflect new issues or perspectives (Creswell, 2007). I began interviews by asking patients to describe how their brain injury occurred, some of the important milestones leading up to their discharge home, and if they considered these activities risky or safe. In the case of families, I initially asked them about some of the risk-related challenges they experienced when preparing to bring their loved one home. For clinicians, I first wanted to know what they considered to be a “safe” discharge for their patients, as well as the factors that can threaten or enhance patient autonomy as patients and families prepare to transition beyond their care. In all cases I used probes for elaboration and clarification to elicit further detail. And while the interplay between data collection and interpretation was useful, the simultaneity of the two allowed me to explore ideas that I did not initially anticipate. For example, while a “safe” discharge
meant different things to different people, all participants discussed the importance of a stimulating and nurturing environment as critical to respecting autonomy at home. What also emerged was that, for these clinicians, LTC poses a significant threat to autonomy. The reaction against LTC was so strong that I felt that I needed to explore it more detail. During subsequent interviews it became clear that clinicians view institutional living as isolating and not goal-oriented. Both of these issues turned out to be significant factors when considering autonomy at home.

*Theoretical Sampling and Saturation*

This study consists of a theoretical sample of patients, families, and clinicians following intensive brain injury rehabilitation. Theoretical sampling is a method of data collection where the investigator selects a group of “information-rich” individuals to study based on their insights and contribution to the development of analysis (Creswell, 2007). The purpose of this approach is to gather material that will maximize opportunities to develop themes, uncover variations, and identify relationships among themes (Corbin & Strauss, 2008). Theoretical sampling is distinguished from other approaches to sampling as it seeks to collect relevant data to elaborate and refine categories in an emerging theory. It is not about representing a population, nor increasing generalizability of results; instead, its sole purpose is develop concepts and move analysis forward (Corbin & Strauss, 2008). This approach follows the logic of grounded theory as I did not collect the entire set of data before beginning data analysis (Charmaz, 2002). I began analysis immediately following the first day of data collection. Corbin describes this early analytic approach as a cycle: “Analysis leads to concepts. Concepts generate questions. Questions lead us back out into the field,” (p. 216.) This circular process continued until I reached saturation - the stage where no new
categories or themes emerge. But, as Corbin also points out, I view saturation as more than a matter of no new data. It also denotes the point where concepts are well defined in depth, breadth, and scope (p. 148).

There is also the question about how many interviews are necessary in order to reach saturation. Guest, Bunce & Johnson (2006) point out that although theoretical saturation has become the gold standard in health science research, there are very few guidelines that help researchers estimate the sample size they require. This study involves interviews with 16 participants. Corbin, Charmaz, and Guest et al. all agree that total saturation (complete theme development) is probably never achieved; however, a minimum of 15 interviews likely have enough “analytic power” to offer considerable breadth and depth among major categories, clear relationships among concepts, and well defined gaps within and between categories.

**Memos and Diagrams**

Theoretical sampling involves starting with the data, constructing tentative ideas and then examining these ideas through further empirical inquiry (Corbin & Strauss, 2008). Memo-writing and diagramming are pivotal intermediate steps between theoretical sampling and writing drafts of papers (Charmaz, 2006). Following each interview (and also during transcribing), I used memos and field notes as a written record of my evolving analysis. My style of recording and managing memos involved the computer program ATLAS.ti (Berlin, Scientific Software Development, 2006), which is extremely useful as a warehouse of analytic ideas that can easily be sorted, ordered, and retrieved according to evolving themes. This program also allowed me to organize text, graphic, audio and visual files, along with memos and diagrams into a single project.
While the contents of memos are crucial to keeping a record of analytic thinking, diagramming is another way of stimulating new insights and generating ideas (Gubrium & Holstein, 2002). I frequently used diagrams as a visual device to help depict relationships between my emerging analytic concepts. My approach to diagramming involves concept mapping software (SmartDraw, 2007) as a graphical tool to help me organize and represent knowledge. I use diagramming as an analytic tool to think through key concepts and relationships in my research and help make the implicit, explicit. Consistent with the logic of grounded theory, memoing and diagramming were very helpful as a way of keeping track of cumulative and complex ideas. Initially, they were extremely emergent and rudimentary representations, but grew in complexity, clarity and accuracy as my research progressed. For an example of my approach to diagramming see Figure 2.

Data Transcription, Managements and Analysis

Data Transcription and Management

Transcription involves taking audiotaped material and presenting it in textual form for coding and analysis (Oliver, Serovich & Mason, 2005). All interviews for this study were audiotaped and transcribed verbatim by myself immediately following the interview. My approach to “textualizing data” took a middle road between naturalized and denaturalized modes to transcription, orienting towards the latter. In denaturalism, idiosyncratic elements of speech (e.g. nonverbal, pauses and stutters) are removed (Oliver et al., 2005). The emphasis is on meaning and perception in context, rather than a verbatim portrayal of speech (Sandelowski, 1994). This approach strives to provide a faithful representation of what was said, yet it has less do with do with depicting accents or involuntary sounds and is more concerned about the substance of the interview. I followed fairly conventional notation
system as outlined by Poland (2002) (adapted from Silverman, 1993). This system offers instructions that establish a clear and consistent approach to transcription. For examples of transcription conventions used to represent various functions see Appendix F. My approach to transcription reflects my view that we should focus less on how people with a brain injury communicate, but rather on the insights and experiences they bring to the interview. Critics might point out that by changing transcripts from their natural state, researchers commit a kind of “theoretical imperialism” (Schegloff, 1997, p. 174). While this may be true, no transcript will ever be a truly faithful reproduction of what was said (Poland, 2002). Many aspects of interpersonal interaction and nonverbal communication are missed in the audio record, which reflects the inherently representational and interpretive nature transcription.

Data Analysis

My journey with grounded theory analysis began with Barney Glaser and Anselm Strauss (1967) who have had a lasting influence on my early entry into this qualitative approach. I have based my logic of grounded theory, however, on the intersection of the writings of leading grounded theorists Kathy Charmaz (2006) and Juliet Corbin (2008). Both researchers have moved away from Glaser and Strauss’ postpositivist approach to grounded theory. While Charmaz is a firm constructivist whose worldview lies solidly in the interpretivist paradigm, Corbin’s view of grounded theory has postpositivist leanings. Both, however, understand grounded theory methodology as a set of, “principles and practices, not as prescriptions or packages,” (Charmaz, 2006, p. 9), and believe that, “multiple interpretations can be constructed from one set of data,” (Corbin, 2008, p. ix.).

The objectives of this study lend themselves well to the analytic approach of constructivist grounded theory. This approach consists of systematic, yet flexible guidelines
for collecting and analyzing qualitative data to construct concepts “grounded” in themselves (Charmaz, 2006; Corbin & Strauss, 2008). While most qualitative methods encourage researchers to follow up on interesting findings, grounded theory methods have the additional advantage of offering guidelines on how to proceed. Both Charmaz and Corbin offer prescriptive approaches to the rigor of grounded theory that consist of a clear set of tools from which to build explanatory frameworks that emphasize relationships among concepts. Grounded theory strategies, as described by Corbin and Strauss (2008), offer a classic set of “analytic moves” that include:

- Simultaneous data collection and analysis
- Constructing analytic codes and categories from data, not from preconceived a priori hypotheses
- Using a constant comparative method that involves making comparisons of patterns, similarities, differences during each stage of the analysis and taking them back out to the field
- Advancing theory and analytical development at each stage of data collection and analysis
- Memo-writing to elaborate categories, specify their properties, define relationships between categories, and identify gaps
- Sampling aimed toward theory construction, not representing study populations

Critics suggest that this approach to grounded theory is too prescriptive and rigid (Locke, 2001). While this may be true, I counter that this description of coding and analysis is an accessible and meaningful way to begin analyzing data, while leaving plenty of opportunity for an interpretive stance. Over the course of the analysis, I amended my initial grounded theory approach and did not adhere rigidly to all of the steps outlined by Corbin and Strauss; in doing so, I found my own points of departure. At all stages of the analysis, however, the software program ATLAS.ti was an invaluable tool to facilitate data labelling, search the relationships between codes, and manage and retrieve data. See Figure 2 for the high level steps I used in my data analysis.
Reflexivity can be a valuable tool to examine the impact of the presence of the researcher; evaluate the research process, method and outcomes; promote rich insight by examining personal responses; and offer a methodological map of research decisions (Finlay, 2002). Charmaz (2006) writes that reflexivity involves:

“…the researcher’s scrutiny of the research experience, decisions and interpretations in a way that brings the researcher into the process and allows the reader to assess how and to what extent the researcher’s interests, positions, and assumptions influence the inquiry,” (p. 188).

Consistent with these and other pivotal thinkers, (see Chesney, 2001; Cutcliffe, 2003; Gearing, 2004), my notion of reflexivity involves being conscious of the goals, values, and expressions that I bring to qualitative research. Finlay (2002) responds to critics of reflexivity by acknowledging that any reflexive analysis can only ever offer a partial account; yet, this provenance is critical for transparent, trustworthy, and ultimately political charged research.

One area of my research that requires particular reflexivity is my approach to the interview process. This study involves in-depth interviews with patients who have sustained a brain injury, their families, and the clinicians who have played key roles in their long and often challenging inpatient stay. I am one of those clinicians. As a physiotherapist working in the area of neurorehabilitation for the last decade, I bring some expertise in treating people with complex care needs, in educating their loved ones, and working within an interprofessional team. I also know many of the clinicians at Toronto Rehab who provide care on the brain injury service. One of the benefits of being an “insider” is a deepened appreciation of the issues around risk-taking and safety that are relevant to my participants (Perry, 2004).

Another potential advantage is that I bring a heightened sensitivity and understanding to rehab-specific terminology, including the meaning and significance of “insider language” (in
this case, the language specific to healthcare and brain injury). However, some of same factors that give me access, are the very ones of which I need to be vigilant. I am aware of the danger of imposing an agenda on the process of data collection and analysis, and am critical of the impact my beliefs may have on the research process. For instance, at several points during my interviews with clinicians, they turned to me and said, “Well, you know what I mean!” My aim is that by explicating these potential biases, I can bracket them as part of an iterative and reflexive journey. Borrowing from phenomenology, bracking involves putting aside beliefs, avoiding judgments, and remaining open to the data as it is revealed (Gearing, 2004). Therefore, rather than seeking to “neutralize” the impact of my emotional and professional involvement, Ahern (1999) suggests that it is instead important to recognize the inevitability of my connection, and the potentially significant part it can play in developing a reality-congruent picture of the complex issues related to patient autonomy and brain injury. I also felt that it was important to process my thoughts through writing. Following each interview I kept a reflexive journal with the aim to understand the values, attitudes, and beliefs that I was bringing to my research, and how they may affect both my interviews and the study. Reflexive writing also bestows a notion of believability and fidelity to my research by establishing an audit trail that is a testimony to my decision-making pathways (Finlay, 2002).

**Ethical Considerations and Consent**

The research proposal was reviewed and approved by the Toronto Rehab’s research ethics board (REB). Participation in this study was on a voluntary basis. At any point a participant may have chosen to not respond to a question and was free to withdraw from the study. Prior to the interview I also met with the two program managers on the ABI service at
Toronto Rehab to ensure their support and address any of their questions or concerns (see Letter of Program Support Appendix E).

This study involved ABI clinicians in two ways: First, clinicians were asked to identify potential patient participants and pass these names and contact information along to myself; second, they may have been approached to participate in the study. When participants confirmed that they wished to participate in an interview, I sent them a written informed consent form (see Appendix G). All participants had at least one week to read and sign the consent form prior to our interview, and were encouraged to contact me with any questions or concerns regarding the consent form or the study. Participants were given a signed copy of the consent form for their files. In all cases I obtained consent from a patient first, followed by a member of his or her family, and then a key member of his or her clinical team. The clear understanding was that if at any time a patient withdrew from the study, then all of the data in that patient-family-clinician triad would necessarily be removed. No participants withdrew from the study.

The following list summarizes the measures that I took to maximize privacy and security of participant information for this research:

- A master list with all participants and their unique identifying numbers are kept in a locked filing cabinet separate from transcripts and audiotapes.

- All transcript and demographic data are stored in a locked cabinet and will be destroyed five years following the completion of the study, as per Toronto Rehab REB guidelines.

- I transcribed the interviews myself immediately following each interview, so there was no third party involvement. No names were used in the transcripts.

- The transcription and data were all analyzed on my personal computer which is double password protected.
Figure 2: High level Grounded Theory Analysis (adapted from Corbin & Straus, 2008; Macintosh-Murray, 2003)

Data from interview transcripts field notes, memos

Open Coding
- Specify concepts
- Identify their properties
- Identify dimensional variability
- Identify differences and similarities
- Group into categories

Axial Coding
- Relate categories and subcategories according to their properties and dimensions
- Identify patterns (of conditions, actions/interactions, consequences) with explanation as goal

Selective Coding
- Integrate and refine categories
- Identify central category
- Integrate categories around central category
- Fill in poorly developed categories

 Coding for Process
- Identify patterns, variations
- Link categories
- Identify the structural conditions that give rise to these situations
- What is going on here?

Theoretical Saturation?

Stop data collection and analysis

Yes

No
Patients, families, and clinicians were all interviewed separately. This both protects participant confidentiality in the event that there are opposing views between groups, and optimizes data integrity as it increases the potential for honest perspectives. However, it also requires the interviewer to maintain complete confidentiality of information shared by the participants.

While Toronto Rehab is explicitly identified within the study, all other identifying labels were removed to ensure the confidentiality of participants.

Consistant with my REB agreement, data was analyzed individually and within groups, but not across patient-family-clinician triads, in order to assure complete confidentiality and anonymity of participants.

Criteria for Judging Soundness in Qualitative Inquiry

As qualitative inquiry continues to take its place as a valuable form of empirical knowledge in healthcare, it is important that clinicians, decision-makers, as well as the broader research community have confidence in the quality of the research. Increased acceptance of qualitative inquiry has resulted in numerous guidelines and frameworks for evaluating quality (Creswell, 2007; Cutcliffe & McKenna, 1999; Eakin & Mykhalovskiy, 2003; Kacynzski, 2006). Amid this rise to prominence is also considerable debate about the epistemological, ontological and methodological tensions inherent in evaluating research that is interpretive and creative (Dixon-Woods, Shaw, Agarwal & Smith, 2004; Whitmore, Chase & Mandle, 2001). My approach to quality in qualitative research is based on the assumption that the procedure for critiquing qualitative research is not simply one of judging rigid adherence to rules or specific prescriptive criteria, but is a process that weighs the various elements of the study in an effort to determine their appropriateness given the purpose and context of the inquiry (Curtin & Fossey, 2007).
With this in mind, I have drawn from the work of Piantanida and Garman (1999) who bring a methodological and interpretive rigour to their quality criteria. They argue that in a qualitative dissertation that is well-written and well-conceived, the researcher offers a clear “logic of justification” for her methods and format. This means that she can logically justify in a clear and cogent way how her procedures and lines of reasoning are congruent with the epistemological and methodological assumptions guiding the study. They suggest the following criteria for judging soundness in a qualitative dissertation (pg. 147):

Integrity (as in architecture)
Is the work intellectually sound? Does it hang together? Is the research rationale logical, appropriate and identifiable within an inquiry tradition? Is the proper persona (or voice) used for author(s) and other participants?

Verité
Does the work ring true? Is it consistent with knowledge in the field? Or if it departs, does it address why? Does it fit within the discourse in the appropriate literature? Is it intellectually honest and authentic?

Rigor
Is there sufficient depth of intellect, rather than superficial or simplistic reasoning? Are the conclusions carefully crafted from sufficiently thick and rich data? Does the researcher avoid solipsistic reasoning? Was reflection done in a careful/systematic rather than haphazard fashion? Has the analysis/interpretation of the core portrayal been thorough/exhaustive?

Utility
Is the inquiry useful and professionally relevant? Does it make a contribution to a recognized field of study or established bodies of discourse? Does the piece have a clearly recognizable professional and/or scholarly audience? Is it educative?

Vitality
Is the inquiry important, meaningful and nontrivial? Does it have a sense of vibrancy, intensity and excitement of discovery? Do metaphors and images communicate powerfully? Does it have creativity and artfulness?

Aesthetics
Is it enriching, pleasing to anticipate and experience? Does it give me insight into some universal part of my educational self? Are connections between the particular and the universal revealed in powerful, provocative, evocative and moving ways? Does it challenge, disturb or unsettle? Does it touch the spirit?
Ethics
Is there evidence that privacy and dignity have been afforded all participants? Has the inquiry been conducted in a careful and honest way? Has every effort been made to represent the views of others accurately and in the spirit in which they were shared/intended? Has the researcher recognized and acknowledged his or her own preconceptions/assumptions and considered how these might distort understanding? Does the language of the dissertation adhere to the principles of nondiscrimination? Does the inquiry have an ethical sensibility?

The Study Participants

This study explores how patients, families, and clinicians balance risk-taking and safety during the transition from brain injury rehabilitation to home. In total, 16 people participated in this study, including five patients, five family members and six clinicians. I collected demographic information (see Appendix D) at the beginning of each patient interview. This information included age, length of rehab admission, length of time since discharge to home, access to on-going therapy, and education level. While many of these feature were revealed during the interview, this structured set of questions allowed for more detailed description of the patient group. The following is a brief introduction to the patients, families, and clinicians who participated in this study, as well as an overview of the ABI unit at Toronto Rehab. All participant names are fictitious, and while global facts such as diagnosis have been maintained, specific details such as gender and geographical locations have been changed, in some cases, to protect the identity of all participants.

The Patients and Families

Five former inpatients and family caregivers of the ABI service at Toronto Rehab were interviewed for this study. This inpatient distinction is important to make as the issues relevant during the transition from inpatients to home may vary from those relevant to outpatients discharged directly from acute care or to those receiving rehabilitative services in
their home or other care settings such as LTC. The characteristics of these participants were
typical to an urban rehabilitation hospital, and varied widely in age, ethnicity, and
socioeconomic and diagnostic status. All patients and families speak English and have
sufficient verbal communication skills to participate in a one-on-one discussion. They were
all capable of making free and informed decisions and all had been discharged home from
inpatient rehabilitation within four months of their interview. This time frame allowed
participants adequate time to reflect on issues of risk-taking and safety at home, but was
recent enough to ensure sufficient recall of their inpatient experiences.

Two of the five are women, and all have completed at least a high school degree. One
of the aims in sampling this particular cross section of patients was to choose participants
with perspectives and experiences relevant to the brain injury population at Toronto Rehab.
For example, the incidence of non-TBI patients admitted to the hospital annually is
approximately 70%; this is reflected in the patients selected for this study. The intent here is
not to make broad sweeping generalizations about the nature of risk-taking, safety and
autonomy following intensive rehabilitation, but rather to recognize that these learnings may
have relevance across other care setting when taken in context by the careful reader. The
following is a short introduction to the patients and families in this study.

**Karl** was hit by car while cycling near his suburban home. The 46-year-old was airlifted to a
regional acute care center where he was in a coma for seven days with severe brain
compression, as well as multiple fractures and soft tissue injuries. Just prior to his accident,
Karl's wife had initiated divorce proceedings. Karl's brain injury has significantly impacted
his speech, as well as the entire left side of his body. Despite his significant physical
impairments, Karl is determined to return to independent community living.

Although very close growing up, **Karl's Dad** has been estranged from his son since Karl’s
marriage several years ago. After Karl’s accident, however, he was his son’s primary support
through his long acute care and rehabilitation stays. He supports Karl’s goal to live on his
own and has taken a step back from his highly supportive role. He has returned to his farm
outside of Toronto, but cannot understand why his son would choose to live in the “big city” instead of closer to him.

**Erin** was diagnosed with multiple sclerosis (MS) when she was 16. Now 42, she lives in an accessible condominium with her husband. When they first met, Erin was using a cane; she now uses a manual wheelchair and has regular visits from community care to assist with her morning routine. Erin is an artist and has traveled extensively around the world raising awareness for MS. Despite being a professional speaker and strong advocate for people with disabilities, she has never accessed rehabilitation services.

**Erin’s Husband** is self-employed and works full time. He is 20 years older than Erin and has been her primary support since they met over a decade ago. His caregiving efforts have increased to meet Erin’s changing needs, and so too has his chronic back injury. He hopes that rehabilitation will help maximize Erin’s physical independence, as well as focus on deep-seated emotional concerns about her disease progression and future uncertainty, concerns that are not being addressed in the community.

**Tomoko**, age 52, was leaving her job as a librarian when she collapsed with the worst headache of her life. She “woke up” three months later at Toronto Rehab with her two children and husband by her side. She could not remember their names. Tomoko’s goal is to return to driving, as well as the job that she loves. Despite her large aneurism, she has few remaining physical impairments; yet, she struggles in her role as a mother, wife and active community member, to be the person she was “before”.

**Tomoko’s Husband** met his wife when they were both taking English language classes in Toronto. Prior to Tomoko’s brain injury, he had not accessed healthcare services in Canada, nor managed the family’s finances. In the months following his wife’s stroke he has taken on new familial and work responsibilities; however, he is terrified that his wife will have another aneurism and wants to protect her from taking even the smallest risk at home.

At 67 **Dave** has spent most of the last 25 years alone in his basement apartment. He smoked three packs of cigarettes a day and drank heavily. One day, shortly after Dave arrived home from his work as a fork lift operator, he was rushed to acute care with a large left hemisphere stroke. He was later transferred to palliative care. The only family the hospital could locate was Dave’s niece, whom he had not seen since she was a teenager, and whom he did not remember.

**Dave’s Niece** had not seen her uncle in over 25 years. Although wary about meeting “Uncle Dave”, she immediately assumed the role of his primary caregiver. Over the next three months she nursed him slowly back to health, and eventually convinced a reluctant healthcare team to apply to ABI rehabilitation. At Toronto Rehab he took his first steps, but still did not know who she was, or anything from his past. Despite these challenges, Dave’s Niece invited her uncle to stay with her; otherwise, they both agree, that Dave would have spent the rest of his life in long term care.
On his way home from university, 22-year old Blair suffered a massive seizure. He was rushed to acute care and following a brief stay, was admitted to Toronto Rehab with a moderate anoxic brain injury. With the exception of right hand tremor, Blair has few physical deficits, though struggles with impairments to his short term memory, and decreased insight and judgment. At home, his mother continues to provide for all his needs though balks at his lack of motivation and constant use of the computer. Blair’s main goal is to return to university, though he is not quite sure how that is going to happen.

Blair’s Mom has been in Canada for several years and speaks Cantonese as her first language. When her youngest son was diagnosed with epilepsy and cardiac issues, she vowed to protect him from all harm. She blames herself for his brain injury and wants to keep him safe from further injury. She is frustrated, however, with his lack of initiation and constant desire to be on the computer. She has had limited involvement with Blair’s therapy team and feels unsure how to reinforce the team’s discharge recommendations, nor give her son more responsibility around the house.

The Clinicians

Six clinicians participated in this study, including a physiotherapist (PT), a physician (MD), two occupational therapists (OTa and OTb), a social worker (SW) and a rehabilitation therapist (RhT). The RhT is a role unique to rehabilitation. Rehab therapists are generic therapists who are not members of a regulatory college and who are supervised by registered therapists. They have backgrounds in areas such as psychology and behavioural science, and provide continuity and integration between therapy sessions. Rehab Therapists are also available on evenings and weekends to provide consistency of care.

All of the clinicians in this study work at the inpatient level with the exception of SW who is an outpatient therapist. Three clinicians are aligned with the neurophysical stream and three with the neurocognitive steam (the relevance of this is explained below). Their rehab experience ranges from three years to 21 years. These therapists were approached because of their in-depth knowledge of both the discharge planning process and safety issues relevant to the patients and families in this study. Some, in the instance of OTa and MD, have treated more than one of the patients. The following is a brief introduction to these clinicians. The
aim here is to provide some context for their role in the rehabilitation environment, and how, in their own voices, they locate themselves as members of their healthcare team.

**MD:** Well, I think first of all I am a physician, so my core responsibility is to optimize people’s medical health. Imbedded in that is certainly a lot of education that goes to patients and families and staff. Also imbedded in that is the research that I do, which is about optimizing patient’s health in the long run, after significant disability. Well medically I’m most often discussing issues such as spasticity management, cognitive, maximizing cognitive function, um, mood, behaviour management and seizure control. So those are the big categories of things that are at the forefront. And I think safety is imbedded in all them in different ways. Of course, the overriding principle for me is medical health. [pause]. No, I shouldn’t say that. The overriding principle is the whole person’s health, because we’re treating the whole person. My role as part of the team is to optimize their medical health.

**OTa:** I am a relatively new grad on the neurocognitive team. I am someone who facilitates on-going function, and the progression towards longer term goals. Specifically, working towards more productive goals like returning to school or returning to work, or you know, getting back to parenting duties, community involvement, or volunteering. So working more on their productive roles; but, also to integrate into the team and provide assessment information so that everyone is working on the same day to day functional roles, which include IADLs or ADLs. The neurocognitive team is very heavily weighted towards cognition, assessing capacity and using strategies for deficits like memory, attention or problem-solving. Often the physical role falls solely to the PT in all aspects, and that is because the cognitive piece is so big. Sometimes, however, patients only want to work on their physical goals, despite many, many cognitive issues. It’s hard not to address them, but if that is their goal… So as a fairly new grad, that can be hard.

**OTb:** Well, I am on the neurophysical team. We see people who have primarily physical deficits. But as well, significant cognitive and communicational difficulties and behavioural disturbances or changes. So a huge scope. Everybody looks very different, but obviously a lot complex systems and a lot of changes both to their thinking processes, their ability to move, the way they conduct themselves, memory impairments, attention, insight, judgment. Some people can’t manage basic tasks; others return to work or to driving, or are heading in that direction. The average person? [laughs] Well most of the time people need assistance with their basic activities of daily living. Many of them will use a walker or a wheelchair to get around. Most have cognitive impairments that preclude them from living independently. And most are going back to an institution, or to home with a lot of support. So quite complex and interesting patients, but at the same time very diverse.

**PT:** I am on the neurophysical stream and for me specifically, my role is obviously more targeted towards [a patient’s] physical well-being and functioning, how they are moving around. Whether it’s in their bed, in their room, walking around the hospital.
Getting them as safe and as mobile as we possibly can in order to help them function safely at home. Looking at all aspects of their physical abilities and working very closely with OT and the other team members, nursing, to facilitate a safe stay and promote recovery as much as we can. But at the same time, helping them, by changing the way they do things, to allow them to be more independent.

**RhT:** But I think though too in my position, they [other clinicians] see you as a job, or a position within the organization. They don’t understand that you are a person capable of problem solving and assessing, and you know, thinking on your feet. Or good old fashion, “I don’t think we should do this right now.” As if you don’t have any intuition or you don’t have any understanding of how a brain injured person might behave. Like, if they’re normally doing pretty well walking with their walker, but one day they’re really dragging their left foot, maybe they’re tired that day, or maybe they have a pain. So should we do our regular walk? Well, obviously not. But, it’s as if the team doesn’t understand that you would ever pick up on that. Maybe part of the reason – and I think this is true – is that they feel pressure from their own College to be ultimately responsible for anything they ever refer to us, ever ever. They don’t allow us or them to take risks. It’s over-ownership of our patients.

**SW:** So outpatient social work involves many of the same skills and interventions of the inpatient social worker, the main difference being that people have already made the leap into community. The focus of my work then, is how they’re transitioning to a new stage of life. Their new environment, seeing how changes in their ability are playing themselves out day-to-day in real life situations, with the people they live with and love. Trying to work towards the next steps in the road to recovery, which is really being able to manage their life, outside the hospital. So that involves providing both very practical interventions around getting them connected with resources, to facilitate their independence and safety. As well as interventions that are geared toward their adaptation emotionally, socially; how [their brain injury] is affecting their relationships and their ability to fulfill the roles that bring them meaning and joy.

*The ABI Unit*

The ABI unit at Toronto Rehab offers a full continuum of care for patients and families with brain injuries, including inpatient and outpatient services, and follow-up clinics. The program has been designed to allow patients to enter at any point along the care continuum and to transition smoothly, in theory, between services based on individual need. Patients are referred from hospitals across Ontario, Canada, and internationally; rehabilitation services are delivered by an interprofessional team of clinicians representing more than a
dozen disciplines. Within the secured (or locked) unit, care is separated into two distinct streams: One for patients whose rehab needs are primarily cognitive and one for those whose needs are primarily physical. Assessment, treatment and education are also offered to people living with MS.

The neurocognitive (NC) stream provides rehabilitative care to individuals whose central goals are related to cognitive and behavioural skills. Typical goals of patients in the NC stream include improving their ability to focus, remember and learn new things, and perform ADLs such as dressing, or instrumental ADLs such as shopping and using public transit. While some NC patients also have physical impairments, these tend to be less significant than their cognitive and behavioural needs. The inpatient NC stream has 16 beds with an average length of stay ranging from four to six weeks. After discharge, individuals often transition to outpatient services where their goals tend to be more complex, such as driving, and returning to work or school.

The neurophysical (NP) stream provides intensive rehabilitation to meet the needs of individuals who have a brain injury with significant impairments to their physical mobility and function. Many also have issues relating to behaviour and cognition; however, their needs in this area tend to be not as complex as the needs of patients in the NC stream. Rehabilitation aims to address their cognitive needs, but primarily seeks to improve physical functioning relating to strength, balance, mobility, fine motor skills, communication and swallowing. The inpatient NP stream has 15 beds with an average length of stay of six to eight weeks. Five beds are also available for patients who have especially complex care needs and require more time for rehabilitation. Again, many patients transition to outpatient services following their discharge. As part of the NP stream, the MS service specializes in
providing assessment, treatment, and education for adults with MS in both inpatient and outpatient settings.
Chapter 4: Results

In rehab, as much as we can, we look ahead into this person’s life, to the world they will be returning to, and in our very standardized hospital environment providing them an experience as close to, you know, what it might look like at home. Trying to project into the future, preparing them to return home. So I think we are a place where they can practice risky behaviours under, our guidance, our recommendations, our supervision. (RhT)

Introduction

In this chapter I will present a descriptive, as well as interpretive analysis of the factors that influence how patients, families, and clinicians make decisions about risk-taking and safety during brain injury rehabilitation. Despite the emphasis on safe transitions in care and patient autonomy in healthcare, little progress has been made on engaging patients, families, and clinicians in a discussion of these ethical and clinical issues. Two concepts form the sensitizing context for this study. The first is that a liberal individualist approach to autonomy is not sufficient in brain injury rehab where complex physical, cognitive and behavioural impairments are common. In this setting, an expanded and more nuanced approach to autonomy is needed – one that understands a patients’ decisions and behaviours in relation to their social contexts, and dependent and interdependent relationships. The second is the WHO’s International Classification of Function and Disability (ICF). During inpatient rehabilitation, patients largely experience health and disability at the impairment level, which is the first level of functioning in the ICF model. Impairments are largely expressed in terms of body function and structure, where patients and families learn to cope with lifelong anatomical and physiological changes and their psychological consequences. Activity limitations are the second level of functioning and represent a shift from
conceptualizing limitations at the physical and psychological level, to limitations at the activity level. For example, as patients and families prepare to transition home, contextual factors such as environment barriers and individual characteristics interact to limit or enable certain activities. Finally, challenges in participating in meaningful life activities are classified as participation restrictions in the ICF’s third level of functioning, and reflect, for example, limitations in returning to work, recreation, and education.

The aim of this chapter is to present key themes related to patient autonomy and safe transitions in care that emerged from in-depth interviews with patients, families, and clinicians from Toronto Rehab’s ABI service. In the passages that follow I have used participants’ quotations as transcribed verbatim from the interview tapes. For three of the participants, English is their second language. To reflect the authenticity of responses, sentences been only minimally altered; however, on occasion, I have added words, which I have placed in square brackets, for clarity.

**Key Factors to Balancing Patient Risk-taking and Safety in Brain Injury Rehabilitation**

The following chapter explores factors that influence how patients, families, and clinicians make ethical and clinical decisions that give precedence to either risk-taking or safety during brain injury rehabilitation. These factors are presented as five tensions: The extent to which views on risk-taking and safety align or conflict among patients, families, and clinicians, and the implications of this; the ethical and clinical challenges of providing patient-centered care as it relates to decisional and functional autonomy; the influence of

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8 As I present the results of this research and offer my discussion in the following chapter, I do so with the assumption that when I use the term “patient autonomy” or “autonomy”, I am referring to both decisional and/or functional autonomy (Collopy, 1988). I will, however, draw the distinction between the two concepts where necessary.
social and systems factors on risk-taking and autonomy; the extent to which the principles of respect of autonomy are linked to on-going recovery at home; and, the impact of community supports on re-discovering decisional and functional autonomy following discharge from rehabilitation.

_Tension #1: Patients, Families, and Clinicians Have Diverse and Conflicting Views About Risk-Taking and Safety_

The first tension that influences how patients, families, and clinicians make decisions about risk-taking and safety is related to the fact that these groups often view risk-taking and safety differently. These differences are evident both within and across the participant three groups, and can cause conflicts among clinicians, as well as those in their care. MD shares that creating an environment that supports risk is something that, “we are getting better at”, and feels that the clinicians that he works with are less paternalistic than they were a decade ago. Part of this evolution means moving away from acting as a supervisor to the patient, to functioning more as an advisor and collaborator:

MD: We the clinicians are not the police; we are just advising…and I think we are better at it than we used to be. Um, I started doing this 10 years ago and at that time there was more a policing attitude. More of a, “I’m the parent and this is what you should do, and if you don’t than you are a bad child”, kind of attitude.

These clinicians express their view that some degree of risk-taking is an important, even necessary, part of the rehabilitation process; however, their perspectives on patient risk-taking are not homogeneous. Their views can be situated along a continuum that points, at one end, to decisions that prioritize safety, and at the other, to decisions that prioritize risk-taking. The extent to which clinicians prioritize risk-taking and safety in their personal lives, seems to be congruent with how they approach risk-taking in their professional practice. MD
corroborates this parallel; if clinicians are more risk-tolerant in their everyday lives, then they
tend to be more comfortable with their patients taking everyday risks:

I personally a bit of risk taker, so I have no problem with my patients wanting to
explore their limits. And sometimes they have to find out…by their own mistakes,
what’s a safe and happy medium.

However, not all clinicians are as comfortable with risk-taking and there are those who
maintain more of a middle ground. OTb is an example of the clinician who approaches risk
in moderation, and feels a large part of her role is to provide patients and families with the
worst-case scenario:

Um, I’m probably in the middle…I always start with the question: Can they make the
decision to take this risk? And then I go from there. I mean, if with family members
you think, “oh they’re making a really bad decision”, but sometimes I think, you
know they can make a bad decision, you try and push for what you think is a better
decision. But then how much are you pushing your opinion instead of doing what you
should be doing, and that is outlying all the risks, the worst case scenario.

At the other end of the spectrum is the clinician who takes fewer risks and tends to make
decisions that prioritize safety. PT finds it difficult to “let go” of her patients, both literally
and figuratively:

And there’s a huge trust there that develops between a clinician and a client…I know
for myself, I have a hard time letting go when I’m here at work. I’m much more on
the conservative side. I am less of a risk-taker I think, than some of my counterparts.

When asked to define autonomy in the context of brain injury rehabilitation, these
clinicians value the fact that the rehab environment at their hospital - in general - offers
patients the opportunity to struggle, experiment and push the boundaries of their abilities
within a relatively safety and structured environment. PT shares her thoughts on the
importance of measured risk as important to brain injury recovery:

So basically when I think of respect for autonomy for my patients that I see day to
day is providing empowerment to them, in order for them to have control over the
decisions they make and the risks they take, while, um at the same time keeping their
best interests in mind, which includes safety and their well-being in the context of their lives.

However, clinicians also struggle with the “delicate balance” of permitting their patients to engage in risky behaviours with their need to keep patients safe. MD reflects on the challenges of balancing risk-taking and safety as they relate to quality of life for his patients and families:

Some families would rather their loved one be happy and feel independent – and in so doing let them take risks that may not be the best for their safety, but for their quality of life. And when you balance those two things out – quality of life wins. So they take more risks. Other people are so obsessive about taking risks, that they take away independence.

While there is agreement among clinicians that the rehabilitation environment should encourage some degree of risk-taking as part of brain injury recovery, therapists struggle with including what they perceive to be unsafe activities into their day-to-day interventions. OTa uses the example of Dave to illustrate this struggle. One of Dave’s goals is to volunteer at his local hardware store; however, he struggled to find his way to his inpatient therapy appointments alone and on time (skills that he would need in the community). Instead of accompanying Dave to his therapy session on the unit, OTa encouraged him to find his way to therapy on his own and practice some of the same route-finding and orientation skills that he would need to navigate independently in the community. Although she wanted Dave to practice being more independent, she was taking the risk that he might (and did) become lost within the hospital setting:

But you know, it was giving Dave just that right challenge, so that if he failed it wasn’t going to be disastrous or huge risk for his safety. But that he felt satisfied when he would make these achievements, even if they were the tiniest of achievements. So you know, it was, that acceptable level of risk. So it was, “Okay, Dave, I want you to come to OT today at 10:00,” and I’m telling him this at 9:00… Or, you know, just giving him the freedom that, if he went for a coffee downstairs [in the lobby], and he wasn’t necessarily supposed to be leaving the unit on his own…
that he would have the freedom to come back. So yeah, Dave was definitely one example of finding that acceptable level of risk.

**Conflicts Between Clinicians and Teams**

The diversity in perspectives between risk-taking and safety can create conflict between individual clinicians, as well as entire healthcare teams. Clinicians are required to make decisions about the day-to-day activities of the patients in their care. Can they walk to the bathroom alone? Can they leave the secured unit unaccompanied? Are they safe enough to leave the hospital and go outside? The implications are two-fold: First, clinicians must determine whether a patient is capable of understanding and appreciating the consequences of a decision that is made without coercion (that is, “decisional autonomy”); and second, they need to consider these decisions in the context of the patient’s abilities, including physical, cognitive, and behavioural function and relevant goals (or, their “functional autonomy”). As patients become more independent, their degree of risk-taking also increases. Consider, for example, the relatively low risks associated with walking to the bathroom versus those associated with crossing a busy urban street. What is less straightforward is that as a patient’s risk-taking increases in response to his or her recovery, clinicians must also renegotiate how they balance risk-taking and safety. For RhT this negotiation can be frustrating. He shares his recent dissatisfaction with his team, when a patient who he felt was “clearly” ready for increased freedom of movement around the hospital, was constrained by more dominant team members who were not as comfortable as he was with such an increased level of risk:

Letting somebody go down to the patio on their own… I think because we are in downtown Toronto we don’t want people to wander off the patio and or take off from the patio because it’s so, bloody busy. They could disappear, like that [snaps fingers]. But, I mean, it isn’t the same for every patient! I mean, recently [name]’s OT and PT said, “Well, I think they’re okay to find their way to and from the patio and they won’t take off.” He’s been ready to do that for weeks. I mean like… finally!
PT also describes a time when the values and agendas of her team conflicted with both Karl (her patient), as well as her own attempts to advocate on his behalf. She argued with reluctant team members that if Karl was going to engage in risky activities at home (in this case, climbing stairs with no hand rail), than why shouldn’t he practice those same activities within the relative safety of the rehab environment? As a relative novice on the team, she wonders if her approach is too inexperienced or too reckless, or does she instead bring a fresh perspective to the group?

I see rehab as an opportunity to practice things within our supportive environment. I think if someone is going to do something that is seen as a risk within our own environment, I think it is a struggle, a little bit, to get the team to be okay with that. But why is that any different than saying, “it’s okay for you to go home and do this?” Am I alone in this thinking?

Regardless of how clinicians view risk-taking and safety, or whether there is always agreement, they recognize that balancing such decisions takes a skilled therapist who is able to guide patients and families through many complex factors. SW shares her nuanced approach to decision-making in brain injury— one that understands that a patient’s wishes are often manifestations of more subtle and emotionally driven values and beliefs:

I think it means, not always rushing in to problem-solve. It means, you know, “tell me more.” If a patient says, “I don’t want to go to a nursing home. This is what I want.” And it doesn’t match what we think is the right thing, I think we spend a lot of time trying to convince people that our way is the better way, the right way. And we don’t spend enough time thinking about what it is that the person wants and is there any way to make it happen. And can we understand why this is what they want. So when they say they want to go home, is it really the physical home they want, or is it the feeling of home. The feeling of being safe and being surrounded by things that are familiar and people that are familiar. The life and the lifestyle that they know.
Conflicts Among Patients, Families, and Clinicians – “I Need To Make My Own Mistakes”

This next section illustrates some of conflicts that arise when decisions about risk-taking and safety conflict among patients and their healthcare team. Like the clinicians in this study, patients also approach autonomy based on their own life experiences. Tomoko tells me that if she was a swimmer, she would “stay close to shore”. During her rehab stay she closely followed the recommendations of her team and seldom deviated from their guidelines. She felt this was in her “best interest” (Tomoko’s emphasis), even when the outcome involved what other patients in this study may have perceived as a loss of autonomy, and even dignity:

AA: So, when your healthcare team said, “Tomoko, you have fallen a few times, please don’t walk to the bathroom without supervision,” was that okay with you? Were you at a place in your healing where you could agree with them, or did they need to remind you?
Tomoko: Oh no! I don’t know, maybe it’s my personality too. If they said, “no”, then I wouldn’t do it. But the bathroom was the biggest thing.
A: So what did you do when you really had to go to the bathroom and you called, but no one came right away?
Tomoko: Well, if I couldn’t wait any longer… I just went to the bathroom in my diaper. In the diaper. Because I was told not to go to the bathroom. Even though I was able to go [to the bathroom] on my own.

Karl is the opposite of Tomoko. Since his injury, he values freedom of choice and self-determination above all else. Yet, the risks he takes are not random; they are calculated decisions aimed, in his view, at continually testing the waters of his physical independence.

Karl shares a conversation that he had with his Dad during his rehab stay. Unlike Tomoko, rehabilitation was a journey that he needed to take on his own:

Karl: There are times when [my Dad] was here all the time for my therapy, which I appreciated. But on the other hand I wished he would go away sometimes too, and let me make my own mistakes. Make my own mistakes. Let me fall down so I can get back up. Whereas he wouldn’t let me fall.
AA: Did you ever have that conversation -
Karl: - with him? In a roundabout way, yes.
AA: How did he respond?
Karl: At first he was a little upset, but then after he thought about it, he gave me the room to fail. Or to fall down.

In contrast, Tomoko welcomed the assistance and guidance offered to her by her healthcare team. Instead of feeling confined or restricted, she felt safe. She only fell once while at Toronto Rehab; however, it was enough to irrevocably change her behaviour.

AA: Tell me about your fall.
Tomoko: I can’t even remember if it was in the morning or at night, but I fell down beside my bed.
AA: And did you get up by yourself?
Tomoko: Yes. And I never fell again.
AA: It tells that me that you are getting stronger, that you are more self-aware. What else does it tell you?
Tomoko: That I learned my lesson.

Karl and Tomoko stand in stark contrast to each other and represent the differences between decisional and functional autonomy. During the course of their rehabilitation stay, both patients made autonomous decisions. Tomoko autonomously chose to follow her healthcare team’s instructions and made decisions that prioritized safety. Conversely, Karl autonomously chose behaviours that directly conflicted with his team’s recommendations and made decisions that prioritized risk-taking. While both have maintained their decisional autonomy, Tomoko may not achieve the same level of functional autonomy. Karl seems to understand the implications of this: Although his actions created tensions among his therapeutic relationships, he feels that they also contributed to his recovery.

Karl: I was just pig-headed.
AA: And “pig-headed” means – ?
Karl: – I just did it. I wanted to do things on my own. I would just go ahead and do it, even though someone would tell me, “you shouldn’t”. I figure I would give it a try and see where I ended up… For example, what I did when we are on the top of the stairs. My physiotherapist wanted me to slow down [mimicking her voice]. “Put your hands on the handrail”. There were times when I would purposefully not listen to her…After I did that, she would give me hell. But at least I knew then that I could do
it...So even though she may not have liked it, as another human being, she could understand why.
AA: Do you consider that risky?
Karl: Yes, to a point. But I also realize that I need to take certain risks... let me rephrase that – calculated-risks – if I’m going to get any better. To see if I can do things by myself or not. Does that make sense?
AA: So as a result of your calculated risks, your experiences, would you say that you are further ahead [in your recovery]?
Karl: I think so.

_Tension #2: Ethical and Clinical Challenges of Providing Patient-Centered Care_

This second tension explores some of the struggles that clinicians experience as they attempt to balance issues of risk-taking and safety within a model of patient-centered care. The benefits of patient-centered practice are based on two implicit assumptions: The first is that an interprofessional team enhances care and service delivery, and contributes to increased satisfaction for both the patient and the clinician. The second is that patients and families are integral members of the healthcare team and, as such, should collaborate with clinicians in setting goals and making ethical and clinical decisions. While these clinicians seem committed to providing care that places patients and families at the centre of their care, respect for autonomy does not always fit neatly into this model.

_The Ideal of Patient-Centered Care_

The clinicians in this study value working within an interprofessional model of care that supports both the separate and shared knowledge of their skills. They see themselves as part of a larger team who, as a group, identify and analyze problems, and assume joint responsibility for these problems. SW agrees that for her, working collaboratively serves to strengthen team process:
I would say that I am very lucky because the team that I work on, we work very well together. People are really comfortable with each other – we understand the, um, skills, expertise and experience that we all have.

At the core of patient-centered care is a commitment to goal-oriented practice, and no activity is more deeply valued than the goal-setting process. Clinicians describe the process of setting functional rehabilitation goals as one in which patients and families are encouraged to take an active and leading role. One of the aims of goal-setting is to help patients regain, to the extent this is possible, their ability to live autonomously. In particular, it gives them control to make decisions and determine their day-to-day lives. Karl’s Dad expresses his appreciation to the therapists at Toronto Rehab for their efforts to support Karl’s goals:

They were all great [names therapists]…They asked him, “What’s your main goal, what you want to be?” Okay, he wanted to be on his own, and wanted to do his things. They worked on the stairs, but oh God! I still see him and crying when he went all the way up the stairs. There were so many great things… I’m not a writer, but I could write a book!

_The Reality of Clinical Practice_

The clinicians in this study strive to set relevant goals with their patients, involve families in treatment decisions, and recommend a discharge plan with which everyone agrees. However, in the reality of daily clinical practice, these ideals are often difficult to achieve. For most of these practitioners, the concepts of patient-centered care have formed the cornerstone of their academic and clinical experiences; yet, they are challenged at times to provide such care. One example of this challenge is determining decision-making capacity. OTa assesses decision-making capacity on an almost daily basis, but consistently struggles with the implications: “Despite all of the assessments we do, none of the functional tasks or occupational [tasks], make capacity that clear. I don’t think it’s ever really that clear.” In this example she conflates decision-making capacity with functional capacity; yet, I feel that she
appreciates that establishing decision-making capacity is a nuanced process that changes over time and under different circumstances. OTa describes how she struggled to determine if Blair was capable of making an informed decision about returning to university in the fall. She feels that Blair is capable “in the moment” of understanding the extent of his cognitive impairments; however, he is unable to extrapolate this understanding in the process of rational judgment:

I struggle with the whole capacity thing. [Blair] is very much on the cusp of capacity… And I think Blair’s capable in the sense, in the moment of a test, he’s aware of his memory issues and how bad they really are. But his ability to know that maybe he won’t be successful in school… to make a decision that may not be the best decision, but to know all the consequences, and then do it. He can’t. He couldn’t make that connection. So yeah, he’s a hard one.

Accurately assessing decision-making capacity is further complicated when patients make, what clinicians perceive, are poor choices. It is often difficult for clinicians to accept as a rational choice, patients who refuse help for problems that seem amenable to fairly simple interventions. SW gives an example, in the words of some of her colleagues, who struggle to balance respect for autonomy against the demands of beneficence:

“Because I might get into trouble. A patient may be capable, though I’m not quite convinced. They seem to be capable, but they want to go and they want to live in sub-standard living conditions that I don’t think is in their best interest. They have other choices, better choices. There are services that they could consider, but they don’t want people encroaching on their privacy.” So then we start to question their competency. “How could they be competent and want those things? And if I let them go, we let them go, where does our responsibility end?”

Assessing decision-making capacity is a complex and challenging process that has significant clinical, legal and financial implications to the patient and family. Given this, I was interested in how decision-making capacity is assessed and managed by these healthcare teams. The response exposed an interesting dichotomy: While clinicians agreed that determining decision-making capacity was best done as a group process, on this unit the responsibility
falls largely to a single profession – the OT. Not only do OTs have the sole responsibility of assessing decision-making capacity, they are also looked upon to structure the related treatment interventions. This includes interventions that the OT is proposing, such as discharge planning, but also interventions from other team members, such as financial management by the SW. For OTb, this is a “burden” that she would rather share, like other decisions, with the rest of her team. She is looking for clear and specific guidance to help her navigate through the “murky territory” of decision-making capacity. As a fairly new graduate, this responsibility weighs heavily:

And I think there is a huge issue right now around consent and capacity. But I think we need, whether it’s someone who is consultative that we can liaise with, or if we had almost like a checklist of things that would be ideal for us as a group to do, to come to that decision, to make the best decision for that patient, ethically. To have more of a clear guide to help us come to a conclusion about whether someone is capable, or not. Without relying solely on the OT. Because, I think it often kind of falls on our shoulders... And we always worry: Is it the right decision? The most appropriate decision?

A second example of how patient-centered philosophy can conflict with ethical and clinical practice occurs when patients set goals about which clinicians do not agree. The clinicians in this study strive to support their patients in making what, in their view, are reasonable goals, based on an understanding of the risks and benefits of these goals. However, supporting patients’ goals can be difficult when they make choices that conflict with a clinician’s own ethical and clinical views. This conflict is further heightened by cognitive and behavioural impairments, and goals that deviate from societal norms. Clinicians brought up smoking as an example of this conflict. Clinicians struggle to set aside their often negative attitudes towards smoking (which dramatically increases the risk of a second brain injury), and support their patients in their goal to smoke. OTa shares her views about Dave’s recent choice to start smoking again after several weeks of “being clean”: 
It was something that was really hard… It is really hard for me to be saying, “Oh Dave, you’re smoking, but you haven’t smoked in so long!”… Well, I guess obviously there’s the cognitive component of someone being capable of making that decision. And… I believe, I think if that’s your choice and you’re capable of making that choice, then what can you do but provide them with the education to know that this is a huge risk factor. Maybe if I was a smoker I might feel different. But I’m not. So it’s, it’s hard to say where my values end and theirs begin.

While not everyone is as morally conflicted as OTa, the clinicians in this study struggle to support patients’ goals that they do not agree with. With the benefit of clinical experience, MD has largely come to terms with this conflict. He educates his patients about the (considerable) risks of smoking, but has little moral difficulty in permitting capable patients to make their own decisions:

I think patients and families need to be aware of the risks that they may be taking. Ultimately, it is their decision to make. Um, and they, they need to know that this is not usually something that we can enforce. And certainly people have freedom of decisions, if they’re competent. So if I’m smoking a cigarette, I want to know what the risks of that cigarette are, but then I get to choose, even if it means I’m going to get cancer or heart disease and die at the age of 47. Because ultimately, it comes to down to competent adults get to choose.

_Tension #3: The Influence of Social and Systems Factors_

Decision-making related to risk-taking and safety is also influenced by the social context in which clinicians practice. While values, attitudes, and beliefs about risk-taking and safety are critical to how clinicians make ethical and clinical decisions, these decisions are not made in a vacuum. Social and systems factors also influence how clinicians balance risk-taking and safety, particularly as patients and families transition beyond their care. These factors are context-dependent and reflect the intersection of a complicated brain injury and a dynamic healthcare environment. As a result of these factors, clinicians may respond to a similar ethical dilemma in radically different ways.
One Safety Issue – Two Different Clinical Outcomes

The impact of context can be viewed through the actions of OTa and OTb who make different, and in many ways conflicting decisions, given a similar safety scenario – the aftermath of a patient fall. While falls on a brain injury unit are fairly common, these two clinicians choose different recommendations. In the first scenario, the patient fell while attempting to get to the bathroom during shift change. Although OTb felt he was at risk of falling again, the patient continued to engage in the behaviour that contributed to his fall (transferring independently to his wheelchair). She recounts her decision to not take away his wheelchair as this would have left him dependent on others for mobility.

OTb: Recently, a patient of mine confidently chose to crawl to the toilet and then transferred on his own, and fell because he felt that he didn’t have any other choice. AA: Was it ever discussed to take away his wheelchair?
OTb: I know that my team brought it up, but I just said, “that’s not an option”. Patients have the right to choose. I would weigh out the risks and benefits and ultimately let them choose. If it came down to giving him a wheelchair or leaving him essentially restrained [in bed], I gave him the wheelchair. Leaving him restrained is not an option.

Tomoko also fell while trying to dress herself one morning. She was unhurt; however, OTa discouraged Tomoko from attempting this activity again even though being independent in her self-care was critical at home, as Tomoko’s Husband left for work early in the morning and would not be there to assist her. OTa was concerned that Tomoko would fall again and made the decision to take away her wheelchair. OTa discusses how she also had to negotiate with Tomoko’s Husband who – happy that his wife was showing signs of improvement – was confused why her therapist wanted to limit her independence.

In terms of dressing, that was one area where she progressed very well. But at the beginning it was difficult for me because [Tomoko] would do it on her own. And I would ask her not to. And that was a conversation that I also had with her Husband, because he was like, [lower voice] “Oh that’s great she got dressed on her own this morning!” and then the next day she fell because she tried to transfer to her chair to
get dressed. I think he was pretty in tune with our decision to not, like, limit that
initiation and independence, but we also obviously wanted to keep her safe. So she
was one of those people who we took away her wheelchair…for a little while.

The implications of this comparison are two-fold: The first is that it examines the
issues of autonomy and paternalism characteristic of brain injury rehabilitation. Both of these
patients made autonomous choices. Tomoko made the decision to autonomously abide by her
healthcare provider’s recommendations, and as a result, she was largely dependent on others
for mobility. In contrast, the first patient autonomously chose to continue to make unsafe
transfers, yet his mobility was less compromised. In both these instances, the risk-related
values of both the patient and his or her clinician were largely congruent. Had the scenarios
been reversed, however, (had the OTs switched patients, for example), one might envision a
scenario where, by taking away her patient’s wheelchair, OTb would have been reacting
paternalistically, and by encouraging Tomoko to take risks with which she was not
comfortable, OTa would have also been acting in a paternalistic way (justified or
unjustified). The second implication is that there are additional factors that can also
influence decision-making beyond the extent to which patient and provider values about are
aligned or in conflict. Clinical, environmental, system and policy factors can also influence
how patients, families, and clinicians make decisions about risk-taking and safety. The
following section attempts to unpack some of these factors.

Clinical Experience

One factor that can influence ethical and clinical decision-making during
rehabilitation is clinical experience. Among these six therapists it seems that the greater their
clinical experience, the more willing they are to take risks in their clinical practice. The two
most experienced clinicians in this study are MD and SW. They both feel that that supporting patient choice requires a change in the very fabric of the culture on the unit.

MD: I think I am less paternalistic than I used to be. We, the clinicians are in a role to be an advisor... I have been doing this for 10 years and a decade ago I had more of a policing attitude. So I think we've actually lengthened the leash that we've given people in their struggle for independence and autonomy.

One area that is particularly vulnerable to a lack of clinical knowledge and expertise is providing emotional support for patients and families. Participants consistently expressed that the emotional care needs of patients and families are both great and largely unmet. While there is a clear need to provide emotional support, novice clinicians feel unprepared to deal with extreme grief and sadness. Clinicians recognize that substantial suffering can compromise a person’s self-efficacy and his or her ability to pursue meaningful goals for the future. Thus, patients experiencing significant loss often need emotional support to rediscover their autonomy. Karl has largely regained his decisional and functional autonomy despite a brain injury that has left him with significant physical impairments. He feels that this was due, in large part, to the emotional and physical support he received while an inpatient.

Karl: I was a little bit different than most people. Because I was not just dealing with my physical injury, but also the emotional aspects of the breakup of my marriage. So I had to deal with two things. Still dealing with two things.
AA: Did you feel that you were able to get some support for these issues while you were here?
Karl: It was more than okay. I spent a lot of time with the social worker, so I cannot say that she did not give a damn. Because I probably spent more time with her than most people do. I think I saw her sometimes two or three times a week. Whereas most people probably saw her only one.

Now that Karl is home, his support needs have not changed, but his access to them has. He receives several hours of physiotherapy per week, but virtually no support for the break-up of his marriage, nor for his severe brain injury:
AA: And how about at home? Who provides that emotional support piece for you now?
Karl: Nobody.

Clinicians recognize that patients rarely receive optimal emotional support following their brain injury; however, they hesitate to provide this care because they often feel ill-equipped to deal with the complexities of strong emotion, emphasizing that they lack the skill and experiences.

PT: I don’t, I don’t really think that we have that knowledge. Speaking as a PT, it’s not like this was something that we worked on, in, in our schooling. … Yeah, I think sometimes it’s just the level of comfort or feeling that it’s not within our scope. “Well maybe spiritual care can handle that one, or social work…” Like dynamics between family members or sexual health issues…we’re a little fearful of providing that information or being confident that we’re providing the correct information. I don’t know that we really feel that we are the ones that are equipped to deal with the emotional issues.

“This Environment is Too Supportive!”

The second factor that can influence how clinicians balance patient risk-taking and safety is the rehab environment itself. An overly-supportive environment can threaten patient autonomy in two distinct and somewhat contradictory ways. Clinicians observe that if patients receive too much help with making decisions and performing certain tasks, such as scheduling their day or maintaining their medication regime, they may be unprepared for the reality of life outside the institution. While clinicians value the importance of a healthcare environment that is safe and caring, they also feel that a setting that is too structured threatens rather than supports autonomy.

OTb: I think one of the challenges is that there are always people here, helping… environment is just set up that way. I mean, often I want [my patients] to be independent with their schedules. But that is almost impossible to achieve here, because there is almost always somebody around to help.
Preparing patients for real-world problems is particularly important for patients with more complex and long-term goals, such as returning to work or driving. RhT feels that an environment that, “always rescues its patients,” can lead to a false sense of security:

> Breakfast comes at a certain time, your meds come at a certain time, and appointments come at a certain time. And if you don’t remember any of that, then we bring it to you. But it’s a false, it’s a false sense of safety. It doesn’t reflect what goes on in real life. We need to have it though, at least in the short term, because these people are still, they’re just so fresh… and not ready for anything. I think the structure is important, but it’s just hospital structure – it’s not generalizable to the outside world.

The second threat of an overly protective healthcare setting is that patients may take risks because they know that there will always be someone who will, quite literally, catch them.

PT explains:

> …often I think our patients become very comfortable in doing the things they do day-to-day because they know we are here, and because they know they are safe. And I think that’s a key issue: That as clinicians we should always keep in mind that our presence may influence a patient’s participation, their performance…It may be very challenging and risky for them, but they will do it simply because we are here.

**Patient Flow Pressures**

Patient flow can also influence ethical and clinical decision-making during rehabilitation. Clinicians are keenly aware of the health, human and resource constraints that contribute to patient flow pressures along the continuum of care; however, they struggle to discharge patients who they feel are not yet ready to return home. This creates an inherent tension. On one hand clinicians feel they need to “work miracles” in order to prepare patients and families to safely transition beyond their care. Yet on the other, they describe themselves as “constant advocates” acting in support of patients and families desperate to extend their rehab stay. PT is particularly sympathetic to non-TBI patients who often have little third party coverage and limited opportunities for intensive therapy outside the rehab environment:
And I’ve had this conversation twice in the last month with families who are advocating, advocating strongly for their sons, their usually younger sons, to [stay] in-house for a longer period of time, because they’re slow-to-recover. They need more time. They’re making gains, but it’s slow. Why not give them a year, if that’s what it takes? Because we don’t have the resources, is why.

Target length of stays are determined the moment a patient walks (or wheels) in the door; however, MD feels that they are based on an incomplete understanding of the differences in the rates of recovery between TBI and non-TBI patients. Length of stay has direct implications on a patient’s recovery and as a result his or her degree of independence at home. PT was able to advocate for an extended discharge date for her patient; MD, however, was not.

MD: But, somebody’s made that decision along the way. I think they’ve put everyone in one pot [Okay]. And, okay, all our literature in TBI says that most of your recovery should take place in the first 6 months. Um, well that’s fine; but our fraction of TBI patients is about 30% now. What about the 70% who are not TBI? They’re not going to make as quick a recovery. We don’t have literature to support on-going rehab, but we know they take longer to recover. Why are we kicking them out the door? Cause a bean counter is saying, eight weeks are your allotment and goodbye!

Organizational Policy Factors

Hospital policies can also have a powerful influence on how clinicians make decisions about risk-taking and safety. Two specific and opposing policy issues emerged from clinicians in study. One encourages clinicians to take risks; the other compels them to prioritize safety. The first issue is the degree to which hospital policies may lead to deviant behaviour that is in contrast with traditional or generally accepted standards within the hospital. On this unit, such deviant behaviour is sometimes in reaction against rules that restrict rather than respect patient autonomy. One example is the policy that no patient may leave the hospital premises unaccompanied. Some clinicians feel that this policy restricts rather than promotes their attempts to prepare patients to reintegrate back into their lives.
OTa is openly frustrated with this policy because it is not context-dependent. She feels that it does not take into account a patient’s degree of recovery, his or her goals, or family preferences, nor does it allow patients to practice balancing the (potential) harms and benefits of their own decisions and actions. In response she turns a “blind eye” to some patients who leave the hospital grounds for short periods.

But, I think [our patients] generally follow the rules, even the rules that there aren’t good explanations for! Like, you aren’t allowed to leave the hospital or cross the street on your own, even though you’re safe to do this, and we’ve been practicing it in therapy. And most importantly – you’re going to be living independently and doing this every day once you go home!

PT is another example of the clinician who prioritizes her patient’s autonomy over hospital policy, even if it meaning putting her patients at risk. She questions team- and management-imposed restrictions that do not reflect her patient’s functional abilities. When I asked her to elaborate on what some may describe as enabling behaviour, she had this to say:

Some patients openly “break the rules” [gestures with hands] that we have here, whether we’re recommending that you ask somebody to help you get out of bed, recommending that you do not leave the unit on your own. We put boundaries in place and our patients choose to step outside of those boundaries. Um, so at that point it’s our role to evaluate, you know, the reason why we’ve put that boundary into place, whether there is a valid reason for these restrictions, and whether we need to reconsider that boundary. And sometimes it goes either way. [Yes]. And as the PT on the team, I kind of go through that process: do I put a stop to it or not? On more than one occasion, I have not.

The second policy issue is the perceived threat of legal retribution or liability. While some hospital policies provoke clinicians to take more risks with their patients, the threat of liability encourages them to take less. Although no one could name an instance where a therapist at Toronto Rehab (or any other rehab hospital) had ever been successfully sued, all clinicians were concerned about their professional liability to some degree. Many felt that
their colleagues viewed their clinical practice through a legalistic prism. When I asked if this view of the world impacted patient care, RhT had this to say:

Too much…I would say. I think that’s what drives a lot of our behaviour. I think in the back of our heads some are thinking, “well, I’m 99% sure [this patient is] going to be completely fine. The risk here is so small, it’s negligible. But it’s still a little bit of a risk, because we are a hospital and we might get sued,” and blah blah blah”. And people talk about [gestures with hands] “College” and “ethics…Because I might get into trouble”.

The extent to which some therapists feel they may be deemed liable impacts the risks that they take in their clinical practice. One area that highlights this issue is determining a patient’s security status. On this unit, a patient’s security status determines whether they are able to leave the secured unit independently, or if they require accompaniment. Those patients who actively try to leave the unit, or “exit-seekers”, wear a bracelet that triggers an alarm if they come within a short distance of any exit. Others are given a four digit code that releases the locks on the doors allowing them freedom of movement around the hospital.

Again, it is the OT who is charged with determining the security status of the patients in her care. The two OTs in this study are not entirely comfortable with this responsibility and see themselves as legally vulnerable.

OTa: There is always that concern, I think more so on the OT, a sense of liability. You know, “if anything happened to this patient, and I’m the one in sole charge of security status...” I feel I would be held accountable. Legally, I mean.

*Tension #4: Linking Patient Autonomy to On-Going Recovery at Home*

The fourth tension that emerged from this study is that family supports are critical to patient autonomy; however, it is the quality of these supports and not the degree of a patient’s impairments that seems to be important. Family supports emerged as the number one predictor of whether a patient returned to his or her home environment or is placed in
LTC. One of the distinct features of an environment that enhances agency and independence is the extent to which it links the goals of rehab with the goals of home. SW emphasizes that no matter how extensive their recovery, without solid supports at home patients inevitably decline:

I feel like it’s the black hole of discharge for a lot of our patients who don’t have the family or support systems in place, to help them to get into the community and be able to continue to work on some of their goals. For many of our patients, without family who love and care for them, they do not do well.

In other words, regaining autonomy in the face of loss is largely dependent on the type of supports at home, and less so on the degree of a patient’s impairments. Clinicians describe a supportive family as one who is willing to push patients with a “demanding tenderness”, and engage in new activities in order to maximize recovery. However, providing such supports can be challenging and requires that families recognize the difference between providing too much support, versus offering support that is stimulating and nurturing. MD describes the challenge that patients and families experience while trying to balance these differences:

So, trying to find the balance between, how much support do they actually need, um, to keep them safe and nurtured and thriving, versus this business of smothering them with protectiveness – it’s a tough balance to strike. But if they can strike it, I think that the recovery is much more effective, because people are encouraged and rewarded for their safe choices, their good choices, their attempts to be independent, without taking unnecessary risks. That’s probably the crux of the delicate balance.

Despite a supportive home environment, however, two distinct factors can threaten patient autonomy: Isolation and boredom and a shift in the relationship between patients and families.

Boredom and Isolation

To further understand how the quality of supports at home can impact patient autonomy, I have contrasted the home environments of Dave and Blair. Both of these
patients require 24-hour supervision at home, both are receiving outpatient therapy, and both have a moderate brain injury. Yet despite these similarities, their functional recovery is on very different trajectories. OTa reflects on how the quality of support from Dave’s Niece has had a significant impact on Dave’s recovery:

But for Dave, he had a very wonderful support system in his Niece...And you know, she understood and she saw, “What can I do? What can I continue to work on?” you know, and accepted our feedback about where our concerns lie. I think she was someone who almost in a therapeutic sense, got it. “Okay I’m going to let him try and see how it goes. But I’m still there. So let him try this, let him try that. Okay this works, so let’s continue with it. This doesn’t work, so I’m not going to do this with him anymore.” So for Dave, it was essential for him to have someone who is such a strong advocate...Because if not, he would have ended up in long term care.

OTa does not share the same optimism for Blair. In her view, he lives in an environment that is supportive but not nurturing; safe, but not stimulating. This puts him at a significant disadvantage of ever achieving his most fervent goal – returning to school:

Blair’s somebody who’s lived a very sheltered life. Mother is a doting mother who does everything for him. He’s the oldest male in a Chinese family, everything’s done for him. All he needs to do is eat, sleep, go to school and that’s it. So yeah, it was difficult because we never felt like we were moving forward in our therapy... the autonomy piece never happened, because he never took ownership.

When I asked OTa if she felt Blair’s environment was supportive, she responded this way:

Very supportive. Supportive in the sense that you have family members who are very caring, but um... but too supportive in the sense that he wasn’t given the autonomy that he needed...So, you know, family members, more specifically his mother want to see her son get better, and go back to school and be successful. But not really taking that essential step back and saying, “I’m not – I can’t do this for you anymore because you need to learn do it for yourself. You need to be challenged. You need to do this on your own.”

A Shift in Patient-Family Relationships

Another issue that can threaten patient autonomy at home is a shift in the relationship dynamic between patients and their family caregivers. As patients transition home following
brain injury rehab, there is a tremendous increase in the roles and responsibilities of the family. Unlike other caregiving populations, ABI caregivers often assume this role unexpectedly. This combination of sudden onset and increase in responsibility can contribute to a change in the roles and dynamic between patients and loved ones. For some parents, following the brain injury of an offspring, this shift involves reverting back to a previous role that they understand; for others, it involves a shift in the balance of what was once an equal partnership. SW feels that clinicians have a role to play in helping patients and families deal with this shift:

I hear it from both sides. I hear it from patients, “I don’t know why my family won’t let me go to the store, get behind the wheel, go to the bank. I think they’re being over protective. Um, it’s creating conflict. And I know why they’re doing it, and I can appreciate that, but this is my life and I’m not a child.”

However, returning to a more balanced relationship can be difficult. MD describes some of the challenges that families experience while trying to balance risk-taking and safety with their adult brain-injured child:

And, I think, if they have a parent who’s kind of reverted to treating them like a child, first of all and they become ostensibly controlling, that young person is going to rebel against that, as anybody would. And those people tend not to do that well…This poor young person, who is now an adult, just balks. They know they’re an adult; they’re being treated again like he is four. And I think that is a perfectly natural thing for a young person to do. A 22-year-old is trying to be independent at the best of times, and these aren’t the best of times.

Karl and his father are an example of a relationship that is close to becoming an equal partnership again. This is all the more interesting because Karl takes more risks that any other patient in this study. Karl now lives on his own in the community; his father, who was his constant hospital caregiver, has gradually let go of his parenting role. PT witnessed this transition and shares her views:
His father did a remarkable job in facilitating Karl’s autonomy. He was acutely aware that Karl’s goal was to be as independent as possible. So we saw a beautiful transition in his father, from a very loving, caring, supportive, very concerned father…to seeing him go from being here every day, to being here three times a week, to not being here at all. Allowing Karl to practice that, you know, those risky behaviours on his own. So his father just had a beautiful sense. He got it. He got rehab. And Karl’s lucky to have him, because I think a lot of family members, especially parents, have a hard time with that role.

_Tension #5: The Impact of Services and Systems of Care on Autonomy_  

Following discharge from brain injury rehabilitation, many patients and families face on-going barriers to accessing coordinated supports, services and systems in the community. The most effective services are those that address system issues of ABI, and long term, real-world functional issues. Access to community supports can influence how clinicians approach transitions in care, such as the decision to recommend a discharge to LTC. Community care is often unable to provide the supports that patients and families need in order to safely return to home. This has implications for the non-TBI patient and family who have decreased access to third party coverage as a result of a dual-tiered healthcare system.

_Dual-Tiered Healthcare System_  

A patient’s access to on-going care and support in the community is critical to how clinicians make discharge recommendations. Such recommendations occur in a healthcare system in which health coverage is not uniformly available, and a healthcare marketplace in which patients with third party coverage – work place and motor vehicle insurance, for example – have far greater access to services. All groups were concerned with the fact that a dual-tiered system places their patients with a non-TBI at a clear disadvantage.
MD: Because we have, for all the talk of universal health care, in our world we have a
dual healthcare system: One for the insured and one for the non-insured. It’s a big gap
for these people. So, so that’s where my sympathies lie, is with the non-trauma
people. That’s where my research interest is. The more I do this research business, the
more I want to know, “okay, what about the non-trauma people, and how can we help
them?”

MD often follows his patients and families throughout their lifetimes. He describes firsthand
how dual-tiered healthcare favours some of his patients, while leaving others looking for
handouts:

If, you have an MVC patient, you can just say, “You need a psychologist; let’s put a
treatment plan in and we’ll get you one.” It’s no big deal. If it’s an MS patient with no
supports, then you can link a little bit; with an anoxic brain injury, there is virtually
no, …very little support for them out there, other than what CCAC provides, which is
precious little. The other option is charity groups, like March of Dimes, but you are
basically looking… you kind of feel like you’re looking for handouts, on their behalf
[pause]. Trying to find the right support is hard.

Patients and families – particularly those with non-TBI – consistently expressed that
they wanted to stay connected to a rehabilitation team that understands their goals, needs, and
values. In many cases, they have few people to turn to for on-going questions and concerns.

Medicine may have adequately addressed their physical survival, but many have a long way
to go in their recovery and are not ready to let go of rehab completely. Alone in the
community, patients and families struggle to balance risk-taking and safety without the
support of a healthcare team.

SW: And I hear from families, often, “we’ve been told by the [ABI] team that this
person needs supervision and shouldn’t be doing x, y and z on their own. And so
we’re trying to be responsible and provide the support that we were told to provide.
We’re not really sure if they still need it, because time has passed. But we have no
way of evaluating whether they are going to be safe or not. So we keep doing it. But
now they are starting to resist. And we know they have a brain injury so their
judgment might not be very good, their awareness might not be very good, so we feel
like we need to keep doing it.”
A discharge to LTC is the reality for many non-TBI patients who do not have access to third party funding or an extensive support network able and willing to take on the burden of often full-time caregiving. Despite recommending LTC to many patients and families, the clinicians in this study largely feel that institutional care represents the antithesis of an independent life. It is viewed as the “ultimate last resort”, to be considered only when all other options have been exhausted. When I explored some of the reasons for this view, clinicians expressed that institutional care is “like a death sentence”. RhT summarizes some of their negative feelings this way:

I think it’s because it’s the end of the road. You’ve got one foot in the grave, you know. You’re half asleep in your big dirt nap, that type of thing No, I’m not kidding! You think, you think of smelly diapers, you think old people hunched over in their chairs, you think one foot in the grave, literally. Zero quality of life.

Part of this disdain also stems from the fact that clinicians are frequently required to send a young person with a non-TBI to an environment, “where everyone is dying”. But the age disparity is only part of the issue; an even greater dilemma is that clinicians do not view LTC as goal-oriented. “Condemning” a patient to an environment that does not promote their functional goals is a large part of why these clinicians view LTC as such a negative outcome.

PT: Someone who is, at the age of our patient population, much younger than the typical long term care applicant. There’s nothing for them to do; they’re not working on functional goals. They’re eating and sleeping and everything’s provided for them. They sit and watch TV! So it’s just, it’s really like a holding ground, because there’s not much for them to do, there’s no function goals or functional independence in that environment, so, you know, it’s impossible to continue to improve!

Clinicians also feel that the LTC environment does not support the emotional needs of their patients, particularly in the areas of belonging, love and self-esteem. Although it meets basic physiological and safety needs, institutional care satisfies little else. SW describes a young
ABI patient whose goal of living independently was put on hold the moment he arrived at LTC. For her, this scenario is not an isolated case:

And they had put in papers for him [to supportive living], everywhere, but with long waitlists. And he wasn’t very happy at [LTC]; he was in his 30s. He felt like it was a very confining atmosphere, socially. And, the approach to care there was very much custodial, which did not really afford him much independence. It was quicker, more efficient for them to give him a shower, than to allow him to shower with support. Um, to me this is a very impoverished setting. So when you say, “Is it safe?” Yes, physically it is safe. But in terms his function, it certainly didn’t allow him to continue to work on being independent, which was so important to him.

For these clinicians, LTC represents a “holding tank” for patients who have no other options. It embodies the opposite of getting on with life, and is instead the very essence of a life left behind. In the case of Dave, OTa feels that the support and commitment of his Niece was the only thing standing in the way of a life-time of institutional care. As someone who understood Dave’s potential for recovery, for her, home was by far the better outcome:

So in terms of Dave going to long term care and sitting there watching a television show, and not really doing much else with his time – I couldn’t imagine it for him, at all.

“The Bottom Line”

Clinicians face many challenges as they help prepare patients and families to transition beyond the support and security of brain injury rehabilitation. For many, home represents an opportunity to explore what it means to be an autonomous person again; but, it is also a place of constant change and uncertainty. Under challenging circumstances patients and families exhibit courage, wisdom, and resilience, demonstrating the universal human strengths that often prevail following a life-changing experience. The clinicians in this study strive to honour a philosophy of care that views patients as autonomous human beings who are not so very different than themselves. For RhT, that is “the bottom line”:
We can’t forget that once somebody walks through our doors and we live with them as a patient, to not think of them as a patient. And put yourself in their shoes. That would be the one thing I would say: Never, ever forget that this could be you, this could be your mother, your brother, your sister. Put yourself in that mindset and go from there. Often we just put on our [clinician] hats and forget that there’s a person under there who has every right to make their own decisions, to live at risk, to do what they want to do. That’s the bottom line.

Summary

This study examines the factors that influence how brain injury clinicians balance the importance of patient risk-taking against the importance of patient safety during transitions in care. The transition from rehabilitation to home poses challenges to respecting patient autonomy that are different than acute care and not well understood. For most patients, respecting their autonomous decisions is seen as being in their “best interests”; however, the results of this study suggest that for the brain injury rehabilitation patient, these decisions are often complex and require an approach to autonomy that is more nuanced that a traditional liberal individualist interpretation. A relational approach to autonomy emphasizes the concepts of dependent and interdependent relationships, and recognizes that patients, families, and clinicians make decisions about risk-taking and safety within the context of their social environments. However, this study suggests that decision-making is also influenced by conflicting values, system pressures, and patient abilities. Relational autonomy may provide clinicians with an enhanced framework for understanding decision-making within these contexts, and ultimately help them make better decisions related to respecting patient autonomy and advancing patient safety. The results of this study suggest that relational autonomy is relevant to brain injury rehabilitation in four ways.

The first reflects the fact that patients may autonomously choose to make decisions that give precedence to risk-taking, or they may autonomously choose to make decisions that
give precedence to safety. Both are autonomous choices and both need to involve a deliberation between the personal and professional views of the clinician, and the goals and values of the patients and families in their care.

The second reason is that social and systems factors such as clinical experience, the hospital environment, system pressures and hospital policy, can also influence decision-making, particularly as patients and families prepare to transition home. While these factors are characteristic of brain injury rehabilitation, they are also highly variable and context-dependent. A relational approach to autonomy emphasizes that autonomy is social in nature, and that social factors can influence a patients’ decisional or functional abilities. Determining decision-making capacity is an example of when such factors are important, and where there are few, if any, definitive conclusions. Accurately assessing decision-making capacity is particularly challenging for the ABI occupational therapist who is often required to make assessment and treatment decisions that apply across all contexts and levels of patient ability.

Third, in healthcare and broader policy decision-making, clinicians determine the acceptability of risk-taking by considering the probability and magnitude that it will result in patient harm, together with the benefits of taking the risk. Again, these issues are more nuanced in brain injury rehab where patients’ decisional and functional abilities also influence how clinicians make decisions; however, this chapter raises two other relevant considerations: Such patient abilities need to be considered in (1) relation to individual and team values about risk-taking and safety, and (2) the ethical and clinical complexities of the decision or action.

The final issue concerns the distinction between autonomous decision-making (decisional autonomy) and autonomous action (functional autonomy). Patients, families, and
clinicians vary in how they translate the goal of respecting patient autonomy into practice. One clinician may understand respect for autonomy as respecting a patient's decision to take, or not to take, a particular risk that may impact (either positively or negatively) on their functional ability; whereas, another clinician may understand respect for autonomy as doing everything she can to help restore her patient's ability to function independently. This is particularly relevant during transitions in care where a family supports, and services and systems of care in the community can either threaten or enhance autonomy. The following chapter explores these issues in the context of the literature and offers implications for clinical practice.
Chapter 5: Discussion, Implications and Future Research

All models are wrong. Some models are useful.
(George Box, Statistician)

Introduction

This study examines the challenges that clinicians face in balancing risk-taking and safety during transitions in care from brain injury rehabilitation. Issues of patient autonomy and transitions in care have been studied in the literature; however, usually from the perspective of the acute care provider and often in a mechanistic way. There is little evidence to guide clinician decision-making related to risk-taking and safety in the context of rehabilitation. This study contributes to the growing rehabilitation literature by elaborating on the complex issues that influence ethical and clinical decisions among patients, families, and clinicians during brain injury rehabilitative care. The results of this inquiry suggest that there are inherent tensions between rehabilitation and patient safety efforts. Risk-taking lies at the core of brain injury rehabilitation; however, healthcare professionals are frequently required to make decisions that conflict with each other, as well as the patients and families in their care. Social, systems, and support factors also influence decision-making about patient autonomy. A relational approach to autonomy that addresses patients’ decisional and functional abilities within their social contexts may provide clinicians with a more nuanced approach to making decisions that better balance risk-taking and safety.

The stories related in Chapter 4 explore the factors that influence decision-making during transitions in care from brain injury rehab. These factors were examined in relation to the concepts of relational autonomy and the WHO’s ICF model introduced in Chapter 2. In
Chapter 3, qualitative, interpretive methods were used to investigate the nature of these factors. In this final chapter, I discuss the main findings of my research in the context of the relevant rehabilitation, bioethics, and patient safety literature. Here, I examine some of the ethical and clinical conflicts that can arise during brain injury rehabilitation, and elaborate on opportunities for clinicians to examine their commitments and practices to supporting decisional and functional autonomy, as patients and families transition beyond their care. Finally, I offer the implications of this research for future practice and future inquiry, as well as the study’s limitations.

**Summary of Main Findings**

I set out to study the perspectives of how patients, families, and clinicians make decisions related to risk-taking and safety in the context of brain injury rehabilitation. Specifically, I wanted to explore the:

- Ethical and clinical challenges that patients, families, and clinicians experience in deciding how to balance patient risk-taking and safety in brain injury rehabilitation.

- Relevant social and systems factors that also influence how these stakeholders make decisions related to decisional and functional autonomy, particularly during transitions in care.

My goal was to develop an in-depth understanding of the tensions that patients, families, and clinicians experience in how they balance patient risk-taking and safety, why these tensions may be characteristic of brain injury rehabilitation, and how they influence safe transitions in care. I used an ethical lens that understands autonomy as socially situated and contextualized, and a clinical lens that recognizes that ABI impacts function along a continuum ranging from body impairments, to activity limitations, to participation restrictions. A relational approach to autonomy may provide clinicians with the guidance
they need to understand and respond to these issues because it provides a framework for examining patients’ decisional and functional abilities in the context of their dependent and interdependent relationships. At a more conceptual level, the following are the main findings of this research situated within the relevant literature.

1. **Clinicians balance decisions about risk-taking and safety along two intersecting axes.** The first reflects their own values, goals, and experiences about risk-taking and safety; the second reflects the extent to which these values align with other members of their healthcare team, and the patients and families in their care. Despite attempts to remain unbiased, these values often conflict. This has implications in how clinicians plan, deliver, and evaluate patient care. Clinicians have very personal values and beliefs about risk-taking and safety that are a large part of their assumptive worlds. In the complex area of clinical decision-making, several models over the past two decades have attempted to describe the practitioner-patient relationship. The majority of these frameworks conceptualize decision-making along a continuum that distinguishes between provider paternalism and patient autonomy. The most widely discussed analysis in this area is the work of Emanuel and Emanuel (1992) who propose four decision-making models that deliberate among the values of the patient, the values of the practitioner, and the pluralistic tensions between autonomy and beneficence. In the **paternalistic** model, the clinician makes decisions for the patient’s benefit, independent of the patient’s values or goals; in the **informative model**, the clinician provides information, and the patient decides what to do based on his or her own values and beliefs; in the **interpretive** model the patient is uncertain about his or her own values, and the

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9 This interaction is often referred to in the literature as the “patient-physician relationship”, however, it is commonly understood to also include other members of the healthcare team.
clinician acts as a counselor to help clarify and deliberate regarding the patient’s values; finally, in the deliberative model, the patient is open to self-development and the clinician as teacher helps to determine and act on the patient’s most worthy values. Emanuel and Emanuel argue in favour of the deliberative model where, “freedom and control over medical decisions alone do not constitute patient autonomy,” (p. 46). Here, autonomy requires that patients critically assess their own values and beliefs, reflect on which values should justify their decisions, and then freely initiate an action. Thus, the process of deliberation is an essential part of “realizing autonomy” (p.46).

This decision-making model is limited in three ways. First, it views the patient as a person who makes decisions in a vacuum outside of his or her social context. While such decisions are relational in the sense that the clinician plays a role in the deliberation, in this model, patients are viewed as capable of making critical decisions alone. The results presented in Chapter 4 suggest this is not the case; patients are frequently unable to make decisions independently and want their loved ones to be involved, particularly in the challenging area of discharge planning. Second, this framework seeks to discover the “best” decision-making process for patients (Clarke, Hall and Rosencrance, 2004). This approach may be problematic if patients are divided in their preference for decision-making relationships. The patients in my study differ greatly in their decision-making preferences. Some want their clinical team to act paternalistically, while others want to deliberate on all of the information, and still others are unready to trust any treatment recommendation until they have fully explored the alternatives. Thus, the search for the “best” model may actually undermine patient autonomy (Clarke et al., 2004). Finally, Emanuel and Emanuel’s approach to healthcare decision-making focuses primarily on critical and end-of-life care.
This model needs to be broadened to include factors relevant to rehabilitation settings where ethical and clinical issues are complex, yet rarely involve such urgent life and death situations.

Despite its limitations, the deliberative model is helpful to patients, families, and clinicians as they decide among medical decisions and discharge options that are often challenging and life-changing. This model sees the healthcare provider as a guide who helps patients and families clarify their values, and offers advice about what patients and families could and should do given their values and goals (Emanuel & Emanuel, 1992). Such professional guidance is especially relevant to patients and families who are overwhelmed with information, foreign terminology, and unknown environments and expectations. It is also helpful to clinicians who are committed to the principles of respecting autonomy, but disagree with their patient’s approach to risk-taking or safety. While clinicians seek input from their patients and families, they often do not make their own beliefs explicit (Ells, 2001). Patients and families look to their care providers for support and guidance, and as a result, are susceptible to their values. Agich (2003) cautions clinicians to not impose their personal beliefs and attitudes on those in their care. Haas (1994) (and others) have also called for patients and providers to align their values and goals. In a later and more nuanced reflection, Agich (2007) responds to himself and others by reminding clinicians that autonomous individuals are situated within social contexts; therefore, choice is contextual and there are costs associated with any choice (p. 77). The practical implications of relational autonomy, or autonomy in context, do not mean that providers or caregivers are precluded from influencing the decisions of dependent adults. To be exposed to influence, especially influence that aims to preserve or enhance well-being, in most instances, does not
violate autonomy. This echoes the deliberative model that recognizes that clinicians have a role to play in influencing behaviour based on shared values. Quill and Brody (1996) agree. They argue that most patients and families want to hear their clinician’s perspective about risk-taking and safety, and engage in a negotiation and deliberation that incorporates the values of all of the stakeholders involved in the decision. Thus, clinicians who have strong views should openly acknowledge them. In this way, biases and relevant experiences are not hidden, but are instead an integral and explicit part of the discussion. The results presented in Chapter 4 suggest that it is challenging for clinicians – no matter how reflective, in tune or intent – to set their personal beliefs and past experiences completely aside. But nor is this preferred or likely possible. This study suggests that decisions related to risk-taking and safety are unavoidably value-laden. That which makes rehabilitation unique – its emphasis on the patient and family as collaborators in their care – also makes it susceptible to circumstances where the values of patients, families, and clinicians collide.

2. Risk-taking lies at the essence of brain injury rehabilitation where patients push the boundary of their functional abilities; however, decisions about risk-taking and safety are also influenced by social and systems factors. Much of the discussion in the ethics literature on autonomy and decision-making suggests that clinicians make decisions about risk-taking and safety along a continuum that gives precedence to autonomy or beneficence, risk-taking or risk-adversity. Closely linked to these discussions is the frequent finding that these values are seldom in alignment among clinicians and those in their care. The results of this study help inform this debate and are consistent with other studies that suggest that values, attitudes and experiences about risk-taking and safety are often in conflict. However, my study further suggests that decision-making in brain injury rehabilitation is more complex than this. Social
and systems factors are also critical to how clinicians make decisions about risk-taking or safety. Thus, all three of these factors – the decisions of the provider, patient and family, the extent to which these decisions align or conflict, and the relevant social and systems factors – all need to be considered when preparing patients and families for safe transitions in care. Figure 3 summarizes these issues.

Understanding clinical decision-making as embedded within multiple and interrelated contexts echoes complex systems theory that emphasizes the interdependence of people, technology and organizations as opposed to considering these factors in isolation (Morath & Turnbull, 2005). Complex systems thinking requires clinicians to consider how the hospital environment and the patient’s social world are connected, even though they are separated by distance, time, safety considerations and culture (Reason, 2000). In her discussion of the application of systems theory to rehabilitation, Cary Brown (2005) argues that in dynamic and adaptive social systems such as healthcare, a small input can have an unanticipated large effect. The huge infusion of funds into spinal cord research after the death of Christopher Reeves is often cited as an example of this phenomenon. Complex events are also multidimensional and have the features of high uncertainty and disagreement; but they are still governed by basic rules (Sweeney & Griffiths, 2002). When complex systems thinking is applied to how clinicians make decisions that aim to balance risk-taking and safety, some important social and policy issues arise. Social issues such as clinician experience, the quality of the caregiver supports at home, and access to on-going rehabilitation services in the community all become important. Also related are broader policy concerns such as hospital policies, the threat of liability, and bed flow pressures.
Figure 3: Factors That Influence How Patients, Families, and Clinicians Make Decisions About Risk-taking and Safety in Brain Injury Rehabilitation
This study raises some questions for debate as brain injury rehabilitation clinicians attempt to prioritize risk-taking and safety: Why do some clinicians and patients get away with breaking the rules? To what extent do a clinician’s experiences vary over time – does “getting burned” or your having your “wrists slapped” change one’s risk-taking behaviour? What are the attributes of novice clinicians relative to the team’s approach? Are they more conservative and make decisions that err on the side of caution, (“You shouldn’t get dressed by yourself, you might fall!”) or do they questions other team members (“Why shouldn’t this patient be allowed to go outside alone?”)? Under what circumstances do novice clinicians bring a fresh perspective to a team that might otherwise do what they have always done? Decision-making about risk-taking and safety during transitions in care needs to be understood against a backdrop that extends beyond classically defined acute care issues such as informed consent and surrogate decision-making capacity (Agich, 2007, p. 74). It needs to include instead, an understanding of the factors that impact recovery as patients and families return home, as well as the delicate interplay between balancing patient risk-taking and safety.

3. Clinicians work within a collaborative patient-centered model of care that is committed to the principles of respect for autonomy; however, there is a gap between the theory of this model and the reality of clinical practice. The concepts and assumptions of rehabilitative practice related to decisional and functional autonomy need to be critically examined in light of this gap. There is a growing emphasis in healthcare settings on approaches that put patients and families at the center of their care (Bernsten, 2006). Posted prominently at the elevators doors and websites of many hospitals (Toronto Rehab included)
are mission statements that emphasize that the goals, values, and expectations of patients and families are critical to healthcare decision-making. At the core of this patient-centered model is the ideal of shared responsibility among a wide range of practitioners working in partnership with those in their care (Caplan, 1987). Several studies have focused on how a patient-centered approach may enhance patient care and safety, provider satisfaction, team behavior and professional competencies (Reeves, Zwarenstein, Goldman, Barr, Freeth, et al., 2008; Zwarenstein, Reeves, & Perrier, 2005). In reality, however, patient-centered care is difficult to achieve. Clinicians often operate within fragmented and complex systems, and may become disillusioned with how to truly focus on the needs and goals of patients and families (Bernsten, 2006). A recent qualitative study of academic institutions in Toronto identified patient-centered care as an unfulfilled “illusion” for patients, families, and clinicians (Jeffs, Affonso & MacMillan, 2008, p. 492). The results of this study are consistent with these findings. Even in a rehabilitation where healthcare teams are larger, hierarchies are flatter, and care is generally more goal-oriented (Caplan, 1987), providing true collaborative care is difficult. System pressures, competing values, reduced efficiency, and variable skill sets all contribute to this challenge. Pam Rycroft (2004) points out that some clinicians can practice patient-centeredness with relative ease, but they are the exception. Building on the work of Donald Schön, Rycroft asserts that there is a kind of “sanitized version” of therapy that is pervasive throughout the literature. It fails to recognize that so much of clinical therapy consists of unique events and moments when, regardless of how much a clinician or an organization seeks to embrace a certain model, there is often no one clear way to proceed (p. 246).
4. Research suggests that transitions in care are challenging for patients, families, and clinicians (Coleman et al., 2003; 2004a, b). Part of this challenge is dealing with short term system pressures given the long term nature of functional recovery. The current debate on discharge readiness suggests that we have made some gains in how we prepare patients and families for transitions in care (Forster, et al., 2003; Grant et al., 2006; Perry et al., 2008). However, my results emphasize the ways in which care transitions create tensions among brain injury rehabilitation clinicians. Extended time in rehab threatens efficient bed utilization and return on investment in health for society (Sweeney & Griffiths, 2002). As many hospitals implement more rigid standards for target length of stays\(^{10}\), patients and families are being discharged to their next care environment earlier and less prepared. In a healthcare system that gives patients only “one kick at the can”, patients and families are at risk of leaving rehabilitation with unmet care needs and, most critically, unfulfilled rehab potential.

Like Fenwick (1979) and others, this study suggests that discharge readiness varies across patients and families, and needs to be considered in the context of patient impairments, activity limitations and participation restrictions, along with supports at home and systems of care in the community. Various factors influence transitions in care, including ethnicity, age, sociodemographics, pre-injury factors, and family supports. This study highlights the need for further reflection of own care processes, and the risks and tradeoffs that arise when reconciling the views from the “sharp end” and the “blunt end” of care during transitions in care.

\(^{10}\) For example, the average length of stay of stroke rehab patients in Ontario decreased from 33 to 39 days between 2003 and 2006 (Teasell et al., 2008).
5. A relational approach to autonomy is relevant to brain injury rehabilitation patients who must often decide among discharge options that may not reflect their own wishes (such as LTC), and clinicians who must consider their own values, as well as relevant clinical, environmental, and policy factors. Relational autonomy offers patients, families, and clinicians the opportunity to negotiate and deliberate among their own values, goals and, beliefs. The dominant liberal individualist view of autonomy in health care is described as, "self-rule that is free from controlling interferences by others and from personal limitations, such as inadequate understanding, that prevent meaningful choice," (Beauchamp & Childress, 2008, p. 58). From this perspective, an autonomous person is one who, “freely acts in accordance with a self-chosen plan,” (p. 58). Beauchamp and Childress derive their view of autonomy from a liberal individualist tradition, particularly from John Stuart Mill’s conception of individuals as free, equal (in deserving of concern and respect), and rational. This study supports the view that a traditional individualist approach to autonomy is not sufficient in the context of complex care needs (Agich, 2003; Collopy, 1988; Sherwin, 1998). An expanded and more nuanced view is needed – one that examines a patient’s decisional and functional abilities in relation to his or her social contexts.

A relational approach to autonomy contributes to ethical and clinical decision-making in rehabilitation in three ways. First, issues raised in settings such as ABI rehab are an ideal domain to explore an expanded concept of autonomy. While rehabilitation lacks the visibility of the high tech dramas played out in acute care settings (Ells, 2001; Scofield, 1995), the ethical and clinical dilemmas raised by rehabilitation are no less important than those in acute care. Rehabilitation clinicians recognize that patients can be emotional and creative, and their decisions are embedded with a network of dependent and interdependent
relationships (Agich, 2003; Sherwin, 1998). Patient autonomy is not some strictly cognitive or functional property inherent in an individual. Rehabilitation offers patients the social context they need to begin exploring what it might mean to become an autonomous person again. In essence, rehabilitation is where the work of rediscovering autonomy begins.

Second, relational autonomy reinforces the importance and implications of positive autonomy in brain injury rehab. Positive autonomy encourages healthcare providers to take a “positive” step forward, not a step back in helping patients and families make important healthcare decisions. This approach requires clinicians to provide resources, offer assistance, and advocate for choices in a way that accurately recognizes their own emotions and values (Halpern, 2001). Without this self-reflection, clinicians are less able to respond effectively to the needs of their patients and families. Positive autonomy is particularly relevant in brain injury where patients and families are often dependent on others for many aspects of care, yet are required to make difficult and often life-changing decisions, such as considering a transition to LTC. A relational approach to autonomy challenges fundamental assumptions in healthcare's dominant conception of autonomy (e.g., autonomous people are largely independent and equal in society and moral problems are those "solved" by respecting autonomy), and recognizes that individuals with disability are only as independent as the boundaries of their social and physical environment (Agich, 2009; Sherwin, 1998).

Third, relational autonomy informs the on-going discussion about the principles of autonomy and paternalism in the context of disability, and offers rehab clinicians a relevant and practical framework to help them evaluate their actions, resolve conflicting values, and justify decisions. While many authors have discussed the tension between autonomy and
paternalism in acute care\textsuperscript{11}, these deliberations are only slowly emerging in rehabilitation. Understanding the dichotomy between autonomy and paternalism is especially relevant to brain injury where such issues are often complex. For example, it may be necessary for clinicians to over-ride a capable patient’s decision to not engage in daily therapies because the patient feels they are too difficult or painful. During this period of adjustment, where patients have yet to find meaning or the will to move forward in a radically altered life, paternalism may well be justified.

Results from this study concur with the view that paternalism is usually something to be avoided, and that autonomy is usually a positive value. Yet, a number of scholars identify a paradox. Kittay (2007) questions whether healthcare practitioners must choose between patient autonomy and paternalism. Devettere (2000) doubts the ability of clinicians to make an absolute distinction between paternalism and autonomy, and to prefer one over the other. The driving force behind paternalism is beneficence, doing good for our patients. The motivation behind autonomy is the recognition that patients are ultimately responsible and free to make important life decisions. Conceptually, this is consistent with what Pellegrino and Thomasma (1993) suggest is “true beneficence”. In this way, Chin (2002) argues, beneficence and autonomy are not conflicting, but congruent principles.

An approach that promotes a harmonious interplay between paternalism and autonomy probably serves our patients and families best. However, even a nuanced approach to paternalism raises subtle dangers in rehabilitation. Heike Smidt-Felzmann (2007) points

out that clinicians need to be particularly attuned to, “hidden forms of influence” (p. 180). Decision-making in brain injury rehabilitation is seldom value-free, nor does it generally involve interaction among equals. In order to mediate the potential dangers of paternalism, clinicians need to make their values transparent and clearly delineate when their authority shifts from helpful expertise to moral counseling. Relational autonomy calls for a genuine process of shared decision-making among patients, families, and providers (Chin, 2002). This approach to autonomy recognizes that relationships in healthcare are inherently dependent and interconnected. Yet, it also understands that when these stakeholders engage in shared decision-making, the meaning, richness and accuracy of a patient’s choices can be enhanced by the clinician’s recommendations and expertise. Relational autonomy can guide and be guided by a growing understanding of the implications of patient autonomy that moves beyond the debates and boundaries of traditional healthcare ethics.

**Limitations of the Study**

*Intimate Familiarity*

One source of credibility for grounded theory is the degree to which the researcher has achieved intimate familiarity with the setting or topic under investigation (Charmaz, 2006). Familiarity plays an important role in granting the researcher greater understanding and thus, greater depth of analysis. Two ways of achieving familiarity are *prolonged engagement* and *persistent observation* (Corbin & Strauss, 2008). Interviewing participants over a period of time is one way to engage them in the research process. While I value this approach, I also appreciate the burdensome nature of this request, and instead chose to interview participants at a single point in time. However, on several occasions following our interview, patients and family members called or emailed me with a revelation or
clarification that they wanted me to hear, or better understand. Meeting with all patients and families prior to our scheduled interview created another opportunity to increase familiarity for both participant and researcher. Despite these efforts, I do not feel that I was particularly successful in achieving a prolonged engagement with participants.

This study was also limited in the area of persistent observation. My main source of data included in-depth participant interviews and demographic information. Together with extensive field notes and memoing, they made up my data set. Another source of rich data collection is participant observation, which would have brought me into the homes and communities of patients and families. While this would be extremely relevant data (and a consideration for future inquiry), I chose not to use participant observation as a method of data collection. Given the potentially complex ethical issues raised by participant observation and the time it requires, as well as the fact that this research took place in the context of a Master’s degree, I eliminated this approach in the early stages of this study.

Singular Approach to Data Analysis

For the purpose of this project I interviewed and coded the interview data myself. I did not have the budget, nor was it appropriate as a Master’s student, to involve multiple people in the analytic process. I did, however, use peer debriefing as a technique to enhance the authenticity and audit trail of this inquiry (Willis, 2007). On four occasions I met with my thesis committee – once, following the first five interviews, again, after all interviews were complete and finally, as I prepared for early thesis drafts – to discuss my early analysis. At each of these meetings, my committee provided me with superb guidance regarding the theoretical and conceptual analysis of my emerging grounded theory.
Scope of Data Collection

Finally, I feel that this study is limited in the scope of its inquiry. In reflecting back on this research, I have this sense that *I could have done more*. While I am cognizant of the importance of a thesis question that was bounded and “doable”, I feel that I missed out by not interviewing a few key clinicians on the ABI unit. One example of a missed opportunity is the chaplain. This role is unique not only for its access to patients and families, but also for its ethical lens. I also felt that the issues important to people with chronic and episodic disease were somewhat overshadowed by the more “traditional” TBI sequelae in this study. Further investigating the issues important to people with MS would have both enhanced and muddled the results of this study, but ultimately contributed to a fuller, more developed theory.

Implications for Practice

Patient Care

This study focuses on understanding complex issues of respect for patient autonomy from three different perspectives – that of patients, their loved ones, and key members of their rehabilitation healthcare team. There is much variability among the views of the these three stakeholders; however, they largely agree that in the course of recovery, two things are unequivocal: The first is that patients take risks and explore the boundaries of their new selves as an important part of regaining decisional and functional autonomy following brain injury; and the second is that such risk-taking can create conflicts among patients, families and clinicians. The results of this study suggest that risk-taking lies at the very essence of brain injury rehabilitation, yet clinicians often take a cautious stance towards risk-taking outside of the institution. As a result, discharge planning is often based not only on a
patient’s physical and cognitive abilities, but also on a clinician’s own fears – fear that a patient will struggle at home, or fear that, “the house might catch on fire” (Frederick, 2001). These uncertainties are heightened by risk management, conflicting team views, and shortened length of stays. As patients transition beyond the support and structure of the rehabilitation environment, clinicians often resolve conflicts between risk-taking and safety in favour of safety. In other words, they set the bar too high. This often comes in the form of making recommendations such as, “If you choose to take your uncle home, he will require 24-hour supervision.” These recommendations are frequently so difficult that families become convinced that disability is not only inconvenient, but all consuming (Frederick, 2001). At the intersection of these issues is an understanding that safety is not an absolute value. Safety too should be examined in the context of other values, and from the perspective of patients who must ultimately take responsibility for their decisions and actions (Collopy, 1995).

In this thesis I argue that clinicians need to recognize that not all of the decisions that their patients make are good ones or are ones that they necessarily agree with. Instead, clinicians are responsible for ensuring that their patients make informed decisions, that they understand the information needed to make the decision, and they appreciate the consequences of the decision. Specifically, providers need to educate patients and families prior to discharge about risk-related activities that they may choose to engage in, to inform them about the risks and tradeoffs of these activities, and document the choices made by capable patients. Thus, clinicians intent on having a thorough and nuanced understanding of the safety-related issues important to patients and families, need to shift their approach to autonomy from one that focuses on the individual alone, to one that understands that patient
choices are relational and made in context. This broader ethical lens has implications for the rehab clinician who seeks to enhance patient and family decision-making in ways that prioritize both autonomous living and safe transitions in care.

Over their life-times patients and families may have unmet care needs. Care models that prioritize regular access to therapy are starting to emerge in the literature to address the decline in function experienced by many patients as they age. Patients and families need programs that are adaptable enough to address specific rehabilitation goals; they also require advocacy from rehabilitation clinicians to access such care. Two approaches to therapy that may be particularly effective for people with complex care needs are outreach teams and “short burst” regular access to therapy. Both of these models offer clear and straightforward opportunities to access rehabilitation services in ways that closely match the needs and readiness of patients and families. Outreach teams have been implemented in other health sectors such as geriatric rehab, but rarely in brain injury settings. These outreach teams contain members of a patient’s own rehabilitation team who spend time in his or her home environment and problem solve safety issues in real-time. In the case of short-burst therapy, patients and families have access to a knowledgeable interprofessional team who offer flexible and timely therapy in a manner that suits their needs, schedules, and goals.

Patient Safety

Members of an interprofessional healthcare team face conflicts of authority and responsibility, as well as conflicts in values. Despite this, most clinicians make every effort to send their patients home, no matter how time consuming, challenging, or inconvenient. They view home as an ideal that maximizes the quality of life of their patients. In contrast, they consider LTC as a threat to autonomous, goal-oriented living. Ironically, institutional
care is somewhat of a convenience to clinicians since it is a place that will assume responsibility for the safety of their patients. Clinicians may believe that LTC offers a solution to the patient who may be unsafe or socially isolated. But disability is an inherently risky and socially isolating condition (Agich, 2003); the young adult with an ABI will rarely find age-appropriate company in institutional care. In terms of safety, clinicians should not be naïve enough to think that LTC offers superior protection against adverse events such as falls and infection (Frost, 2001).

Collopy (1995) and Halpern (2001) note that safety considerations in rehabilitation are frequently framed in acute care terms, where autonomy is often equated with independence and means leaving patients and families alone to determine their own course of treatment. But for patient and families with complex care needs, safety is less about medication error and disclosing adverse events, and more about functional recovery and interdependent relationships. Cardol et al. (2002b) write that the ultimate goal of rehabilitation is to support autonomy. Collopy (1995) suggests that the ultimate goal should be community integration. The results of this study suggest that it is the intersection of these two objectives that should be the true aim of rehabilitation. Embracing a broader concept of autonomy that examines patients’ decisional and functional abilities within shared values, goals, and networks, is an important area where rehabilitation can make a contribution to patient safety.

*Broader Policy Issues*

The broader policy and ethical issues facing rehabilitation at the societal level are similar to acute care medicine, such as the allocation of resources, yet the context is strikingly different. Unlike acute care, there is little pre-existing literature, few specialists,
and almost no tradition of collaboration between clinicians and bioethicists (Collopy, 1995). Moreover, the priorities within healthcare are skewed in favour of complex interventions and advanced technology, creating an acute care system that is well ahead of the care and services that are available to patients with chronic disease (Jennings, Callahan & Caplan, 1988). Still, the need for rehabilitation services is slowly being recognized. While the numbers are relatively small, people who are receiving rehabilitative care for a brain injury are highly visible to providers, decision-makers, and third party payers in terms of direct healthcare costs, lost productivity, and the level of resources they utilize (Collopy, 1995). Thus, rehabilitation clinicians need to continue to identify relevant ethical and clinical research questions, and consider the need for novel analyses given that acute care analyses may not be fully adequate.

Continuing Education and Clinical Training

There are a variety of ways clinicians, researchers, and decision-makers can direct greater attention towards ethical and clinical issues in rehabilitation. Journal editors need to encourage submissions from bioethical communities that emphasize both the clinical and policy gaps that impact safety in rehabilitation. Funding bodies at local, national and international levels also need to identify rehabilitation as worthy of support, and prioritize such submissions. At the organizational level, many hospitals have introduced ethics committees as a useful forum to discuss safety issues. In contrast, few centers have the equivalent patient safety body tasked with knowledge sharing and capacity building among front line staff. The role of the patient safety officer or equivalent may be a good place to begin such a dialogue. Academic programs in healthcare also have a role to play. Currently, most professional schools offer courses in the area of bioethics and profession-specific safety
issues; however, patient safety from a complex systems theory perspective has received little attention. Finally, rehabilitation professionals need to make greater efforts to align bioethics and safety issues in their own research activities, teaching commitments, and professional college mandates. By partnering directly with both bioethical and safety communities, practitioners may supplement the current literature with more discussions and analyses situated within rehabilitation and for people with complex care needs.

**Conclusion and Future Directions**

This study uses grounded theory methods and methodology to explore how patients, families, and clinicians make decisions about risk-taking and safety in rehabilitation. A relational approach to autonomy and the WHO’s ICF model have offered a lens in which to explore these issues. Both concepts understand patient autonomy and function as socially situated and contextualized. This study examines the complex factors that influence decision-making following a brain injury and contributes to the literature in three ways. First, it examines ethical and clinical issues related to patient autonomy from the perspectives of patients, families, and clinicians. While the relationships between patients and providers, as well as patients and families have been fairly well studied in the literature; rarely have the experiences of all three stakeholders been examined. Second, it contributes to the growing safety and ethics literature in the area of ABI. And third, it asks questions in the relatively unaddressed setting of rehabilitation. Future research in this area requires an assessment of how brain injury impacts individual, familial, and societal relationships, as well as overall systems and services of care. In qualitative research, meaning resides in the context of the study. Accordingly, any conclusions drawn from the results of this research must be made with the recognition that they are based on the people, systems, and environments at Toronto
Rehab. While my hope is that these discussions and implications are relevant across other rehabilitation settings, the onus is on the reader to evaluate their applicability.

The first area of proposed future inquiry continues to contemplate what makes patient safety in rehabilitation different from other settings, and the practice and policy implications of these differences. For example, what does a safety score card for rehabilitation look like? How should we identify and measure these indicators? Surely we need to consider safety measurement in rehabilitation that goes beyond infection rates and fall severity, such as patient satisfaction, length of stay efficiency based on rehab-appropriate outcome measures, and adequately reimbursed secondary prevention programs. As we contemplate these questions, we also need to involve patients and families in both research and safety initiatives. Their experiences and insights at the practice level are essential resources for the design and evaluation of programs that enhance patient-centered care and coordination.

Second, this study seeks to understand issues of patient autonomy from the perspective of people with brain injury who were capable of giving their informed consent. Interviewing patients who are not capable can be challenging; however, rarely are these voices heard.

Third, this study focuses on the transition for rehabilitation to home. As suggested earlier, prospectively following patients as they prepare to leave rehabilitation and again after they transition home, may be interesting as it would provide researchers with a unique lens from which to view safety issues in real time. While it may not give participants the benefit of time to reflect on safety issues, it may reinforce the link between risk-taking and recovery with a sense of urgency and immediacy.
Fourth, this research includes the perspectives of people living with brain injuries at home. The stories of those living in institutional care, such as LTC or CCC, along with their therapy team, would serve to further elaborate and refine categories in my emerging theory. While these settings have been somewhat explored in both the safety and bioethics literature, the perspectives of those with ABI have not. Other populations, including people with MS would also be interesting to investigate. Safety issues for people with MS may be different than those with sudden and traumatic injuries due to the chronicity of the disease, and the ongoing challenges around future uncertainty and access to care in the community. We have a lot to learn from this group, particularly in the design, implementation and evaluation of unique models of care that prioritize rehabilitation throughout a patient’s lifetime.

However, recognizing the multifaceted nature of brain injury is only the first step. We still lack an adequate understanding of the long term ethical implications and safety issues of individuals and families living with ABI at home. This knowledge would support efforts to meet their needs and goals, and support them in living meaningful lives. Carolyn Ells (2001) has called for a comprehensive public discussion on how to meet the present and future challenges of patients and families living with chronic illness. Rehabilitation professionals working collaboratively with patients and families could play a leadership role in this work.

Questions of risk-taking and safety could also be explored in the context of other qualitative methods, such as phenomenology, life history, or ethnography. Charmaz and Mitchell (2002) challenge grounded theorists to move away from, “purely elegant method” towards making articles and theses symbolic of the real world, rather than “snippets of stories and pieces of narrative” (p. 171). Ethnography, for example, shares an appreciation and knowledge of context, sensitivity to unstated and unrecognized meanings, and an awareness
of layers of meaning in language. My interpretation of *bricolage* – or deliberately mixing qualitative methods and ways of thinking – aims to increase awareness and use of different qualitative methods, perspectives and scholarly literature to strengthen emerging theory. Future research in the area of rehabilitation should also consider the benefits of a mixed methods design that foregrounds qualitative research, but asks both “what” *and* “how”.

Therapists in rehabilitation rely primarily on profession-specific publications for ongoing knowledge exchange. If emerging ideas (like relational autonomy and complex systems theory) are not discussed in profession-specific journals, then therapists who do not read literature outside of their own field, may not be exposed to emerging areas of knowledge and best practice. This would leave therapists, and ultimately patients and families, disadvantaged as other team members or more likely, other healthcare sectors would have more knowledge about such current and relevant concepts.

Finally, we need to continue to learn from acute care as leaders in the patient safety and quality movement in healthcare. In order to understand what makes rehabilitation different, we must also understand what makes us similar. Rehabilitation needs to reposition safety research that is aligned with and integrated into the continuum of care, and include our acute, as well as our community care partners to truly make an impact in safe transitions in care.
References


Appendix A: Interview Guide for Patients and Families

1) Tell me a little bit about your/your loved one’s injury and how you/your loved one came to be admitted to Toronto Rehab?

2) What were some of your/your loved one’s main goals during your/his/her rehabilitation stay?
   a. What goals do you feel you/your loved one met?
   b. Which ones are you/your loved one still working on? What would you like to be able to do what you are not doing now?
   c. Given this, did you feel prepared to go home when you did?

3) Now that you are home, how are things going for you? How has your life changed since your/your loved one’s injury?

4) While you were at Toronto rehab did you/your loved one do things that you considered risky?
   a) Can you please give me an example? How comfortable were you with this behaviour?
   b) Were there times when you/he/she did the opposite and played it safe? What do you see as the advantages to this behaviour? Any disadvantages?

5) Now that you are at home what makes home a safe or risky place to be? What gets in the way of safety at home?

6) Did you experience situations that you would consider unsafe while in rehabilitation? Are these situations any different now that you are at home?

7) Do you and your loved one always agree about what is safe and what is not? Please provide an example.
   a. What do you do when your opinions or decisions are in conflict, or you don’t agree. How do you resolve this?

8) Was there ever a time when you did something that went against the advice of your healthcare team? Your family? If so, please tell me about it.
   a. What about your healthcare team was helpful, or not helpful in making going home as safe as it could be?

9) What can we do at Toronto Rehab before you go home that may help make the transition home easier? Looking back on it, would you do anything differently next time?

10) If you had a meeting with the CEO of Toronto Rehab for 2 minutes what would you say?
Appendix B: Interview Guide for Clinicians

1) Tell me a little bit about your role on the brain injury service at Toronto Rehab. Describe your patient population for me.

2) We sometimes talk about rehabilitation as an opportunity for our patients to take risks. Do your patients take, what in your view, are risks?
   a. How comfortable are you with this behaviour?
   b. Would you consider yourself risk-adverse or more a risk-takers in your clinical practice? In your personal life

3) Do you feel our patients and families would say they feel safe here at Toronto Rehab?
   c. Adverse events happen – have you had anything “go wrong” over the last little while. What did you learn?

4) Respect for autonomy is a complex issue; how would you describe autonomy in the context of brain injury rehab in general? Your team?

5) When thinking back to [patient name]’s inpatient stay, what were some key goals that were important to him/her? Where they achieved? Where these similar or different from their family member? From your own clinical goals?

6) Did [patient’s name] prefer to take risks or did they prefer to play it safe? Can you tell me a bit more about this?

7) Thinking about the period leading up to [patient’s name]’s transition back to home, what were some of the safety issues that were important to you/that you were dealing with?
   a. Would you consider his/her discharge home, safe? What would you do differently/what did you learn for next time?

8) We know that our patients and families are dealing with a lot of social and emotional issues. How do you deal with strong emotion? Is this different than your colleagues?

9) Do we have an obligation to our patients and families when they leave our walls, or do we need to focus on our current patients? Is what we are doing sufficient? Please tell me more about this.

10) Finally, if you had two minutes with Mark Rochon what would you want him to know about brain injury rehab at Toronto Rehab?
Appendix C: Letter of Invitation

[printed on Toronto Rehab letter head]

Understanding the balance between respect for autonomy and promoting safety among patients, families, and clinicians following discharge from brain injury rehabilitation

LETTER OF INVITATION FOR TORONTO REHAB PATIENTS, FAMILY MEMBERS, AND CLINICIANS

We are inviting you to participate in an interview to examine your perspectives and experiences with patient safety at home. We are particularly interested in how personal decisions can influence making a safe transition in the first six months following brain injury rehab.

Why are we studying patient safety?
There are almost no studies in brain injury that ask patients and family members to identify key aspects of a safe and patient-centered environment from their perspectives at home. Through this project we hope to understand patient, family and clinician perspectives on safety and autonomy, as well as personal decisions to take risks following discharge from inpatient rehabilitation. Respect for autonomy can thought of as the right of individuals to determine their day-to-day lives.

Why is this important to you?
At Toronto Rehab, patient safety is a priority issue that has been the focus of many initiatives, programs and research studies. This study is an opportunity for patients, family members and clinicians to express their safety concerns openly and in confidence.

Who is being invited to participate in this study?
We are inviting 5 patients and 5 their family members who have been discharged from the Acquired Brain Injury (ABI) service at Toronto Rehab to participate in this study. We are also inviting 5 members of their clinical team who participated in their discharge planning and is familiar with the home environment. We are holding interviews in triads: one interview for former patients, one for a family member of this former patient and a third interview for a member of this patient’s healthcare team. Each interview will be separate. A member of your clinical team may approach you to participate in this study. The principal investigator main researcher will then contact you to provide the full
What is involved in participating in this study?
We are inviting you to participate in a 60-90-minute interview to talk about patient safety. We will ask you questions about your perspectives on safety and autonomy. For patient- and family-participants this includes asking about your injury and your rehabilitation goals; potential disagreements with your loved one or healthcare team about safety issues; the role of your healthcare team in your discharge; and your age and education level. For clinician-participants this includes your view of autonomy; your role in preparing patients and families for a safe discharge home; and factors impacting a successful discharge home. Clinician-participants may also assist with recruitment by identifying potential participants and passing contact information along to the principal investigator. Clinicians who identify potential participants, are in no way obligated to participate in this study. Similarly, if a clinician participates in the study, he/she does not need to have identified potential patients. Clinicians will be approached in person or in writing by the principal investigator.

The interview will be tape recorded and transcribed word for word.

What are potential benefits and risks to you? Is this information confidential?
Participation in this study is voluntary. There are no immediate benefits to you; however, by participating in an interview, you will have the opportunity to share experiences related to patient safety, and contribute to the development of new knowledge in this field. On the audiotape your voice may be identifiable; however, on the transcript you will be identified only by a unique number. No names will be used and the information you provide will be confidential. When the researchers present the results, general themes from the interviews will be highlighted. Only the research team will know the names of the participants.

A master list with all participants and their unique identifying numbers will be kept in a locked filing cabinet separate from transcripts and audiotapes. Transcripts will contain no names of participants and only the principal investigator will have access to the master list and audiotapes. All data related to recruitment and interviewing will be stored in a locked cabinet following the study and destroyed five years following the completion of the study.

Talking about patient safety may contain some sensitive information. Some participants may share real-life experiences that may be viewed as “high-risk” (i.e. an immediate and severe risk of injury to a current or future patient or family member). In this case, the interviewer will be required to share these details with the Risk Manager at Toronto Rehab. This also includes the name of the participant who brought the information forward. Information will be discussed in confidence. Only details deemed absolutely necessary to prevent the risk of injury will be shared. Except for these incidents that are deemed high risk, participants’ identities and information disclosed in the interviews and
will remain confidential. Due to the nature of this topic, some of the questions asked may be disturbing to some patients or family members. If during the course of an interview you wish to discuss these concerns, we will arrange a time for you to discuss these issues with a member of the clinical staff at Toronto Rehab.

**What are we going to do with the results of this study?**
We will present the results to the ABI service and other clinical programs, as well as Senior Management at Toronto Rehab. Results may also be shared externally with other rehabilitation centers, as well as at conferences and in peer-reviewed journals. In dissemination and publications, we will identify the ABI service at Toronto Rehab; however, all identifying names and labels will be removed. We may ask you to review and provide feedback on a brief summary of the results of this study before we share them with others. This is called a member check. The goal of a member check is to make sure that we understood what you said and captured your perspectives and opinions accurately.

**Who is leading this study?**
The principal investigator of this study is Angie Andreoli, MSc candidate and physiotherapist at Toronto Rehab. The co-investigators of this study are Dr. Ross Baker, Professor in the Department of Health Policy, Management and Evaluation at the University of Toronto and Dr. Barbara Secker, Leader Clinical Ethics at Toronto Rehab.

**Who do I contact if I want to participate in an interview or if I have more questions?**
Please contact Angie Andreoli, Principal Investigator (416) 597-3422 ext. 3984 or Dr. Gaetan Tardif, Chair of Toronto Rehab Research Ethics Board, (416) 597 – 3422 ext.3730.
Appendix D: Patient Demographic Information

Date ____________________     Study ID Code __________

Location __________________

The information requested below will be used to help us describe our participants. Information will be presented as group information only. No individual information will be used, and you will not be identified by name.

How long were you an inpatient at Toronto Rehab?
- 4 – 8 weeks
- 8-12 weeks
- 12-16 weeks
- Greater than 16 weeks
- Not sure

How long ago were you discharged home (approximately)?
- 2 months
- 3 months
- 4 months
- 5 months
- 6 months
- Not sure

What kind of outpatient services are you currently receiving? Please indicate all that apply:
- Outpatient services (e.g. at a day hospital or clinic)
- Services in my home (e.g. CCAC)
- Services from my family doctor
- Services from a medical specialist
- Other
- None. I am currently not receiving any outpatient services.

What is the highest level of schooling you have completed?
- Grade school/some high school
- High School Diploma
- Post-secondary/technical degree
- Bachelor’s degree
- Master’s degree (e.g. MA, MSc)
- Doctoral or medical degree (e.g. PhD, MD)

What is your age category?
- Under 20 years
- 20 to 29 years
- 30 to 39 years
- 40 to 49 years
- 50 to 59 years
- 60 years or over

Thank you for completing this form and for your participation in this study.
Appendix E: Informed Consent Form

[printed on Toronto Rehab letter head]

Date

Dear Participant,

THANK YOU so much for considering to participate in an interview on patient safety at home on __(date)__ at __(time)__ in ___(location)__.  

Please find enclosed two copies of the Informed Consent Form for this study. We need all participants to read the form and to sign it prior to the interview.  

Please bring one signed copy to the interview, and return the form to me at that time. Please keep one copy of the consent form for your records. If you have any questions about the research study or the consent form, please contact me at the coordinates below. I can also answer any questions prior to the interview.

Thank you again for participating in our study. I look forward to meeting you at (location).  

Kind regards,

Angie Andreoli, BScPT, MSc (c)  
Principal Investigator  
Toronto Rehabilitation Institute  
(416) 597-3422 ext. 3984  
andreoli.angie@torontorehab.on.ca
INFORMED CONSENT FORM

Title of Study: Understanding the balance between respect for autonomy and promoting safety among patients, families, and clinicians following discharge from brain injury rehabilitation

Investigative team
Principal Investigator
Angie Andreoli, BSc (PT), MSc (candidate)
Principal Investigator
Toronto Rehabilitation Institute

Co-investigators
Dr. Ross Baker, PhD          Dr. Barb Secker, PhD
Professor, Department of Health Policy,        Leader, Clinical Ethics
Management and Evaluation,                                Toronto Rehabilitation Institute
University of Toronto

Background and Purpose of the Study:
The goal of this study is to understand patient, family and clinician perspectives on safety and autonomy following brain injury rehabilitation at Toronto Rehab. Autonomy can thought of as the right of individuals to determine their day-to-day lives. We also hope to understand why patients may take risks at home and what we can do make their discharge safer.

Who is being invited to participate in this study?
We are inviting patients who have been discharged from the acquired brain injury (ABI) service at Toronto Rehab to participate in this study. We are also inviting their family member and a member of their clinical team who participated in their discharge planning and is familiar with the home environment. We are holding interviews in triads: one interview of the patient, one of a family member of this former patient and a third interview of clinician involved in the discharge planning to home. Each interview will be separate. In total 15 participants (or 5 triads) will be interviewed.

What is involved in participation for this study?
We are inviting you to participate in a 60 - 90-minute interview to talk about patient safety in a confidential, one-on-one setting. For patients and family-participants this includes asking about your injury and your rehabilitation goals; potential disagreements with your loved one or healthcare team about safety issues; the role of your healthcare team in your discharge; and your age and education level.
For clinician-participants this includes your view of autonomy; your role in preparing patients and families for a safe discharge home; and factors impacting a successful discharge home. Clinician-participants may also assist with recruitment by identifying potential participants and passing contact information along to the principal investigator. Clinicians who identify potential participants, are in no way obligated to participate in this study. Similarly, if a clinician participates in the study, he/she does not need to have identified potential patients. Clinicians will be approached in person or in writing by the principal investigator.

The interview will be audiotaped and transcribed word for word. Information from the interview will be confidential; however, you may know the other participants in your triad. On your transcript, audiofile and in all reporting of this research you will be identified only by a unique number. A master list with all participants and their unique number will be kept in a locked filing cabinet separate from transcripts and audiofiles. Only the principle investigator will have access to this list. All data related to recruitment and interviewing will be stored in a locked cabinet following the study and destroyed five years following the completion of the study.

The results of this study will be presented in group format only. Within Toronto Rehab we will present the results of this study to the ABI service and other clinical units, as well as to Senior Management. Results of this study may also be presented at external conferences and published in peer-reviewed journals. In dissemination and publications, we will identify the ABI service at Toronto Rehab; however, all identifying names and labels will be removed.

Potential Risks and Benefits:
Participation in this study is voluntary. By participating in an interview, participants will have the opportunity to share experiences related to patient safety and contribute to the development of new knowledge. Due to the nature of this topic, some of the questions asked during the interview may be disturbing to some people. If during the course of an interview you wish to discuss these concerns, we will arrange a time for you to discuss these issues with a member of the clinical staff at Toronto Rehab. You are not obligated to answer every interview question and may skip questions at any time.

Interviews are 60-90 minutes in length. During the interview you may become tired or distracted. At any point you may take a break from the interview or choose to conduct the interview over multiple sessions. Interviews will be conducted at a location of convenience, including your home or workplace to further reduce fatigue or distraction.

Confidentiality:
Information collected in the interview will remain confidential. The interviewer will also maintain complete confidentiality. When presenting the results, general themes from the
interviews will be highlighted. Any quotes containing potential identifying information will not be used. Interview recordings and transcripts will be identified by code and only the principal investigator will have access to the accompanying code book, and have the list of participants. Despite this, your identity may be known to other participants in your triad. It may also be guessed at by members of the ABI service during the presentation of results.

Our goal during the interview is to have open and honest discussions regarding patient safety at home. Some of these discussions may be sensitive in nature. Participants may bring forward real-life situations that may be viewed as “high-risk” (i.e. an immediate and severe risk of injury to a current or future patient or family member). In this case, the interviewer will be required to share these details with the Risk Manager at Toronto Rehab. This also includes the name of the participant who brought the information forward. Information will be discussed in confidence. Only details deemed absolutely necessary to prevent the risk of injury will be shared. Except for these incidents that are deemed high risk, participants’ identities and information disclosed in the interviews will remain confidential.

Contact information:
If you require any additional information regarding this study, please contact the principal investigator at: Angie Andreoli, 416 597-3422 ext. 3984 or andreoli.angie@torontorehab.on.ca
If you have any questions about your rights as a research subject, please call Dr. Gaetan Tardif, Chair of Toronto Rehab Research Ethics Board (416) 597 – 3422 ext.3730.

By signing below, I am indicating that I have read and understood the above information. I agree to participate in the interview and I will receive a copy of the signed consent.

Name of Participant _____________________________________________
Signature __________________________________________________________________
Date _______________________________

Name of Person Obtaining Consent ________________________________
Signature __________________________________________________________________
Date _______________________________
Appendix F: Transcription Conventions

Instructions for Transcribers - Transcription Notational System (adapted from Poland, 2002, p. 641)

It is important for qualitative research that transcripts be verbatim accounts of what transpired in the interview. That is, they should not be highly edited or “tidied up” to make them “sound better”.

| Pauses | Denote short pauses by a series of dots (…). Denote longer pauses with the word pause in parentheses. |
| Laughing, | Indicate in parentheses; for example, “(coughs)”, “(sighs)”, “(laughs)”. |
| Coughing etc. | |
| Interruptions | Indicate when someone’s speech is broken off in mid-sentence by including a hyphen (-) at the point where the interruption occurs (e.g. “What do you - ”) |
| Overlapping Speech | Use a hyphen to indicate when one speaker interjects into the speech of another, include the speech of the other with “(overlapping)”, and then return to where the original speaker was interrupted. |
| Garbled Speech | Flag words that are not clear with square brackets and a question mark, if guessing what was said (e.g. “At that, Harry just [doubled? glossed?] over”). |
| Emphasis | Use capitals to denote strong emphasis; for example, “He did WHAT?” Use italics for somewhat softer emphasis. |
| Held Sounds | Repeat the sounds that are held, separated by hyphens. If they are emphasized, capitalize them as well. For example, “No-o-o-o, not exactly” or “I was VER-r-r-r-r-y happy.” |
| Paraphrasing Others | When an interviewee assumes a voice that indicates he or she is parodying what someone else said or is expressing an inner voice, use quotation marks and/or indicate with “(mimicking voice).” |
Appendix G: Letter of Program Managers’ Support

Study Title: Understanding the balance between respect for autonomy and promoting safety among patients, families, and clinicians following discharge from brain injury rehabilitation

Dear Richard Khoo, Manager, Neurocognitive and
Robin Shan, Interim Manager, Neurophysical, ABI Service

This is a letter requesting your support for a qualitative study taking place on the ABI service in the Fall 2008. The principal investigator for the study is Angie Andreoli and this is part of her MSc thesis at the University of Toronto, Department of Health Policy, Management and Evaluation. The co-investigative team includes Dr. Ross Baker who is a leader in the field of patient safety and has partnered with Toronto Rehab on several patient safety projects and Dr. Barbara Secker who is the leader of clinical ethics at Toronto Rehab and has a keen interest in the area of risk and autonomy in rehabilitation.

Purpose of this study
The purpose of this study is to explore how conflicts between autonomy and concerns for safety compare between patients living with a brain injury, their family caregivers and their inpatient clinical team. This study builds on previous focus groups conducted at Toronto Rehab that identified a wide range of inpatient safety concerns, including the role of the hospital and the interprofessional team in identifying and balancing safety concerns and ethical decision-making. Despite this, very little has been written about the nature of the issues facing clinicians in the area of risk, safety and ethics following discharge from brain injury rehabilitation. Even less has been written about the patients and families perspectives on these issues.

What is involved in participating in this study?
This study will involve patients (n=5) and their family members (n=5) who have been discharged from the ABI service at Toronto Rehab within the last 6 months, as well as the inpatient clinicians who treated them (n=5). Interviews will be conducted in triads: one interview of a former patient, one of a family member (of this former patient), and one of a member of this patient’s healthcare team. In total 15 interviews will be conducted. Clinicians need to have participated in the patient’s discharge planning and be familiar with his or her home environment. We anticipate this to include professionals such as SW, OT, PT, RhT.

Risks and Benefits
This study uses clinicians in multiple ways: first, they will be asked to help identify potential patients and pass along contact information to the principle investigator; second, they may be approached to participate in the study. The clinician is in no way obligated to participate. It is hoped that there will be enough clinical members on the interprofessional team familiar with the patient-participant, that clinicians will not feel obligated to participate.
Clinician interviews will be approximately 60 - 90 minutes in length and take place at Toronto Rehab. Every effort will be made to conduct these interviews outside of work time (i.e. over lunch hour and after work); however, this will depend on the schedule of the clinicians and may spill over into work time. Interviews will not take place on the unit nor impact patient care. The results of this study will be presented to the ABI service, other clinical units and Senior Management.

When presenting the results, general themes from the interviews will be highlighted. Any quotes containing potential identifying information will not be used. Despite this, when presenting to the ABI service, members of the team may be able to guess the identities of patient-, family- and clinician participants. In dissemination and publications, we will also identify the ABI service at Toronto Rehab; however, all identifying names and labels will be removed.

There are no direct benefits to participants; however, by enhancing our understanding of the important ethical discussions involved in discharging our patients to home, this study aims to advance patient safety and quality of care in this relatively unaddressed area. Further, by understanding these conflicts clinicians may be better equipped to address the complex relationship of balancing autonomy and risk and prepare patients and family members for the often challenging transition home.

Lastly, considering the sensitive nature of this topic, if a real-life situation is raised by a participant that is viewed to be high-risk (i.e. an immediate threat to the safety of themselves or family member), the research team will need to come to a consensus on how to proceed with this information. If the group together deems the situation to be high-risk, the PI will be obligated to disclose the details, in confidence, to Rhoda Lordly, Risk Manager.

**Your role**

Our intent is that this project has minimal impact on both you and the majority of the ABI team. I will be requesting to attend an ABI business meeting for both clinicians and nurses in the Fall to disseminate the project and hand out Letters of Invitation (attached), as well as answer any questions or concerns.

Your input is welcomed! Please forward any concerns to me by (date). Your signatures represent your agreement and support to proceed with this project. If you have any further questions about this study, please call Dr. Gaetan Tardif, Chair of Toronto Rehab Research Ethics Board (416) 597 – 3422 ext. 3730.

Sincerely,

Angie Andreoli
Principle Investigator