Everyday Tragedies: People with Severe Traumatic Brain Injury in the Liminal Spaces of a Level I Trauma Centre

by

Lynn Rutledge

A thesis submitted in conformity with the requirements for the degree of Doctorate of Philosophy

Rehabilitation Science Institute
University of Toronto

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Abstract

Sustaining a severe traumatic brain injury (sTBI) can have a devastating and permanent impact on a person’s ability to function, on their selfhood, on their families, and on the spaces where they can exist in the world. Individuals with sTBI in Ontario are often transported to Level I Trauma Centres, as textually mediated by the provincial Life or Limb Policy, to ensure access to expert lifesaving medical care. After entering these trauma centres, transitions across the spaces of the trauma centre, from critical care to intensive care to a trauma ward, can signify recovery through decreased reliance on medical technology and medical care. Rehabilitation is required as individuals with sTBI become medically stable to ensure further improvement. This rehabilitation is needed to prepare these individuals to move to other healthcare spaces, such as inpatient rehabilitation, repatriation hospitals, or to return home. Textually mediated institutional relations through the Ministry of Health and Long-Term Care (MOHLTC), specifically the Acquired Brain Injury (ABI) Resource Rehab Tool, ignite sites of struggle in the provision of rehabilitation for individuals with sTBI. These sites of struggles reveal ruling relations that remain hidden until the institution is brought into view using an empirical method of inquiry, institutional ethnography. Specific methods in this dissertation included: participant observation, interviews, a focus group, and analysis of texts. Findings of this study suggest language in the
ABI Resource Rehab Tool, specifically the discursive organizer ‘rehab ready’ cleaves individuals with sTBI into two groups: (1) those with faster recoveries able to gain access to inpatient rehabilitation, and (2) those with slower recoveries who do not meet these restrictive guidelines and become unaccounted for in healthcare spaces, with limited options for rehabilitation. Trauma centres are medicalized spaces, whereby provincial funding is distributed on the basis of medical procedures, not rehabilitation. One notable contradiction in funding is revealed for individuals with stroke, who access beds for rehabilitation in acute care and other initiatives outlined by the provincial stroke strategy. No such provincial strategy exists in Ontario for individuals with sTBI, leaving these individuals marginalized through more limited access to rehabilitation within the healthcare continuum.
Artist unknown
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Notes to the Reader

In this dissertation, I have employed numerous abbreviations from sociological and anthropological research and medical literature. For the sake of clarity, at the commencement of certain chapters, I have used the unabbreviated term due to the extensive number of abbreviations throughout this dissertation. I have included a list of abbreviations near the beginning of this dissertation. I have included a glossary of terms defining research concepts and medical terms addressed frequently throughout the chapters.

In this dissertation, I refer to the liminal spaces of the trauma centre to signify the transitional nature of these spaces, as many individuals with severe traumatic brain injury can move back and forth through these spaces. I have included a number of vignettes in this dissertation, which are demarked by italics.

I have used single quotations to denote quoted material from another author in a larger quotation from the author of interest and to denote a specific term such as ‘rehab ready’. I have used double quotations in the following ways: (1) to indicate a short quotation from another author or researcher and (2) to indicate a short transcript excerpt.

Both long quotations and longer transcript excerpts appear as block quotes. I have referred to myself in transcript excerpts as Lynn and the informants through a pseudonym or other identifier, such as a family member.
Abbreviations

ABI – Acquired brain injury

CCC – Complex Continuing Care

DOC - Disorder of consciousness

FIM – Functional Independence Measure

GCS – Glasgow Coma Scale

LTC – Long-Term Care

MCS – Minimally conscious state

MOH LTC – Ministry of Health and Long-Term Care

sTBI – Severe traumatic brain injury

PVS – Persistent Vegetative State

RLA – Rancho Los Amigos Scale

TBI – Traumatic brain injury

TTL – Trauma team leader

VS – Vegetative state
Glossary

**Acquired Brain Injury (ABI)** – “Acquired brain injury (ABI) can be defined as ‘damage to the brain that occurs after birth and which is not related to congenital disorders, developmental disabilities, or processes that progressively damage the brain’. By this definition, ABI encompasses a wide variety of disorders of varying etiologies (e.g., traumatic brain injury (TBI), tumour, cerebrovascular accident, infection, etc.)” (Rees, Marshall, Hartridge, Mackie, & Weiser, 2007, p. 261).

**Coma** – “Coma is characterized by the total absence of arousal and of awareness. As opposed to transient unconsciousness such as syncope or concussion, coma must last ≥ 1 hr. Comatose patients have no eye opening and do not speak or move spontaneously. They do not follow commands, and when provoked by noxious stimuli their eyes remain closed, vocalization is limited or absent, and motor activity is absent or abnormal and reflexive rather than purposeful or defensive. Sleep-wake cycles are lacking. Coma is typically a transitional state, evolving toward recovery of consciousness, the vegetative state, or brain death” (Stevens & Bhardwaj, 2006, p. 32).

**Institutional Ethnography** – Institutional ethnography is a method of inquiry which orientates its analysis using a Marxist-feminist theoretical perspective, with work, either paid or unpaid, as its main focus. Institutional ethnography seeks to identify a research topic, specifically identifying a problematic, through recognizing disjunctures in experience between people’s everyday/everynight lives and a politico-administrative regime (D. E. Smith, 2005).

**Liminal** – Downey, Kinane and Parker (2018) suggested liminal moments described by anthropologist Arnold van Gennep (1909) “posited that social-symbolic events such as birth, puberty, marriage, parenthood, and death necessarily presuppose the special and/or symbolic passage of the individual from one state and/or space into another and the essential purpose of these rituals (such as a wedding ceremony or a funeral, for example) is to enable the individual(s) involved to ‘pass from one position to another which is equally well defined’…Van Gennep also contended that the individual could not pass from one defined position or category without transiting through this intermediate stage—what we might understand as the entre-deux. Van Gennep called this intermediate state the ‘liminal’ or ‘threshold site’” (Downey et al., 2018, p. 7). Downey et al. (2018) also contended another anthropologist, Victor Turner, popularized
this term and defined liminal figures or entities as being marginalized due to their intermediate status. “Turner identifies ‘liminal identities’ as those marginal figures who are caught in the entre-deux, who are ‘betwixt and between the position assigned and arrayed by law, custom, convention, and ceremony’” (Downey et al., 2018, p. 8).

**Liminality** – “‘Liminality’ describes a state or location that is transitional, subjective, ambivalent, unstable, and marginal and that opens up new possibilities in a binary system; liminal phenomena occupy ‘middle-way’ positions between two states or locations by being paradoxically neither or both of them at the same time” (Eisenberg, 2018, p. 31). For example, with funeral rites, those in mourning are caught in the indeterminate position between life and death, as figured by the uncanny presence of the corpse.” “Liminality is disorientating; the limits and borders of personality and/or cultural and social identity become ambiguous or dissolve, as the mourners enter into and pass through the mourning period, and assume new structural and relational identities to the deceased” (Downey et al., 2018, p. 7).

**Liminal Spaces** – “Liminal spaces are those which are, simultaneously, place and space. They are familiar, yet unknown; they are secure, and yet intimidating” (Downey et al., 2018, p. 3).

**Minimally Conscious State** – “The minimally conscious state (MCS) describes a subset of patients who do not meet the criteria for coma or vegetative state (VS). Patients in MCS have a severe alteration in consciousness but demonstrate wakefulness and cyclic arousal and intermittently demonstrate self or environmental awareness, such as following of commands, the ability to signal yes/no (regardless of accuracy), intelligible speech, or purposeful behavior. Emergence from the MCS to higher states of consciousness is signaled by the ability to communicate reliably or use objects functionally” (Stevens & Bhardwaj, 2006, p. 33).

**Post-Traumatic Amnesia** – “Post-traumatic amnesia is the discrete and transient phase of coma emergence and is classified according to two primary symptoms: an inability to orientate to the environment and an inability to encode and recall new information. Patients in PTA present with fluctuating levels of consciousness, and impaired cognition and awareness. Agitation is common with patients with PTA” (Bower, Catroppa, Grocke, & Shoemark, 2014, p. 1751).

**Rehabilitation** – “The term rehabilitation stems from the Latin roots re-(again) and -habilitare (make fit); the very definition incorporates the concept of teaching actions, behaviors, or
information that will make the recipient ‘fit’. Instruction is the process of a fact, concept, set of skills, or strategies to another person—precisely the charge to rehabilitation professionals” (Sohlberg & Turkstra, 2011, p. 3). “Once you set aside the acute phase or crises that mark injury or disease, much of modern healthcare is indeed rehabilitation in one form or another” (Henderson, 2016, p. 1).

**Ruling Relations** – “That extraordinary yet ordinary complex of relations that are textually mediated, that connect us across space and time and organize our everyday lives—the corporations, government bureaucracies, academic and professional discourses, mass media, and the complex of relations that interconnect them” (D. E. Smith, 2005, p. 10).

**Severe Traumatic Brain Injury** – For the purposes of this study, severe traumatic brain injury (sTBI) is defined as a head trauma on the Glasgow Coma Scale (GCS) with a score of 3 to 8 (Haddad & Arabi, 2012). Other issues, such as disorders of consciousness, weakness, seizures, coma, and even death can result from severe traumatic brain injury (Ng et al., 2015). The severity of traumatic brain injury is also rated by looking at the period of time to recover consciousness, specifically the initial period of amnesia (de Guise, Leblanc, Feyz, Lamoureux, & Greffou, 2017), such as using the Westmead Post Traumatic Amnesia Scale.

**Social Relations** – “The notion of ‘social relations’ in this sense does not stand for a thing to be looked for in carrying out research, rather it is what is used to do the looking. It operates as a methodological injunction that requires the researcher to examine empirically how people’s activities are reflexively/recursively knitted together into particular forms of social organization” (G. W. Smith, 1990, p. 636).

**Standpoint** – Standpoint refers to whose perspective is being embodied and represented in an institutional ethnography. This representation seeks to outline and explicate a particular sociological concern for this group of individuals.

**Traumatic Brain Injury (TBI)** – Traumatic brain injury is a form of acquired brain injury whereby there is disruption of brain function due to a traumatic event. This can occur when the head is struck or strikes an object, or undergoes rapid acceleration and deceleration movements. Traumatic brain injury is usually classified as mild (including concussion), moderate, or severe (Ng et al., 2015).
**Vegetative State** – “The vegetative state (VS) is notable for preserved arousal mechanisms associated with a complete lack of self or environmental awareness. Patients in VS open their eyes spontaneously; however, there is no evidence of sustained visual pursuit (tracking) or visual fixation. They do not follow commands and do not move in any meaningful or purposeful manner. They evolve through temporal cycles from increased/decreased skin arousal to a “sleep-wake” pattern. Cardiovascular regulatory functions, breathing patterns, and cranial nerves are usually intact. Although some patients regain partial or complete consciousness, others remain for extended periods without significant changes in their neurologic state, prompting the term ‘persistent vegetative state’” (Stevens & Bhardwaj, 2006, p. 32-33).
Preface

Severe Traumatic Brain Injury: Life Changes in an Instant

The final months completing my dissertation were punctuated by North American mass tragedies. On February 14, 2018, a former student entered a high school in Parkland, Florida with an A-15 assault rifle and opened fire. He fatally shot 17 people and injured 17. On April 6, 2018, the Humboldt Broncos junior hockey team was driving to a game in rural Saskatchewan when their bus collided with a tractor trailer at an intersection. Sixteen people were killed and 13 were injured. The Toronto van attack occurred on April 23, 2018. A young man mounted a sidewalk in a rental van on a sunny Monday afternoon in north Toronto, intentionally speeding through crowds of people, killing 10 and injuring 16. A second mass American school shooting book-ended the first on May 18, 2018, as 10 people were fatally shot, and 13 others were injured in a high school in Galveston, Texas. A second mass casualty event in Toronto, Ontario also book-ended the first, with a mass shooting on July 22, 2018. Two people were killed, and 13 others were injured. These types of tragedies—mass shootings, van attacks, and major transportation accidents—mark an unfortunate zeitgeist of our time, illustrating the dramatic and shocking circumstances of mass trauma.

While specifics of these tragedies and many details of the lives of those who died dominate newsfeeds, the traumatic injuries of people who survive are usually shrouded in mystery. Trauma can involve injuries to multiple body systems and the brain, and can have a permanent, life-altering impact. If you pour through these news stories as I do, you are aware that many people go into the hospital, usually Level I Trauma Centres, after such mass tragedies. The number of people admitted to hospital on these newsfeeds often do not add up with the number of people we learn have been discharged afterwards, leaving a sense that some patients linger in acute care liminal spaces following these mass tragedies. For individuals remaining in hospital, we are often unaware of the full extent of their injuries, as these details are usually not released to the media. The absence of this information flutters uneasily at the borders of our consciousness; the final trauma patients’ hiddenness from view leads me to wonder if these remaining individuals ever fully recover.

Beyond these mass tragedies, everyday tragedies ending in serious physical trauma—extensive injuries involving the brain and body—happen daily but are rarely reported in the
news. Everyday tragedies resulting in severe traumatic brain injuries are the focus of this dissertation. Examples of these tragedies include: an older man going downstairs in the middle of the night, falling from the top step and hitting his head while landing; a middle-aged woman riding her bicycle through an intersection when she is hit by a vehicle speeding through a red light; a young man shot in the head in a dark alleyway; or a young woman driving to her first day of work at 5:30 a.m. on a major highway when her vehicle is struck by a speeding tractor trailer, causing near fatal injuries. These sorts of everyday tragedies, including high-velocity motor vehicle collisions, falls from heights, and assaults with weapons and blunt objects, can lead to severe brain trauma. Extensive rehabilitation is required after these types of injuries.

My aim in this dissertation is to examine the social organization of rehabilitation in a Level I Trauma Centre for individuals who have sustained severe traumatic brain injuries (sTBI) to examine how rehabilitation is organized and why it is organized in this manner. I consider how social relations shape this rehabilitation using the sociological method of inquiry known as institutional ethnography (IE). In IE, we often talk about the everyday/everynight activities, individuals engage in and how these activities are coordinated by institutional relations occurring at local sites, and translocal sites—sites far from the site of study (D. E. Smith, 2005). With sTBI, there is a sudden and distinct rupture between individuals’ usual and customary activities before and after the event. The changes in these individuals’ lives afterwards are often profound and recovery can be tenuous. Before such an event occurs to a family member or friend, those living in close social proximity to the individual move through their usual routines and responsibilities, unaware of any impending change.

After sTBI, people closely associated with this individual gather at the hospital to wait for news. Their daily and nightly routines are shaped by the institutional environment in Level I Trauma Centres, filled with many hospital employees, unfamiliar liminal spaces, blinking and beckoning machines and technology, and endless reams of documents, forms, and policies. Other roles and responsibilities of those close to the injured individual fall by the wayside in the

---

1 These are not the actual stories of any of the individuals with sTBI in this study.
wake of doing the work of caring for their loved one. They are soon engaged in assisting their loved one and addressing gaps in service provision. This is not to say that institutional care, including medical and nursing care, are not provided; this work clearly occurs. However, rifts and fragmentation in the full spectrum of care, specifically rehabilitation, are apparent as health professionals struggle to meet the needs of individuals with sTBI in acute care contexts.

To describe some of happenings in a Level I Trauma Centre for individuals with sTBI, I have included a fictionalized account of a young 18-year-old woman, Hailey, who sustains a sTBI in an everyday tragedy. This vignette illustrates the unfolding of events that led to this injury. Additional vignettes regarding Hailey and her family appear in the first two analysis chapters of this dissertation. This is not any particular individual I observed during my fieldwork at a Level I Trauma Centre; she represents an alchemy of issues for individuals with sTBI in a trauma centre. The vignettes in this dissertation are written in the style adopted by Timothy Diamond (1992, 2006), an institutional ethnographer whose book *Making Gray Gold: Narratives of Nursing Home Care* (1992) explicated the economic and political forces influencing elder care in nursing homes in the United States.

During ethnographic fieldwork, I observed and heard many devastating scenarios regarding how severe traumatic brain injuries occurred and the ensuing circumstances for individuals and their families. In these vignettes, I have described similar events recounted to me by families of individuals with sTBI and by health professionals during interviews in this study. I use the term ‘health professionals’ to include anyone I encountered during fieldwork who worked in the trauma centre, including physicians, nurses, and rehabilitation professionals. Vignettes also reflect my observations during multi-disciplinary rounds on the trauma ward, and medical rounds in critical care and intensive care. Many families and health professionals wished to keep personal circumstances private; these vignettes maintain their requested anonymity. They reveal some of the sites of struggle and experiences for individuals with sTBI and their families in a Level I Trauma Centre.

**Hailey’s Story: A Vignette about an Everyday Tragedy**

_Hailey rushed past her 18-year-old identical twin sister, Shailene, as she frantically searched the tack room at the stable where they complete their weekly riding lessons. “Where is my riding helmet?” she bellowed in exasperation. “I don’t know” replied Shailene. “Maybe_
you left it at home last week.” Shailene continued playing with the six-week-old calico kittens running around in the barn. Shailene, even at 18 years old, was always far more interested in spending time with the kittens than brushing or tacking up her horse for her weekly riding lessons. Their mom really wanted them to keep up their riding skills despite moving back to the city after selling their southwestern Ontario farm following the financial crisis of 2008.

“Oh” sighed Hailey, “I’ll just go out and practice a few jumps before my riding instructor gets here. I really need to practice my course, or she is going to kill me!” Hailey quickly finished tacking up her horse Hunter and they walked into the riding ring. She deftly climbed onto the riding step and slid easily into the well-worn English saddle. “We’ll do the course once or twice before my instructor gets here and then I’ll borrow a riding helmet. I haven’t had a chance to practice my jumps all week and I was so busy last weekend with rugby practice.” She quickly squeezed her legs around her horse, Hunter, lifting the leather reins forward to guide him around the ring several times before she attempted her first jump.

After three quick trots around the ring, she turned Hunter toward the first three-foot jump. She nudged Hunter into a brisk canter and signaled the first jump. Just as Hunter’s rear haunches crouched down and his chest rose into the air to clear the first jump, a plastic grocery bag fluttered past the jump. Hunter, spooked at the sudden apparition directly in his field of view, attempted to brake with his rear haunches. He careened violently into the right side of the jump. Hailey, unable to hold on tightly enough with her muscular legs, torqued through the air. The left top part of her head banged noisily into the vertical cement pole holding the horizontal bars of the jump. Hailey then catapulted through the air in a complete somersault, landing on the back of her skull first and then on the rest of her body.

Shailene, hearing the commotion from the tack room, sprinted out of the barn and across the riding ring to her twin sister. Shailene screamed at the top of her lungs as she held Hailey and tried to rouse her. Blood was slowly oozing from Hailey’s left temple and the back of her head, soaking her long wavy blonde hair, coloring it bright crimson red. She shook her twin sister. “Can you hear me?” she gasped as her voice quivered. No eye movement, no limb movement, no verbal response from Hailey. Shailene ripped her iPhone from the back pocket of her jeans, quickly tapping in the numbers her teachers had ingrained in her head since grade school: 9-1-1.
The operator answered immediately. Shailene shouted, “I need an ambulance! It’s my sister Hailey. She was thrown off her horse and hit her head really badly. Her head is bleeding everywhere!” The operator replied: “Please calm down. We will get to you right away. I see we have an ambulance very close by from the GPS call tracking system. What is your exact location?” Shailene replied, “Hillside Equestrian Stables, 699 Hillside Drive, the riding ring right behind the large green barn. Please come quickly!”

After reading such a dramatic introduction and vignette, you may wonder: Why have I chosen such a topic for a dissertation?

Choosing to Examine sTBI in a Level I Trauma Centre

I arrived at this research inquiry through the personal position and experience of having been a caregiver for a friend with a sTBI. After years of working with individuals with TBI as an occupational therapist, I suddenly found myself as a primary caregiver to a friend who sustained this devastating injury. As I observed the sequence of events of her care and rehabilitation unfold in the early days post-injury, I found myself and observed others taking on a pivotal role in her acute care rehabilitation. When I refer to rehabilitation, I am referring to care beyond basic medical and nursing care intended to promote her independence and recovery. Yet this anticipated rehabilitation was minimally addressed in the neuro trauma units of the Level I Trauma Centre. These experiences as a former caregiver shaped my intention to explicate the social organization of rehabilitation for individuals with sTBI in a Level I Trauma Centre.

Many limitations in the provision of rehabilitation were readily apparent as I completed daily visits to this Level I Trauma Centre to assist my friend. The notable absence of rehabilitation represented a disjuncture in experience (D. E. Smith, 2005) I found quite surprising, given my professional background as an occupational therapist. With limited hospital resources seemingly allotted for rehabilitation, myself and other friends soon found ourselves

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2 Various personal attributes in these vignettes are derived from my sister and her two daughters, who ride horses.
promoting rehabilitation as informal caregivers. I was soon helping other families to promote recovery, as they observed the diverse range of activities I provided to my friend with a sTBI. How had this limited rehabilitation come about?

I sought an empirical approach to address this inquiry. I considered how the social organization of rehabilitation in a trauma centre had a profound impact on the course of rehabilitation for individuals with sTBI as they embarked on their recovery. According to Townsend, Langille, and Ripley (2003),

The explication in an institutional ethnography describes critically how and why experiences of tension are invisibly organized by conceptual practices of power that regulate what people know and do in the everyday world (Smith, 1990b). The aim is to generate knowledge about invisible, interconnected, taken-for-granted forms of governance that rule everyday life (p. 18).

Using IE as a method of inquiry would allow me to make visible ruling relations which were not apparent to me in being an informal caregiver for someone with sTBI. In being a participant in this scene and in the midst of these activities in a trauma centre, I could not grasp the ruling relations, far from the immediate scene, that generated institutional policies and shaped the activities I observed and participated in. In this doctoral dissertation, I have followed this thread of social organization in order to explicate the ruling relations of rehabilitation for individuals with sTBI in a Level I Trauma Centre.
Chapter 1

Introduction

1.1 Why Complete This Study in a Level I Trauma Centre?

Rehabilitation work occurs with individuals with sTBI across various institutional sites, ranging from trauma centres, acute care hospitals, inpatient rehabilitation facilities, complex continuing care, through community agencies, and in individuals’ homes. However, for the focus of this study, I was most interested in discovering how initial rehabilitation work was organized immediately after injury, laying the groundwork for future rehabilitation. The most suitable setting for this inquiry was a Level I Trauma Centre, where most trauma cases are transported soon after injury in urban centres.

My ethnographic exploration began at the point when emergent care transforms from being critical, life-saving medical care, including neurosurgery or medical stabilization in a critical care unit, to a point of medical stability with a focus on future functioning and rehabilitation. I investigated work processes that organize activities devoted to rehabilitation. These are activities focused on improving the individual’s performance to enable them to participate more fully in daily life and require less assistance from others. Rehabilitation is differentiated from the medical and nursing care intended to sustain life and prevent further injury or disability as a consequence of this medical condition. There are points of intersection across medicine, nursing, and rehabilitation for individuals with sTBI; I will address these junctures in the analysis chapters of the study.

1.2 Scope of the Problem of sTBI in North America

While there are no clear statistics regarding the number of individuals who sustain severe traumatic brain injuries in Ontario, an estimate can be drawn from several data sources. A report from the Ontario Brain Institute published data regarding all brain disorders in Ontario from 2004 to 2011 (Ng et al., 2015). Traumatic brain injury “occurs among persons of all ages but some individuals are more susceptible than others, in particular children, teenagers, and seniors. Males are at a greater risk than females” (Ng et al., 2015, p. 147). In 2010, in terms of prevalence, 227,605 Ontarians were identified as having a TBI; males accounted for 62% of
these individuals. The number of individuals identified as having a TBI was noted to increase from 2004, when 142,140 individuals in Ontario were identified as having a TBI. Incident cases of TBI were described as 20, 354 new cases in 2010. The Ontario Neurotrauma Foundation (2013) estimated 10% of TBIs will be severe in nature. From these two data sources, severe TBI can be estimated at approximately 2,000 new cases in Ontario per year.

Gray (2000) also estimated sTBI accounts for approximately 10% of TBI cases; however, sTBI accounts for 91.6% of admissions to Ontario TBI rehabilitation programs (Gray, 2000; Wong et al., 1993). According to American reports, sTBI can account for 68% of the referrals to rehabilitation programs in the Model Systems database, while average financial costs associated with acute rehabilitation care were estimated at $200,000 (Gray, 2000). The costs of chronic facility-based care are described as staggering as individuals can live with sTBI indefinitely; lifetime chronic care for individuals with sTBI dependent on care is estimated as nine million US dollars (Gray, 2000). Gray (2000) indicated that many individuals with sTBI are young and otherwise healthy, and brain injury survival rates have improved with better medical care. Gray (2000) identified how many studies to date have focused on rehabilitation programs and largely ignored patients deemed not ready for rehabilitation. My plan of study involves examining sTBI in acute care, considering individuals with sTBI likely to attend inpatient rehabilitation, those who stay in the initial trauma centre due to lack of improvement, and those discharged to other locations, such as home, complex continuing care, or other hospitals.

1.3 Plan of Study

In institutional ethnography (IE), sites of struggle are transformed into a problematic to be investigated. These sites of struggle are known as the lines of fault or points of disjuncture within IE. A line of fault is a point of rupture within an individual’s conscious experience (D. E. Smith, 1987). I noted a disjuncture between the kind of rehabilitation my friend received and what I would have expected, given my own work knowledge as an occupational therapist. As I observed rehabilitation unfold in an inconsistent manner, I actively became involved in ensuring it did occur, as did other family members present on the neurotrauma units. G. W. Smith (1990) acknowledged that for certain individuals “their knowledge of everyday events situated them on one side of a line of fault separating them from the objective bureaucratic domain of a politico-administrative regime” (p. 631).
I became interested in the theoretical and methodological approach of IE as I sought an empirical method to formally investigate how my observations of early acute rehabilitation as a caregiver for an individual with sTBI had transpired. IE begins with a sense of the problem and seeks to explicate why things work as they do and how they are put together (Dobson, 2001). “The general problematic in institutional ethnography takes the everyday/everynight world as an unfinished arena of discovery in which the lines of social relations are present to be explored” (D. E. Smith, 2005; p. 39). This type of research does not seek to answer in single question or a set of research problems, but focuses on examining a problematic representing a larger field of investigation (D. E. Smith, 2005). A problematic refers to:

The translation of an actual property of the social relations or organization of our/people’s ordinary doings into a topic for ethnographic research. It locates the step that is taken from the ordinary doings and ordinary language that are the stuff of people’s lives onto the terrain of a sociological discourse, the business of which is to examine how that stuff is hooked into a larger fabric not directly observable from within the everyday (D. E. Smith, 2005, p. 39).

As I started my ethnographic fieldwork at a Level I Trauma Centre, health professionals on the trauma ward and families of the patients described their sites of struggle in caring for someone with a sTBI. Descriptions of their experience layered one upon the other to further define the problematic of the study.

Families and health professionals identified similar tensions and contradictions in the study—limited time for rehabilitation, health professionals with very busy caseloads, and families overwhelmed in assisting their family member with sTBI. Informants added new perspectives and further dimensions of the problematic of the study. A problematic is only partially visible to the individuals in the proposed research context. D. E. Smith (2005) has suggested individuals would not be able to see into the complex assemblages of social relations that lie beyond what is immediately discernible. D. E. Smith (1987) has noted that social relations can be studied from an empirical position by examining the everyday experiences of the knower in their world, and moving beyond speculative accounts to place micro and macro social levels in determinate relations through organizational and institutional processes:

Making our everyday world our problematic instructs us to look for the ‘inner organization’ generating ordinary features, its orders and disorders, its contingencies and conditions, and to look for that inner organization in the externalized and abstracted

Individuals within the ruling apparatus, or part of the context, do not fully see or recognize how social relations affect and organize their activities: “The subject is then seen not as situated on an Archimedean point outside the world, but as a position within the ruling apparatus” (D. E. Smith, 1987, p. 98). Health professionals, administrators, and patients with sTBI and their caregivers in this study all lie within this ruling apparatus without having a full understanding of how their activities involving rehabilitation are coordinated. The disjuncture in this study is identified as gaps between expectations of rehabilitation and the actual experiences of rehabilitation provided in a Level I Trauma Centre, as identified by families of individuals with sTBI and patients themselves. Health professionals also identified tensions related to the provision of these services. Experiential accounts by various groups of informants identified these tensions and contradictions in their experiences of early rehabilitation, or the lack thereof, as an entry point for the problematic of the study.

My aim in this study is to understand how work practices are socially organized in the provision of rehabilitation in a Level I Trauma Centre, with a goal of creating a documented account of this social organization of rehabilitation. I address the following considerations in this dissertation: How is rehabilitation coordinated in a Level I Trauma Centre? Why is it coordinated in this manner? What documents mediate the social organization of rehabilitation work in a Level I Trauma Centre? Please see Figure 1 below for a diagram of this plan of study.
**Disjuncture:** Gap between expectations of rehabilitation versus actual experiences of rehabilitation for individuals with sTBI and their families in a Level I Trauma Centre.

**Problematic:** Examine tensions and contradictions created by rehabilitation (or lack thereof) for individuals with sTBI and their families in a Level I Trauma Centre as a point of entry.

**Aim:** To understand how work practices are socially organized in the provision of rehabilitation with individuals with sTBI in a Level 1 Trauma Centre.

**Goal:** To produce a documented account of the social organization of rehabilitation in a Level I Trauma Centre for individuals with sTBI.

**Important considerations:**
- How is rehabilitation work coordinated in a Level 1 Trauma Centre?
- Why is rehabilitation work coordinated in this manner?
- What documents textually mediate this social organization of rehabilitation work in a Level 1 Trauma Centre?
1.4 Overview of the Dissertation

The main argument of this dissertation is that inpatient rehabilitation guidelines in Ontario, reproduced by the Ministry of Health and Long-Term Care (MOHLTC), cleave individuals with sTBI into two groups while in a Level I Trauma Centre. These two groups include: (1) individuals with sTBI with a faster recovery likely to meet admission criteria for inpatient rehabilitation admission; (2) individuals with a slower recovery unlikely to qualify for inpatient rehabilitation admission. Different forms of care are reproduced through these textual relations, as individuals with a faster recovery are granted increased access to rehabilitation services while in a Level I Trauma Centre to promote acceptance into inpatient rehabilitation. Individuals with a slower recovery, who do not fit restrictive inpatient rehabilitation admission guidelines, become marginalized with notable limitations in access to rehabilitation while in a trauma centre. Material divisions between these two groups forecast future access to rehabilitation and final outcomes. The term ‘rehab ready’, a discursive organizer, grants the faster recovery group with sTBI access to rehabilitation spaces and rehabilitation work practices in the future. Individuals with sTBI with a slower recovery will linger in acute care liminal spaces until movement to other healthcare spaces, such as complex continuing care, whereby severely curtailed rehabilitation resources are available.

In the remainder of the dissertation, I develop this argument in a series of chapters:

In Chapter 2, I explore the extant literature regarding early rehabilitation for individuals with sTBI. Limited literature regarding early rehabilitation for sTBI contrasts with extensive literature regarding later stages of recovery after TBI.

In Chapter 3, I address IE as a theoretical orientation, the reproduction of ideology through text and work practices, other studies of IE in healthcare, and the political activism of institutional ethnography.

In Chapter 4, I address IE as a method of inquiry, and describe recruitment, the setting, methods, and data analysis strategies employed in this study.

In Chapter 5, the first of the analysis chapters, I describe how the complexity of sTBI sets the stage for rehabilitation work, as the brain is hidden from view in early trauma work.
In Chapter 6, the second analysis chapter, I address the bifurcation of rehabilitation work for individuals with sTBI in a Level I Trauma Centre, who become cleaved into two separate groups through Ontario’s inpatient rehabilitation guidelines: (1) those with faster recovery, designated institutionally as warranting rehabilitation; (2) those with slower recovery, marginalized with decreased access to rehabilitation through institutional practices.

In Chapter 7, the third analysis chapter, I examine how talk and text coordinate institutional practices to marginalize individuals with sTBI with a slower recovery. I explore various interlocking texts from the MOHLTC that transport individuals with sTBI to trauma centres while simultaneously restricting access for those with slower recoveries. I also address how individuals with sTBI are marginalized in comparison to those individuals with stroke, with no provincial or national TBI strategy to address inequities in rehabilitation.

In Chapter 8, the concluding chapter, I explore major findings of the study through the three gossamer walls of reflexivity (Doucet, 2008). I address next steps for future research and limitations and strengths of this study.
Chapter 2
State of the Art Review

2.1 Chapter Outline

This chapter provides a review of the literature regarding acute care rehabilitation for individuals with sTBI. This is a state-of-the-art review focuses on published works covering a broad range of topics in this field, but does not include formal quality assessment (Grant & Booth, 2009). This review highlights current evidence-based practices and policy perspectives, providing a snapshot of sTBI acute care rehabilitation, as reflected in published research. This dissertation explores the social organization of rehabilitation work for individuals with sTBI in a Level I Trauma Centre; these trauma centres are part of a system of acute care. The direction of this review was selected as many family members of individuals with sTBI searched the Internet and sought recent research articles as they assisted the individual with sTBI. Health professionals in the study also commented on the limited research in this area. This literature review will address published work related to acute care brain injury rehabilitation in the following ways: (1) by examining evidence-based literature regarding recent rehabilitation interventions for sTBI in acute care; and (2) by exploring how policy perspectives serve to organize rehabilitation work for individuals with sTBI in acute care. Acute care rehabilitation for sTBI and policies organizing this rehabilitation have not been examined previously in the same review.

2.2 Review of the Literature

Rehabilitation for TBI has been extensively explored after these individuals enter inpatient rehabilitation units or are discharged into the community following departure from acute care hospitals (Cicerone et al., 2000; Cicerone et al., 2005; Ponsford, Draper, & Schönberger, 2008; Swaine et al., 2018). Evidence-based interventions for moderate to severe brain injury have been reviewed extensively by the ERABI Research Group in Ontario (2008) for interventions across the healthcare continuum. Medical management of sTBI upon entry into acute care has also been well explored in terms of lifesaving interventions, including resuscitation, perioperative evaluation, surgery, monitoring, and managing this condition with various pharmacological agents (Atkins & Drummond, 2007; Haddad & Arabi, 2012; Newhouse & St. Laurent, 2007). Absence of early rehabilitation on acute care units has been previously
recognized by the Royal College of Surgeons of England (1999), acknowledging the deleterious effects of individuals with serious TBI “languishing for months in acute care beds” (Royal College of Surgeons of England, 1999, p. 5).

In this review, I focused on research targeted at rehabilitation interventions specific to acute care for individuals with sTBI or how policies and perspectives described in the literature shape the provision of rehabilitation for sTBI in acute care. I conducted searches of scientific and grey literature prior to and after data collection, using scientific databases available through the University of Toronto and Google. The University of Toronto Gerstein Science Library Portal was used to search the following databases: Medline, Embase, PsychINFO, OT Seeker, and PEDRO. Google primarily targets PubMed during literature searches. Search terms were determined based on relevant descriptors addressing rehabilitation for sTBI in acute care. Google and Google Scholar were searched using the same search terms. All terms were searched as keywords. Abstracts identified were screened and full-text versions of the articles that met the search criteria were obtained. As the review progressed, specific searches were undertaken based on previous search results, such as music therapy in acute care for individuals with sTBI.

The literature review focused on published research articles, clinical practice guidelines, and grey literature, including books, addressing issues related to acute care brain injury rehabilitation. Studies that did not specify which interventions occurred in acute care or studies with mixed etiology groups were excluded. The primary aim was to identify research articles focusing on rehabilitation for sTBI in acute care and evidence-based acute care interventions. The focus of this part of the search was to find interventions related to improving levels of consciousness, from a comatose state to being ready to attend formal rehabilitation, moving through Levels 0 to V on the Rancho Los Amigos Scale (RLA). Studies needed to include groups of individuals with sTBI, with data clearly provided in the article. Published work examining policies and perspectives influencing acute care sTBI rehabilitation were collected, including overall system factors, referral patterns, models of care, clinical pathways, and registries for injuries. Articles focusing on early sTBI rehabilitation, specifically in Ontario and Canada were included, in addition to international research.
Relevant search terms

(1) Brain injury, brain injuries, traumatic brain injury, traumatic brain injuries, and severe traumatic brain injury

(2) Rehabilitation, recovery

(3) Acute care, ICU, intensive care, acute care hospital

Inclusion and exclusion criteria

Included: Population - brain injury, human, adult and child

Included Study type - research article, clinical practice guideline, book

Excluded: medical interventions, non-English/non-translated, intervention to individuals only in a rehabilitation centre or community dwelling

2.3 Incorporating Disorders of Consciousness

Rehabilitation for individuals with sTBI is complex as there are a variety of outcomes following this injury. Following the loss of consciousness, individuals with sTBI are often in a coma, which can resolve by progressing to higher levels of consciousness, they may remain in a low level of consciousness, or life support may be withdrawn. Early withdrawal of life support has been evaluated in Canadian Level I Trauma Centres; in one half of the cases of sTBI, life support was withdrawn within 72 hours—considered too early in some cases for accurate prognostication (Turgeon et al., 2011). Changes in consciousness after sTBI are frequently recorded with the Glasgow Coma Scale (GCS) or Ranchos Los Amigos Scale (RLA). “Coma is a self-limiting state that typically resolves within 2 weeks into either a vegetative state (VS) or minimally conscious state (MCS)” (Stevens & Bhardwaj, 2006, p. 32). VS and MCS are disorders of consciousness (DOC); these states may be brief, resolve over a period of months or years, or are relatively permanent. Surprisingly positive early functional recoveries can occur in cases of traumatic injury, with meaningful recovery occurring for extended periods, but these conditions can be difficult to manage medically (Giacino, Fins, Laureys, & Schiff, 2014; Whyte & Nakase-Richardson, 2013).
The vegetative state (VS) is a state of wakeful unconsciousness with spontaneous eye opening in the absence of purposeful behavioural responses, including language (Giacino et al., 2014). A persistent vegetative state is typically described one month after injury and a permanent vegetative state is described three months after non-traumatic brain injury and 12 months after traumatic brain injury (Giacino et al., 2014). Individuals who are minimally conscious are frequently misdiagnosed as being in a vegetative state; the misdiagnosis rate varies between 18 and 43% (Gill-Thwaites, 2006). This state-of-the-art review considers interventions for individuals with sTBI who demonstrate a variety of functional outcomes. These individuals may show cognitive and behavioural improvements in acute care as required to access formal inpatient rehabilitation programs, individuals with more prolonged disorders of consciousness, and individuals referred to as ‘slow-to-recover’ (Gray, 2000) who eventually demonstrate notable recovery after months or years.

2.4 Intervention Studies

Interventions for sTBI have been grouped into categories related to profession, such as physiotherapy, or type of intervention, such as sensory stimulation. Systematic reviews often addressed a number of interventions in the same article, such as physiotherapy and sensory stimulation. Some reviews addressed rehabilitation across a number of contexts, or the specific contexts of intervention were not specified. Aspects of the reviews were included if they typically occurred in acute care, such as serial casting or sensory stimulation, or if the period of intervention in acute care was well-described. If methods were too vaguely described or inappropriate methods were employed, studies and reviews were not included. Most studies reviewed commented on the limited number of studies and lack of methodological rigour in sTBI rehabilitation studies.

Health professions

One systematic review in physiotherapy included interventions provided in acute care; however, studies were based on a limited number of single case studies or small group sizes (Watson, 2001). Purposeful activity/functional task training and behavioral modification were noted to be effective training strategies and splinting/serial casting demonstrated clear benefits (Watson, 2001). Watson (2001) noted limited evidence for exercise training while sensory stimulation programs showed mixed results. Wheatley-Smith et al. (2012) investigated
intensive daily physiotherapy, including passive range of motion and splinting, with ten patients in VS and MCS; carer burden was reduced and patients were seated appropriately at the end of the intervention. However, none of these individuals regained consciousness following this intensive intervention. As noted above, these studies employed small sample sizes or single case studies, diminishing generalizability of these studies.

Two studies were retrieved regarding acute care interventions in speech language pathology, one focused on producing speech (McGhee, Cornwell, Addis, & Jarman, 2006) and the other on listening to familiar speech (Sullivan, Guernon, Blabas, Herrold, & Pape, 2018). The former considered the suitability of providing early intervention with two participants to improve dysarthria (speech deficits related to impaired motor movement of the mouth) from post-traumatic amnesia after sTBI (McGhee et al., 2006). Both participants achieved a score of 10 out of 12 on the Westmead Post-traumatic Amnesia Scale, and were in Levels IV (confused and agitated) or V (confused and inappropriate) of the Rancho Los Amigos Scale (RLA). Treatment plans were developed on the basis of the assessment results and speech therapy was provided twice daily, five days per week, over the course of the study. Both participants were able to participate in the sessions and showed improvements in speech dysarthria, making gains in respiratory, laryngeal, and articulatory function. Both participants made notable gains in single-word and two-word or phrase intelligibility. These studies had very small sample sizes, making it difficult to extrapolate the results to larger populations of individuals with sTBI.

A single case study employed familiar auditory sensory training (FAST) in an individual with chronic sTBI who was minimally conscious eight years post-injury (Sullivan et al., 2018). This training involved listening to audio-recorded familiar stories by known individuals. The study design included four weeks of baseline observation with weekly neurobehavioral assessments followed by an intervention phase with six weeks of FAST intervention and six weeks of sham intervention with biweekly neurobehavioral assessments. Intervention included 10 hours of intervention, administered in 10-minute periods, four times per day, five times per week. Neurophysiological readings using brainstem auditory-evoked potentials and neurobehavioral ratings using the Disorders of Consciousness Scale (DOCS-25) demonstrated significant improvement related to the intervention condition (Sullivan et al., 2018). This study has yet to be applied to a larger population of individuals with sTBI.
One occupational therapy study addressed the provision of rehabilitation in an acute care context through the use of strategies to decrease agitation during post-traumatic amnesia (Nott, Chapparo, & Heard, 2008). Participants (n=10) were at a Rancho Los Amigos Level IV or V, between 14 and 61 days post-injury. The intervention consisted of the Perceive, Recall, Plan and Perform (PRPP) Intervention; baseline periods were employed prior to and in between intervention (Nott et al., 2008). This intervention focused on task analysis integrated with information processing, employing a specific sequence of steps for information processing known as ‘Stop, Sense, Think, Do’. Intervention was provided for four weeks on a daily basis (Nott et al., 2008). Treatment effectiveness was described as having a large to very large effect size. At the end of the study, three of the participants had emerged from post-traumatic amnesia (PTA); however, being in PTA did not appear to inhibit the participants’ ability to acquire information (Nott et al., 2008). This study, which included a small number of participants, could show promise in larger study, given the similarity of the intervention to the CO-OP program—a strategy used effectively with individuals with TBI in later stages of recovery (Dawson et al., 2009).

Music therapy

Numerous studies were identified providing interventions using music therapy in acute care after sTBI. One study with 34 participants with severe brain injury, with a larger sample size than many sTBI studies in rehabilitation, employed in a single case study design. Eighteen of the individuals had sTBI and the remaining 16 experiencing coma due to hypoxia, ischemia, or hemorrhage (Formisano et al., 2001, p. 628). Patients experienced inertia (reduced psychomotor initiative) or psychomotor agitation. Music therapy was intended to decrease agitation and increase participation. The period of music therapy varied, based on the duration of admission (Formisano et al., 2001). “Active music therapy consists of musical improvisation between patient and therapist by singing or by playing different musical instruments, according to the vital functions, the neurological conditions, and the motor abilities of the patients” (Formisano et al., 2001, p. 627). Eight of the nine agitated patients showed improvements, while 17 of the 27 patients with inertia were noted to show improvements during music therapy sessions. The two patients who displayed both agitation and inertia demonstrated improvement as per observation (Formisano et al., 2001).
Bower et al. (2014) investigated the use of music therapy in early stages of recovery after sTBI on PTA and agitation. This type of single case study is typical of many of the music-based interventions studies in sTBI rehabilitation. Music intervention was provided through a live vocalist in this single case study with a 10 year old participant, approximately three weeks post-injury—two music sessions were provided (Bower et al., 2014). The study employed a music therapist who created songs and music in reference to the participant’s behavioral responses to encourage more cognitively aware responses and decrease agitated responses (Bower et al., 2014). It was noted the participant displayed “brief but consistent and repeated periods of awareness and responsiveness to the live singing of familiar songs” (Bower et al., 2014, p. 1). Qualitative evaluation of video recordings demonstrated reduced agitation behaviors of the participant during music sessions, including decreased thrashing of her arm, lip smacking, and plaintive and involuntary vocalizations.

One review study considered both sensory stimulation and music therapy and presented results of the reviewed studies (Schnakers, Magee, & Harris, 2016). Music therapy was characterized as either live music, modified in reference to participant responsiveness or listening to music, usually familiar. Studies reviewed suggested individuals with disordered consciousness demonstrate increased arousal and attention, as indicated through eye blinks and EEG studies with live music (n=21) in comparison to white noise or disliked music (O’Kelly et al., 2013; Schnakers et al., 2016). Individuals with disorders of consciousness (DOC, n=13) are also more responsive with music versus a non-musical control stimulus (Castro et al., 2015; Schnakers et al., 2016). Music has also been employed as a prognostic indicator of later recovery of consciousness in VS and MCS (n=7) when the area of the brain stimulated by music (superior temporal gyri) is activated during functional Magnetic Resonance Imaging (Okumura et al., 2014; Schnakers et al., 2016). Music has been employed as a motivational reward and in detecting consciousness in individuals with VS and MCS (n=3) (Boyle & Greer, 1983; Schnakers et al., 2016). One study noted increased behavioral responses in an individual with DOC to live music therapy interventions, as compared to during neuropsychological evaluation (Lichtensztejn, Macchi, & Lischinsky, 2014; Schnakers et al., 2016).
Multimodal sensory stimulation

The clinical utility of sensory stimulation has been reviewed in terms of translating research findings into concepts applicable in rehabilitation with individuals with DOC (Abbate, Trimarchi, Basile, Mazzucchi, & Devalle, 2014). The use of emotional and autographical stimuli is recommended, in addition to employing stimulation in structured and meaningful ways across multiple sensory channels (Abbate et al., 2014). Dynamic and normal everyday actions intended to produce both cognitive input and output are recommended, with stimuli at an appropriate level and occasionally more intense stimuli (Abbate et al., 2014). A systematic review examining the effectiveness of sensory stimulation in DOC concluded strong evidence exists for multimodal sensory stimulation contributing to increased alertness and arousal (Padilla & Domina, 2016).

A sensory stimulation regime tailored to patient tolerances of premorbid preferences with the addition of modalities moving from unimodal (one sense) to multimodal (five senses) is recommended (Padilla & Domina, 2016). The frequency and intensity of these modalities are increased as the program progresses (Padilla & Domina, 2016). Multi-modal stimulation was noted to demonstrate effectiveness in improving level of consciousness through the use of a coma kit (Megha, Harpreet, & Nayeem, 2013). This coma kit included tools to stimulate all five senses (visual, olfactory, auditory, tactile, and gustatory) that were personally relevant including: familiar smells, favourite perfumes, photos, and auditory recordings of family (Megha et al., 2013). Multimodal stimulation has been recommended for more extended periods of several months, as opposed to several weeks, to maintain therapeutic benefit (Oh & Seo, 2003). However, as per a critique of Oh and Seo (2003) and as noted in this review (Megha et al., 2013), scales such as the GCS lack appropriate sensitivity as a sole neurobehavioral measure; more extensive neurobehavioral scales such as the Wessex Head Injury Matrix are more sensitive to change (Gelling et al., 2003).

Administration of a sensory stimulation program delivered through a regular family visiting program has been described as effective in increasing levels of consciousness (Abbasi, Mohammadi, & Rezadi, 2009). Patients (n=50) were divided into an intervention and control group and placed in two different intensive care units based on group allocation (Abbasi et al., 2009). In the intervention group, family members were trained in the administration of a multimodal sensory stimulation program for six days (Abbasi et al., 2009). Family visit times
were 15 minutes, four times daily only, and involved administering the structured sensory stimulation program (Abbasi et al., 2009). In the control group, families could only see their injured family member through the windows of the intensive care unit or on closed circuit television of the unit (Abbasi et al., 2009). The intervention group was noted to demonstrate significant improvement according to the GCS, while the control group GCS scores decreased (Abbasi et al., 2009).

A 60-patient study incorporating two intervention groups and a control group examined the effectiveness of a seven-day, twice-daily multimodal sensory program administered by either nurses or family members (Moattari, Shirazi, Sharifi, & Zareh, 2016). Levels of consciousness and responsiveness were measured using the GCS, the RLA, and the Western Neurosensory Stimulation Profile (WNSSP) (Moattari et al., 2016). Patients receiving intervention from their family demonstrated greater overall recovery on all three scales, as compared to the other two groups—indicating they demonstrated improvement in consciousness, level of cognitive function, and basic cognitive sensory recovery (Moattari et al., 2016). The nurse-based intervention group demonstrated improvement in basic cognitive sensory recovery as compared to the control group, but did not demonstrate a significant difference in their level of consciousness or level of cognitive functioning.

Cognitive intervention

The administration of a structured reality orientation program has been proposed to reduce the duration of post-traumatic amnesia (Langhorn et al., 2015). A group of patients (n=24) with moderate to severe TBI in the early stages of recovery, at RLA Level IV, were provided with a reality orientation program in intensive care and acute care units. This group was compared with a group of similar patients (n=38) at a similar nearby facility who received usual care with no reality orientation program (Langhorn et al., 2015). The reality orientation program, which included orientation to person, place, and time, was provided on a 24-hour basis by nurses and reinforced by family. Reality orientation clipboards, watches, calendars, maps, and posters were also used to reinforce orientation at least twice daily (Langhorn et al., 2015). No effect of this program was found (Langhorn et al., 2015). The authors proposed that limitations of the study influenced the results. The control group was significantly younger than the intervention group (mean age 44.1 years versus 29.9 years) and GCS scores were lower in the
intervention group, indicating more severe injuries (Langhorn et al., 2015). Administration of this program to well-matched intervention and control groups may have yielded different results, given the clinical utility of the program.

Improving attention has been addressed through virtual reality intervention in individuals with moderate to severe TBI while in an inpatient setting (Larson et al., 2011). Eighteen participants in RLA Level IV to V with functional right upper extremity strength were enrolled in the study; 15 were able to complete this study (Larson et al., 2011). The attention task consisted of a three-dimensional cancellation task, completed in twelve four-minute blocks of trials over two consecutive days. When the participants demonstrated difficulty remaining on task, sensory cues were provided through a robotic arm (Larson et al., 2011). Participants demonstrated significant improvement in this task, particularly with both visual and sensory cues. Some participants expressed that the task was not interesting or it was too difficult. The most notable contribution of this study was that so many participants, five of whom were in RLA Level IV, maintained participation for two consecutive days across multiple trials. The findings of this study suggest individuals who are confused or agitated can participate in meaningful intervention; most inpatient rehabilitation programs will only admit individuals with sTBI in RLA Level V.

**Intensive early multidisciplinary rehabilitation**

Early intensive neurorehabilitation, including interventions specifically targeted at neurological disorders, was examined using retrospective functional data of 449 patients admitted to a hospital prior to and after opening an acute neurosurgical unit in a neuroscience hospital (Thompson, Majumder, Sheldrick, & Morcos, 2013). This unit offered daily multidisciplinary rehabilitation to determine the efficacy of this intensive treatment and length of stay, as compared to usual treatment (Thompson et al., 2013). The usual treatment condition included comparative data from the unit in the period prior to initiating daily intensive multidisciplinary therapy. The goal of the unit was to address any medical events occurring during patients’ stay and to provide early rehabilitation. Patients were stable and no longer required acute neuroscience medical services. The multidisciplinary team consisted of physiotherapists, occupational therapists, speech therapists, nurses, neuropsychologists, and a specialist rehabilitation medical team. The unit also included a physiotherapy gym and therapy
kitchen. Patients had experienced a hemorrhage (intracerebral hemorrhage, subarachnoid hemorrhage) or a TBI prior to admission. The unit accepted patients with a variety of neurological states, including those who were minimally conscious, with challenging behaviors, or with a tracheostomy tube. Patients were discharged to inpatient rehabilitation facilities or the community after leaving this unit.

Retrospective records of 49 patients from the general medical ward prior to creation of the unit in 2001 were crossed matched with 400 records of patients after creation of the acute neurorehabilitation unit from 2006 to 2009. Records were matched on the basis of age, gender, diagnosis, and GCS score (Mild, Moderate, Severe). Functional amelioration was measured using the Functional Independence Measure/Functional Assessment Measure (FIM/FAM) shortly after admission and after discharge to the ward. The first group did not receive specialized acute neurorehabilitation services; however, usual treatment was not well delineated. The second group received daily rehabilitation from occupational therapy and physiotherapy, including working in the gym, therapy kitchen, and fully equipped occupational therapy room. Sessions used focused stimulation in several areas such as mobility, self-care, food preparation, toileting, and multi-tasking (the Multiple Errands Test). Scores examined in various functional areas included: mobility, self-care, psychosocial, bowel and bladder function, and cognition. The second group receiving daily intensive rehabilitation showed statistically and clinically significant improvement of 170%, as compared to usual care, in all areas of functioning with the exception of communication. The lowered scores in communication were hypothesized as being related to the lower intensity of speech therapy. The average length of stay for patients in the first group was 112.7 days and 77.9 days for the second group, a statistically significant difference of 31%. Intensive multidisciplinary intervention significantly decreased length of stay for individuals with sTBI.

Intensive early intervention with sTBI has been previously examined in a large-scale multi-centre study to determine the impact of this type of intervention on long-term outcomes (MacKay et al., 1992). This rehabilitation program was initiated upon admission to the trauma centre once patients were medically stable; the purpose of the study was to determine if early intervention affected long-term outcome (MacKay et al., 1992). Outcomes for patients (n=17) from a trauma centre with a formalized TBI rehabilitation program were compared to patients (n=21) from a comparable trauma centre without a formalized TBI rehabilitation program.
The formalized TBI program included a multidisciplinary team who administered structured multisensory stimulation, orientation, exercise, positioning and goal-directed activity to enhance cognitive and physical skills (MacKay et al., 1992). The frequency of intervention by various health professionals was not described.

For the non-formalized TBI programs, 10 programs were considered with the following attributes: 14% of the participants received physiotherapy, 35% received speech language pathology, and 14% received no rehabilitation (MacKay et al., 1992). One comparable program was selected as the control group (MacKay et al., 1992). Coma duration and hospital stay were one-third the duration for the formalized TBI program group as compared to the control group (MacKay et al., 1992). Level of consciousness at discharge from the acute care hospital and subsequent rehabilitation facility, as measured by the RLA, was significantly improved for the treatment group, as compared to the control group. The formalized TBI program group demonstrated more significant improvement across physical and motor, sensory, and perceptual, and cognitive and language areas, in addition to total impairment (MacKay et al., 1992). In terms of discharge destination, 94% of the early formalized TBI program participants were discharged home following inpatient rehabilitation versus 57% of the non-early formalized programs participants (MacKay et al., 1992).

Early onset, continuous chain rehabilitation has been studied in terms of treatment effectiveness and cost efficiency (Andelic et al., 2012; Andelic et al., 2014). Continuous chain rehabilitation means rehabilitation is started while in acute care and continued during inpatient rehabilitation. This rehabilitation, initiated in a Level I Trauma Centre, was compared to broken chain rehabilitation, which was initiated during inpatient rehabilitation or not at all (Andelic et al., 2012). An early continuous chain rehabilitation group (n=31) was compared to a delayed rehabilitation broken chain group (n=31) (Andelic et al., 2012). Patients who initiated rehabilitation earlier and received continuous chain rehabilitation had significantly better outcomes as compared to patients with delayed admission to rehabilitation facilities at 12 month follow up (Andelic et al., 2012). A comparison of the cost effectiveness of continuous chain versus broken chain rehabilitation for individuals with sTBI suggested continuous chain rehabilitation is more cost effective (Andelic et al., 2014).
A systematic review and meta-analysis of the effect of the timing and intensity of early onset neurorehabilitation examined 11 studies in trauma centres and intensive rehabilitation programs (Königs, Beurskens, Snoep, Scherder, & Oosterlaan, 2018). This review included most of the studies listed in the sensory stimulation and multidisciplinary programs sections of this state-of-the-art review (Abbasi et al., 2009; Andelic et al., 2012; Langhorn et al., 2015; Mackay, Bernstein, Chapman, Morgan, & Milazzo, 1992; Megha et al., 2013; Moattari et al., 2016). This review indicated early onset neurorehabilitation in a trauma center promoted functional recovery for TBI as compared to usual care for individuals with TBI; these studies demonstrated a large effect size when aggregated (Königs et al., 2018).

A retrospective medical record review study by Greenwood, Strems, Watkin, Losseff, and Brown (2004) in London, England, compared 92 individuals receiving acute inpatient rehabilitation after complex mild to severe TBI with 97 individuals who obtained usual care over a period of three years. These individuals were not receiving care at the same facility. Those receiving rehabilitation were on a specialized unit, whereas the control group attended different facilities where acute care rehabilitation was not provided. The rehabilitation group had less severe injuries than the control group. It was concluded length of stays were no longer with the provision of acute care multidisciplinary rehabilitation; patients receiving this type of rehabilitation were more likely to be referred to other rehabilitation services than when treated with less intensive rehabilitation on other units (Greenwood et al., 2004). This study did not include tracking of specific indicators for functional improvement, such as mobility, communication, or independence in activities of daily living.

The implementation of a national TBI strategy in Denmark proposed centralization of subacute intensive rehabilitation for individuals with the most severe TBI at two hospitals (Engberg, Liebach, & Nordenbo, 2006). Participants had a GCS initially recorded between three and 12 (n=77) or a GCS of 13 to 14 (31) with focal cognitive deficits. Participants were admitted to the unit as soon as they were able to breathe on their own (mean 19.6 days) and remained on the unit an average of 131 days (Engberg et al., 2006). Around-the-clock treatment and rehabilitation were initiated on day one with a multidisciplinary team (Engberg et al., 2006). Levels of consciousness were measured using the GCS and RLA, and numerous functional measures were used, including the Functional Independence Measure (FIM) (Engberg et al., 2006). Even when post-traumatic amnesia lasted four weeks, 94% of the participants
demonstrated progress during rehabilitation as measured by the FIM and 8.7% remained totally dependent on care upon discharge (Engberg et al., 2006). Half the patients were discharged directly home from the unit (Engberg et al., 2006).

2.5 System Perspectives

Factors affecting admission to rehabilitation

Part of rehabilitation work in acute care involves determining where individuals with sTBI will be discharged after their stay in acute care; these decisions are usually mediated by policies related to admission criteria of these other facilities. Review of the literature revealed two studies examining factors or decisions affecting discharge from acute care and/or admission to inpatient rehabilitation for individuals with sTBI. Schumacher, Walder, Delhumeau, and Müri (2016) examined the discharge location of 566 individuals with sTBI following discharge from acute care in order to determine predictors of being referred or selected for inpatient neurorehabilitation. Neurorehabilitation was distinguished from general rehabilitation in this study, as neurorehabilitation focused on treating symptoms specific to cognitive disorders. Sixty percent of the individuals with sTBI were discharged to inpatient rehabilitation while 40% were discharged home or to a nursing home (Schumacher et al., 2016).

Discharge to inpatient neurorehabilitation did not occur as: (1) the patient recovered sufficiently in acute care, no longer requiring inpatient rehabilitation; (2) the patient recovered sufficiently physically but cognitive disorders were not identified due to lack of cognitive assessment; and (3) the lack of available beds in inpatient neurorehabilitation was a structural/organizational issue (Schumacher et al., 2016). The main predictors of gaining access to inpatient neurorehabilitation included being: (1) younger in age and (2) male in gender. The authors of the study were unable to provide an explanation for the lower discharge rate to rehabilitation for females. Authors of this study hypothesized older adults were discharged to general rehabilitation as opposed to neurorehabilitation as neurorehabilitation beds were prioritized for younger male patients, presumably more likely to return to work after rehabilitation (Schumacher et al., 2016).

In Canada (Swaine et al., 2018), referral patterns of healthcare providers to inpatient brain injury rehabilitation were studied in two Canadian provinces, Quebec and Ontario.
Healthcare providers in acute care and brain injury rehabilitation programs (n=345) rated the likelihood individuals with TBI or cerebral hypoxia would be admitted for inpatient rehabilitation. Clinicians referring patients to inpatient admission act as gatekeepers as they “play a critical role in the decision to refer a patient or not to rehabilitation by making judgements based on perceptions of patients’ needs and assessing patients’ rehabilitation potential” (Swaine et al., 2018, p. 698).

While the importance of timely access to rehabilitation services has been emphasized through clinical guidelines (Cullen et al., 2012), differential access to inpatient rehabilitation for patients with TBI is acknowledged as an issue—access rates for adults in Canada and the United States vary between 15% and 31% (Swaine et al., 2018). Various patient-related and organizational factors were previously noted to influence clinicians’ decisions regarding referral to inpatient rehabilitation, including: younger age, co-morbid conditions, injury severity, availability of post-acute care rehabilitation resources such as the number of inpatient beds and early supported discharge programs, and proximity of inpatient rehabilitation to the patients’ home (Swaine et al., 2018).

In this study, physicians, nurses, and rehabilitation professionals (n=345) in 13 acute care facilities and 16 inpatient rehabilitation facilities completed a web-based survey. This survey used hypothetical scenarios to determine if they would refer a patient (acute care) or accept a patient (inpatient rehabilitation) based on patient-related factors, such as age, presence of complications, or having a discharge location (Swaine et al., 2018). One scenario involved a younger woman with sTBI and the other scenario involved a 58-year-old man with a hypoxic brain injury after cardiac arrest. Personal factors varied, such as psychiatric history, substance use, tracheostomy, reluctance to participate in rehabilitation, minimal learning history, aggression, access to insurance, older age, or no discharge location. The vast majority of the health professionals indicated the younger woman in the first scenario would be admitted to inpatient rehabilitation while only half the respondents believed the older man in the second scenario would be admitted to inpatient rehabilitation (Swaine et al., 2018).

The authors suggested rehabilitation potential was perceived differently in the two cases (Swaine et al., 2018). The five assessment tools most frequently reported across all acute care and rehabilitation sites, listed from most to least used are as follows: (1) GCS, (2) RLA, (3)
Montreal Cognitive Assessment (MoCA), (4) FIM, and (5) the Galveston Orientation and Amnesia Test (GOAT). One third of acute care respondents and over half of the providers in inpatient rehabilitation were unaware of assessment tools used for referral or admission. Two factors consistently significantly diminished the likelihood of referral or acceptance to inpatient rehabilitation: (1) older age, and (2) the combined presence of minimal learning ability, memory impairment, and physical aggression. Perceptions that age and cognitive-behavioral status would negatively impact inpatient admission to rehabilitation were consistent with evidence-based literature, suggesting these factors were associated with poorer functional outcomes. “Overall, acute care respondents were less likely to refer patients that their rehabilitation counterparts would have accepted” (Swaine et al., p. 703), suggesting increased dialogue was required.

Toronto ABI Network

Referrals to inpatient rehabilitation and community services are often accomplished through formalized referral networks for individuals with TBI (LaMontagne, Swaine, Lavoie, & Carreau, 2011). A local brain injury network, the Acquired Brain Injury Network, was developed with the intention of addressing the needs of individuals with TBI in integrating the whole system of TBI to address fragmented care (VanderLann, Brandys, Sullivan, & Lemsy, 2001). “The Toronto Acquired Brain Injury (ABI) Network, an umbrella organization of 17 partners in the city of Toronto, Canada, is attempting to create a cost-effective, seamless, efficient, and effective integrated system of service” (VanderLann et al., 2001, p. 17). These services extend from acute care to rehabilitation to long-term care—this system is described as rooted in empirical evidence, current research, and family perspectives (VanderLann et al., 2001). The Toronto ABI Network is funded through the Ministry of Health and Long-Term Care (MOHLTC) in Ontario (VanderLann et al., 2001). This network has described best practices through working groups and literature reviews (VanderLann et al., 2001). No evaluation or critique of this network has been described in the literature to date.

New initiatives for TBI

New initiatives for TBI are being developed to promote improved organization of care and rehabilitation. Three main initiatives advocated for to address rehabilitation of individuals with TBI include: (1) the implementation of national TBI strategies (Engberg et al., 2006; Reynolds, Page, & Johnston, 2001) or clinical pathways for acute TBI (Singh, Venkateshwara,
Kirkland, Batterley, & Bruce, 2012) and DOC (Royal College of Physicians, 2013; Sattin et al., 2017a; Sattin et al., 2017b; Sheon, 2013); (2) the development of slow-to-recover programs for individuals with sTBI who cannot access traditional inpatient rehabilitation programs (Gray, 2000; Wales & Bernhardt, 2000); and (3) the development of multi-centre national registries for individuals with DOC (Grill et al., 2013; Pascarella et al., 2018; Reynolds et al., 2001; Royal College of Physicians, 2013).

National registries for DOC, including the German registry (Grill et al., 2013) and the Italian registry (Pascarella et al., 2018) collect numerous statistics, including levels of consciousness, pharmacological therapy, neuroimaging, functioning, rehabilitation, neurophysiological measures, caregiver burden, and attitudes towards end-of-life decisions. These registries are important tools in collecting high-quality data regarding disorders of consciousness (Pascarella et al., 2018). Registries allow multiple centres to pool their data in meaningful ways—most facilities only have a limited number of individuals with DOC. Limited data sets at individual hospitals and trauma centres complicate knowledge translation regarding proper assessment and treatment for persons with DOC.

Growing concern is voiced in the literature in reference to the rights of individuals with DOC as they often receive quite limited rehabilitation (Fins, 2015; Fins, 2018; Fins & Wright, 2018). “Tragically, once lives are saved by brilliant intensive care, many patients are abandoned to what is euphemistically described as ‘custodial care’ where they are deprived of rehabilitation that might help them recover” (Fins & Wright, 2018, p. 670). Neuroethicist Fins completed 63 interviews with the families of individuals with DOC in the United States (Fins, 2015). Fins also provided in-depth examination of the cases of well-publicized individuals with DOC, including Terri Schiavo and Terry Wallis (Fins, 2015). Terry Wallis regained awareness 19 years after a severe brain injury, while Terri Schiavo’s parents eventually lost their case to keep their daughter on life support in the Supreme Court, even after presidential intervention by George W. Bush (Fins, 2015). A mosaic of care recognizing nuanced intermediate states of decision-making capacity and improved programs for individuals with DOC reflects their rights—rehabilitation is usually denied for these individuals, deemed as not a medical necessity by healthcare funders (Fins, 2015; Fins, 2018).
2.6 Chapter Summary

Review of the literature regarding acute care rehabilitation for individuals with sTBI reveals a growing body of literature regarding intervention and policy perspectives in this area. Intervention research is divided according to level of consciousness, and interventions are provided as treatment for individuals in: (1) DOC including coma, VS, and MCS; and (2) evolving and improving levels of consciousness, usually at Level IV or V of the RLA. Effective DOC treatment programs include single modal treatment programs such as music therapy (Bower et al., 2014; Castro et al., 2015; Formisano et al., 2001; Lichtensztejn at al., 2014; O’Kelly et al., 2013; Okumura et al., 2014; Schnakers et al., 2016) or multimodal sensory programs, such as using a coma kit (Abbate et al., 2014; Megha et al., 2013; Oh & Seo, 2003; Padilla & Domina, 2016). Effective early intervention for evolving consciousness includes working on speech (McGhee et al., 2006; Sullivan et al., 2018) or orientation through structured communication (Nott et al., 2008), virtual reality programs (Larson et al., 2011), and functional activity and casting/splinting (Watson, 2001). Sensory stimulation programs administered by family as opposed to nurses have been described as more effective (Moattari et al., 2016). Early, intensive rehabilitation for individuals with sTBI has been demonstrated in numerous studies (Greenwood et al., 2004; Königs et al., 2018; MacKay et al., 1992; Thompson et al., 2013) in addition to continuous chain intervention starting once patients are no longer ventilated (Andelic et al., 2012; Andelic et al., 2014; Engberg et al., 2006).

In terms of policy issues, neurorehabilitation units provide more effective rehabilitation for individuals with sTBI than general rehabilitations units (Schumacher et al., 2016). Material differences in terms of referral patterns indicate some individuals may be referred to rehabilitation more often, such as young males (Schumacher et al., 2016) and younger patients (Swaine et al., 2018). Healthcare providers working in an acute care facility are less likely to refer as many patients as their counterparts working in inpatient rehabilitation would have accepted (Swaine et al., 2018). Formalized networks to facilitate access to TBI rehabilitation services, such as the Toronto ABI Network, have been developed, though evaluation of this network has not been published to date (VanderLann et al., 2001). Various new initiatives have been advocated for individuals with TBI, including: (1) national strategies and clinical pathways; (2) slow-to-recover programs; and (3) multi-centre disorders of consciousness (DOC) registries (Engberg et al., 2006; Gray, 2000; Grill et al., 2013; Pascarella et al., 2018; Reynolds et al.,...
2001; Royal College of Physicians, 2013; Sattin et al., 2017a; Sattin et al., 2017b; Sheon, 2013; Singh et al., 2012; Wales & Bernhardt, 2000). Fins has extensively addressed how the rights of individuals with DOC are disregarded as they are denied access to rehabilitation, deemed as not a medical necessity by healthcare funders (Fins, 2015; Fins, 2018; Fins & Wright, 2018).
Chapter 3
Theoretical Orientation

3.1 Chapter Outline

In this chapter I address institutional ethnography (IE) as a theoretical perspective, describing how this perspective shapes this study. IE starts from a microsociological level, rooted in people’s daily activities. Through analysis, IE draws on macrosociological interpretations, or broader societal perspectives regarding the social organization of the phenomena being explored. Institutional ethnographies are intended to politically disrupt the status quo through empirically-based research seeking to change social relations. Talk and text are integral components formulating ruling relations, and in the production and reproduction of institutionalized ideologies. Talk includes how language, such as the deployment of specific word forms, is a social signifier of material relations. Text refers to policies, forms, and other written formats deployed to organize institutional relations. Other ethnographic accounts of care, rehabilitation, and disability are discussed in reviewing their social organization in other healthcare contexts.

3.2 Institutional Ethnography as a Theoretical Orientation

Engaging in a research inquiry from a sociological perspective involves recognition of the ontological and epistemological assumptions inherent a particular research paradigm. Theoretical assumptions can reflect the researcher’s worldview, guiding research questions, or in this case, the problematic, to situate the analysis (Giacomini, 2013; Green & Thorogood, 2009; D. E. Smith, 2005). Devising a research study from an institutional ethnography (IE) perspective signifies an ontological commitment to Marxist ideas (Walby, 2007), while ways of knowing reflect a feminist doctrine. D. E. Smith’s theoretical underpinnings in sociological theory, in highlighting the theoretical contributions from Bakhtin, Garfinkel, and Goffman to IE, convey her melding of Marxist theory with an ethnomethodological focus on the everyday activities of individuals (1999, 2005). D. E. Smith began with daily happenings as they occur in context to explicate broader social relations, based in material circumstances (D. E. Smith, 1987, 1999, 2005).
IE is a method of inquiry that situates its analysis using this Marxist-feminist theoretical perspective, with work, either paid or unpaid, as its main focus. It considers many facets of work, such as the unpaid work of being a single mother (D. E. Smith, 2005), the health work of people with HIV accessing healthcare services (Smith, Mykhalovskiy, & Weatherbee, 2006), or the paid work of criminal justice professionals as it negatively affects battered women (Pence, 2001). “Institutional ethnographers generally have critical or liberatory goals; they undertake research in order to reveal the ideological and social processes that produce experiences of subordination” (DeVault & McCoy, 2006, p. 19). Through the explication of social relations using this analytic approach, liberatory potential arises through identifying targets for political activism (DeVault & McCoy, 2006).

D. E. Smith developed this method of inquiry as an alternative to popular and dominant methodological approaches at the time in sociology, including post-structuralist approaches and grand theories. “Institutional ethnographers do not cede authority to ideas established in the literature. Instead, they rely on people’s experience as the point of entry into inquiry exploring connections among local settings of people’s everyday lives, institutional processes, and translocal ruling relations” (Deveau, 2008, p. 1). Institutional ethnographers identify a research topic, known as a problematic, through recognizing disjunctures in these experiences between people’s everyday/everynight lives and a politico-administrative regime (D. E. Smith, 2005; G. W. Smith, 1990). This type of ethnography starts at a microsociological level through people’s experiences, and through the process of inquiry, formulates broader translocal conclusions related to class and material relations.

Certain assumptions are made within this approach—people’s activities are organized in response to and in coordination with an institutional regime. It is also assumed people will be marginalized or affected negatively in some way by material relations. However, they are often not fully aware of how their lives and activities are shaped by external social forces, usually not visible to them. Important material relations studied by various institutional ethnographies extend the feminist lens to consider the possible negative societal implications of being: female, a caregiver, of ethnic origin, gay/lesbian, economically disadvantaged, or disabled. IE uses disjunctures in people’s experiences, which D. E. Smith refers to as a ‘bifurcation of consciousness’ to highlight examples of how their daily life is negatively affected by an institutional regime, reflecting broader class relations within society.
Social relations in institutional ethnography

“The aim of the sociology we call ‘institutional ethnography’ is to reorganize the social relations of knowledge of the social so that people can take that knowledge up as an extension of our ordinary knowledge of the local actualities of our lives” (D. E. Smith, 2005, p. 29). The intent of the research is to recognize, explicate, and map the social relations integral to people’s daily activities, as shaped by local and translocal ruling relations. In this process, learning to recognize and map social relations is a fundamental part of the research process, with the view that these social relations can ultimately be changed to improve the material and daily circumstances of people’s lives. Social relations, for a non-sociologist such as myself, require further consideration in understanding the intent of the research in IE:

The notion of ‘social relations’ in this sense does not stand for a thing to be looked for in carrying out research, rather it is what is used to do the looking. It operates as a methodological injunction that requires the researcher to examine empirically how people’s activities are reflexively/recursively knitted together into particular forms of social organization. (G. W. Smith, 1990, p. 636).

Kinsman (2006), in considering social movements in a book examining institutional and political activist ethnographies, described a thought-provoking anecdote in seeking to change social relations, which he referred to as ‘blowing up social relations’. In reference to this term, he described the following historical scenario:

It is thought to have been originally proclaimed by a Russian socialist, who—writing a polemic against the nineteenth-century anarchist factions who were engaged in explosive terrorist acts against the Czar—declared: “You can’t blow up a social relation.” The author’s point was simple: attacking infrastructure, even if it is of more than symbolic importance, cannot do away with a system. Without far-reaching reorganization of social relations, cutting off the head of the king never prevented another from sprouting in its place (Kinsman, 2006, p. 157).

Kinsman (2006) suggested blowing up social relations in IE illuminates these social relations; mapping social processes is a means to finding effective intervention. In terms of this research, I examined the social organization of rehabilitation for individuals with a sTBI in a Level I Trauma Centre. The aim of this institutional ethnography (IE) is to explicate how rehabilitation work is socially organized and why it is organized in this manner.

Selecting IE as a method of inquiry reflected these liberatory goals to change these material conditions of inequity for individuals with sTBI, while embracing a commitment to an
empirical sociological research method. “IE enables people who are marginalized to understand the broader implications of their experiences in localized settings. This is accomplished by mapping those powerful forces operating from afar that hook the local into translocal relations of ruling, including those of the economy” (Deveau, 2008, p. 1). Threads of social organization, recognizable through talk, language, and text, are used to explicate the prevailing social and political regime which organizes people's lives in that particular circumstance: “institutional ethnography makes use of the socially-organized character of everyday life to explore its puzzles” (Campbell & Gregor, 2002, p. 12).

Talk includes language and people's verbal and non-verbal social interactions with one another. This talk can include particular social forms meant to regulate individuals, such as prevailing societal discourses and even gossip. Text includes language in textual forms, such as written texts, institutional policies, and even graffiti (D. E. Smith, 1998). Dominant social relations acting at various locales and across time and space are known as ruling relations; texts are integral to their recursive properties (D. E. Smith, 1987, 1990, 1999, 2005).

Ruling relations are textually mediated

Ruling relations and the ruling apparatus are fundamental to conceptualizing the theorization of the unfolding of social activity and social life in IE. D. E. Smith (1999) highlighted the interactive nature of the social, suggesting “society is emphatically, from this viewpoint, not an ensemble of meaning. The social happens, included in the happening/activities are concepts, ideologies, theories, ideas, and so forth” (p. 75). D. E. Smith (1999) accentuated the fluid, moving, and didactic notion of the social, with ruling relations ontologically guiding these fields of activity. “The ruling relations are a complex and massive coordinating of people’s work. Intentions, desires, opportunities, impediments, blockages, and powerlessness arise within them” (Smith, 2005, p. 183). DeVault and McCoy (2006) summarized D. E. Smith’s conceptualization of these ruling relations in everyday modern society:

In the contemporary global capitalist society, the “everyday world” (the material context of each embodied subject) is organized in powerful ways by translocal social relations that pass through local settings and shape them according to the dynamic of transformation that begins and gathers speed somewhere else (e.g. a local hospital closes, the explanation will not be wholly local). Smith (1990b) refers to these translocal social relations that carry the accomplished organization and control as “relations of ruling”: They are those forms that we know as bureaucracy, administration, management,
professional organization, and the media. They include also the complex discourses, scientific, technical, and cultural, that intersect, interpenetrate, and coordinate multiple sites of ruling (p. 17).

D. E. Smith (2005) theorized that text is a fundamental part of maintaining these ruling relations, allowing these relations to exist and be reproduced recursively across time and space:

The texts that constitute and regulate establish agency, that is, textually specified capacities to control and mobilize the work of others. Textually sanctioned agency produces a power that is generated by the concerting and mobilization of people’s work. It is specific. It has limits, and it would be a mistake to conceive such forms of power as mobilized simply within a single formal organization, such as a business corporation. Corporations exist within the ruling relations and their interconnectness—financial markets, banks, legal systems, mass media, governmental departments and agencies at all levels, and so on (p. 183).

Texts work with one another and speak to one another in a “hierarchical form of intertextuality” (D. E. Smith, 2005, p. 185), meaning that their discursive components of ruling occur as a two-way street (D. E. Smith, 2005). Frontline workers, such as social workers, described by de Montigny (1995), are accountable to the department through these hierarchical forms of intertextuality and these practices are regulated by legal statutes (D. E. Smith, 2005). Similarly, the concepts and categories in these textual forms are related to the actual practices of the social workers (D. E. Smith, 2005). “While keeping in mind that a text always occurs in and as a part of someone’s work, it is handy to think of text-work-text or work-text-work sequences in orienting ethnographic practice” (D. E. Smith, 2005, p. 184). Texts can take on many forms, such as documents from government, scientific research, or publications from mass media, and are used to disseminate ideological discursive components within society (D. E. Smith, 1999).

Ruling relations are reproduced through ideology

Use of texts, through their replication, is one manner through which ruling relations are propagated and maintained. However, many human activities can be shaped not only through material objects themselves, but also the manner through which people commonly come to think about or reflect on certain common situations in daily life. They draw into the broader sociological concept of ideology. G. W. Smith (1998), in the *Ideology of Fag*, conceptualized ideology not as the contents of a mental state, but “a material form of social organization, a set of conceptually ordered practices and procedures dialogically coordinated through speech or writing” (p. 313). Social relations can also be coordinated though these recognizable and
repeatable sequences in social life involving speech, or writing/text, informing what D. E. Smith referred to as ‘ideological codes’ or common codes of conduct that meet common cultural norms or expectations.

In G. W. Smith’s study of the experiences of gay teens in school, gossip was one of the discursive forms identified as a means to exclude and humiliate young gay teens (1998). G. W. Smith used the example of how the social form of graffiti—language in a textual and very public format, was used to out gay teens or presumed gay teens and deride homosexuality in the high school context (1998). G. W. Smith (1998) used language to demonstrate how the behavior of gay male students in high school is hooked into broader gender relations, as they adopt recognizable heterosexual male-related behaviors to pass as straight, extending this analysis from microsociological to macrosociological levels (G. W. Smith, 1998). Male students illustrated the ever-present ideological code (my inference) or ideological organization within the school promoted verbal abuse through epitaphs such as ‘fag’, which thereby “enforces a patriarchal, heterosexual, hegemony” (G. W. Smith, 1998, p. 312). Examining talk and text in my study assisted to cast light on particular social phenomena and explicate how these phenomena marginalized certain individuals with sTBI through discursive and textual social forms.

Ideological codes

Ideological codes constitute hidden and unspoken codes of conduct that can be traced back to modes of ruling. Examples of ideological codes in IE include those of the Standard North American Family (SNAF) and political correctness as an organizer of public discourse (D. E. Smith, 1999); professors who become ‘academic stars’ in response to neoliberal academic institutional policies (Solomon, 2008), or gay teens bullied and harassed in high school by other students and teachers alike, although these are also referred to as ideological practices (G. W. Smith, 1998).

D. E. Smith (1999) suggested ideological codes are integral to the everyday, ever-present, taken-for-granted understandings that we have of the world. “The ideological code generates a common ordering into which descriptive elements from very different societies can be inserted” (D. E. Smith, 1999, p. 160). Ideological codes are analogous to genetic codes in D. E. Smith’s view, as they replicate and reproduce in a consistent fashion across multiple sites, as does DNA. The products of their replication processes represent being a “constant generator of procedures
for selecting syntax, categories, and vocabulary in the writing of texts and the production of talk and for interpreting sentences, written or spoken, order by it” (D. E. Smith, 1999, p. 159).

Ideological codes are proposed to be ubiquitous throughout societies and are textually mediated in D. E. Smith’s view; they operate at multiple sites of coordination (1999). D. E. Smith (1999) grounded the discursive uptake of knowledge, often through discourses and textually mediated information in society, as a part of these ideological codes; these modes of communication are integral to their reproduction across often distant sites of ruling relations.

The ideological code of the ‘academic star’ also generates reflection on the implications of societal codes of conduct shaping individuals’ behaviors (Solomon, 2008). Solomon (2008) focused on how social relations work recursively through the talk of academic stars and those who do not choose this academic path, levying personal and family lives over their professional work and identity. Professors’ talk and language were filled with descriptors of their acknowledgement of star status with phrases such as ‘the best’, ‘giants in the field’, and ‘those who rise to the top’ (Solomon, 2008). Professors recognized various material signifiers of academic stars, including awards, grants, and publications, which increased prestige in the chosen field (Solomon, 2008). Many of these signifiers were textually mediated and served to increase their recognizable status as an academic star (Solomon, 2008).

In having considered the theoretical aspects of IE, I will focus on institutional ethnography research conducted in healthcare settings, examining how social relations affect work practices, producing sites of oppression through discursive and textual coordination. The work of Diamond (1992, 2006) highlights the significance of material relations, particularly the financial capacity to pay for private nursing home care, which significantly shapes the quality of care provided in American nursing homes. Social worker de Montigny (1995) and occupational therapist Townsend (1998) examined how professional work by their respective original vocations could disempower clients these professions sought to serve through documentary and institutional practices. Rankin and Campbell (2006) explored how healthcare reform in Canada has transformed nursing practices through managerial control, endorsing evidence-based practice over client-centred practice. These studies suggest healthcare is constantly being reformulated through institutional practices meant to exert greater managerial and economic control and less concern for quality care of patients.
3.3 Social Organization of Healthcare in Related Contexts

Nursing home care

Diamond studied how institutional and material relations shape the provision of nursing home care in the United States, affecting the quality of care provided to nursing home residents (1992, 2006). The level of care in nursing homes can be substandard in serving some of society’s most vulnerable elderly populations. Diamond’s analysis of the social organization of nursing home care presented material relations as a guiding contingency affecting the quality of care in these nursing homes. Diamond (2006) reflected that nursing homes were sometimes divided into private pay floors and public aid; Medicaid floors or nursing homes were simply private pay or government-subsidized. Dramatically different levels of care and services were offered between these types of services; the best and most extensive services were offered for private pay floors or homes. Once residents could no longer afford private pay services, they were moved to government-subsidized floors or nursing homes with a lower standard of care (Diamond, 2006).

In order to exemplify how material relations influenced the provision of care, Diamond used the example of a material object or a social signifier, a fur coat, belonging to one of the residents of the nursing home named Fern (Diamond, 1992, 2006). Diamond moved beyond observing this material object to employing it as a clue in uncovering the social organization of the care provided in American nursing homes (Diamond, 1992, 2006). Diamond (1992, 2006) constructed a vignette about Fern and her fur coat, describing her movement from an affluent suburban home to a hospital, then to a private nursing home, and finally a government-subsidized home after all her financial resources had been spent on her care. Diamond (1992, 2006) concluded material relations, specifically the financial capacity to pay for care, significantly shaped the quality of care received by residents in nursing homes. This provision of immensely divergent levels of nursing home care in America has arisen from the privatization of nursing homes, whereby making a profit was a deciding factor in the quality of care.

Social work practice in child protection

In terms of critical studies within the rehabilitation professions, de Montigny (1995) examined the social organization of professional social work regarding how these helping
professions can generate practices that disempower clients. He described his experience working in institutional contexts as follows:

As a social work student and later as a social worker for several government ministries, departments, agencies and hospitals, I constantly bridged the gap between two apparently distinct worlds. I bridged the gap between the world of my experience and the world that denied my experience, a world of my thoughts and beliefs and a world that demanded that I perform other people’s thoughts and beliefs—spoken through operational directives, policies, and legislation. I bridged a flesh-and-blood world of embodied or immediate being and a textually cold world of disembodied or institutional being (de Montigny, 1995, p. 6).

de Montigny examined discursive components within his work context, including talk and text, as a means to explicate how social relations coordinated social work practices. de Montigny (1995) highlighted the importance of social signifiers belying certain material conditions. Citing an example of a social signifier, de Montigny focused on the overwhelming smell of urine noted in individuals’ homes during their work, prompting a set of social work practices identifying unfit parents and homes through these purulent smells.

Professional authority regarding smell was also tied into a series of other actions within the social worker’s professional schemata: examining bodies for signs of disease and neglect, assessing an individual’s cognitive capacity for the ability to care for others and themselves, and evaluating them for ‘normal’ developmental milestones (de Montigny, 1995). Professional specifications and process gave authority to these observations and ascribed value judgments, tied into cultural expectations and norms for proper care (de Montigny, 1995). Ideological practices of textual representation elevated the objective accounts of the social worker, locating them within social work professional discourse: “Texts impose an ordered, manageable, and controllable character to the equivocal, messy, chaotic worlds presented to social workers by clients” (de Montigny, 1995, p. 217). Clients’ abilities became constructed by social workers through these professional and textual practices in negative ways. These practices undermined their individual authority and declarations of competency, highlighting power exchanges between clients and social workers (de Montigny, 1995).

**Occupational therapy practice in mental health**

Townsend (1998) examined how the social organization of mental health services constrains client-centered practice in occupational therapy. Townsend (1998) highlighted that
textual and professional practices can govern rehabilitation, such as mental health services: “Textual facts, such as liability insurance and professional licensing, are used to coordinate and control the broad social relations and the ruling apparatus that governs the social organization of knowledge of an institutional function, such as mental health services” (Townsend, Langille, & Ripley, 2003, p. 21). As also described by de Montigny (1995) and Rankin and Campbell (2006), the conceptual practice of objectification, as evident in texts and reports, form conceptual facts that are meant to represent everyday life, and are further used in managerial decision making regarding financial and program requirements (Townsend et al., 2003).

Townsend (1998) presented a critique of the participation of occupational therapists, often unconsciously, in the routine organization of power in working with people with mental health issues. Townsend (1998) addressed how caregiving constitutes an object of care in this mental health context in the one-way process of helping. The individuals who are the objects of care can “remain passive, dependent recipients of care” (Townsend, 1998, p. 4). Townsend (1998) explored empowerment through individuals’ supported participation in their own lives and in teaching professionals to recognize how textual practices and organizational policies promote this dependence of mental health participants.

**Nursing care**

Nursing healthcare reform has been explored by Rankin and Campbell (2006) using institutional ethnography. Both researchers had formerly worked as nurses in Canada’s healthcare system. They sought to explicate how the social relations of nursing care in public healthcare contexts have changed dramatically in the last several decades. The discursive organization (D. E. Smith, 2005) of nursing practices has been reconstituted through the infiltration of newer, evidence-based, state-organized textual requirements and technological advances (Rankin & Campbell, 2006). These findings relate to this study as it focuses on the provision of nursing care in an acute care hospital setting.

Rankin and Campbell (2006) suggested different forms of institutionally organized knowledge are intended to ensure nurses spend their time appropriately, as designated by the institution—with less time for patient care. These forms of knowledge include: how to record patient reports and interactions and how to perform organizationally generated efficiencies. Rankin and Campbell (2006) provided an extensive review of how healthcare reforms, from the
1970s to the 2000s, have significantly influenced the provision of hospital care, with progressively more managerial control over healthcare practices. The expertise of information from professionals, auditors, and managers has become privileged above the knowledge of healthcare professionals within the reformulated and reconstituted hospital context (Rankin & Campbell, 2006).

3.4 Chapter Summary

In this chapter, I have reviewed the aspects of the theoretical orientation of institutional ethnography (IE)—a Marxist feminist method of inquiry employed in this dissertation. The intention of IE is for advocacy or activism with liberatory goals in defining situations whereby material conditions condone and propagate social injustice. This approach is intended to promote advocacy by detailing the actualities of how injustices occur in people’s lives through understanding how social relations are coordinated and why they are coordinated as they are. This coordination occurs through speech, including organizing forms ranging from discourse such as gossip or professional talk, and writing such as textual documents, professional regulations, forms, and even graffiti. Examination of talk and text, in addition to people’s daily activities, can readily allow for deeper analysis of prevailing ideologies and ruling relations imbedded in social life. The work of institutional ethnographers who have produced professionalized accounts in healthcare contexts, including Diamond, de Montigny, Rankin and Campbell, and Townsend, is discussed.
Chapter 4
Method of Inquiry

4.1 Chapter Outline

Method of inquiry is the focus of this chapter. D. E. Smith (1999) employed the term ‘method of inquiry’ rather than methodology, as she asserted IE incorporates both theoretical orientation and methodology in this approach. Progression of the research investigation is discussed as the problematic evolved to include additional locations of inquiry at the research site. I initiated data collection at the Level I Trauma Centre on the trauma ward, where most individuals with sTBI receive acute care rehabilitation. The research study developed to include the critical care and intensive units as sites of investigation, based on sites of struggle described by family members and health professionals during interviews.

Data collection methods at the research site did not occur in separate distinct stages, but evolved as the study progressed. I developed an interest in this study and started to explore the problematic as I performed the work as a caregiver for a friend with sTBI. I assisted this friend for six months on an almost daily basis as she recovered from sTBI. It was during these experiences that I was struck by the surprisingly limited rehabilitation provided to her while in a trauma centre. During an institutional ethnography course afterwards, I completed two interviews with other health professionals who were also graduate students and had worked in trauma centres with individuals with sTBI; one was a nurse and the other was a physiotherapist. I was also interviewed by a fellow graduate student regarding my experiences as a caregiver for someone with sTBI.

I then considered available trauma centres and selected one on the basis of ease of access. There were several processes that influenced the order of methods while at the research site of the trauma centre. As per the Research Ethics Protocols of the trauma centre, I could not contact the families of individuals with sTBI directly; this recruitment needed to be facilitated by health professionals on the trauma ward. Initially, health professionals indicated they had too many time constraints as the study started at the research site. In addition, as I was not familiar with the context in a formal work sense as I had not worked in this context. I did not have a broad understanding of the work roles and processes of many of the health professionals in the trauma
ward, and critical and intensive care units. I started attending multidisciplinary rounds with the health professionals on the trauma ward to meet health professionals on the ward and to identify possible patients with sTBI to be recruited into the study.

To familiarize myself with the job roles of various health professionals in the trauma ward, I observed them performing their job duties, and invited them to participate in an interview afterwards. As I started observing and interviewing health professionals, they became more involved in the study and recruited family members of individuals with sTBI to participate in interviews. I started attending medical rounds in the critical care and intensive care units on the basis of the family/patient interviews as they described these units as initial sites of struggle in their experiences. I continued with family/patient interviews with individuals with sTBI and their families on the trauma ward. I also continued with health professional interviews and also completed interviews with administrators. I completed a focus group on the trauma ward, interviewed more administrators and collected final documents identified as being pertinent to the care and rehabilitation of individuals with sTBI in Level I Trauma Centres. Fieldnotes were taken during various research activities. Ethics review and approval occurred with each changing phase of the study. Data collection occurred in a fluid and iterative process as new insights were gleaned through research informants and activities.

4.2 Study setting

I gained entry to this research site through introduction to the unit manager of the trauma ward through another individual familiar with the research setting. The main setting for this dissertation was the trauma ward of a large urban hospital, a Level I Trauma Centre, in Ontario, Canada. In the interests of maintaining anonymity of the research site, I will not provide specifics regarding the size of the hospital or the number of beds on the units where I conducted this study. Patients residing on the trauma ward have sustained serious and traumatic injuries, which is their primary reason for hospital admission. Patients on the trauma ward often have complex multiple system injuries, including diagnostic categories, such as: TBI, spinal cord injuries, amputations, multiple limb and body fractures, and multi-organ injuries.

The trauma ward is staffed by full- and part-time nurses, a unit manager, a nurse team leader, advanced practice nurses, patient care coordinators, and various specialist physicians.
Rehabilitation professionals on the ward include physiotherapists, speech language pathologists, occupational therapists, dieticians, social workers, and respiratory therapists. Other individuals, such as discharge coordinators and spiritual care, attend the ward when required to address the needs of patients. Nurses staff the unit 24 hours per day to ensure constant care and monitoring for patients on the ward. Various physicians attend the ward to address the patients’ medical needs. Rehabilitation professionals are usually present from Monday to Friday, though respiratory therapists and physiotherapists work weekend shifts. Some health professionals work on other units in addition to the trauma ward.

I also attended the critical care and intensive care units of this Level I Trauma Centre during the study. The critical care unit has a patient ratio of approximately one nurse to one patient; these patients have critical medical needs related to trauma. Patients on the critical care unit normally have a ventilator to breathe and other medical implements to monitor and manage their conditions, such as heart rate monitors and catheters for bodily waste disposal. The intensive care unit has a nurse-to-patient ratio of one nurse for two patients. Most patients in the intensive care unit no longer have ventilators, and normally have other medical implements, including heart rate monitors and urinary catheters. I accessed other areas of the hospital in interviewing non-clinical hospital employees or interacting with administrative staff in locating certain forms and policies, or as I waited for rounds and to complete interviews or periods of observation.

4.3 Ethics Approval

Ethics approval was obtained from two research ethics boards, including the University of Toronto and the Level I Trauma Centre where I completed the study. Primary ethics approval was obtained from the Research Ethics Board of the Level I Trauma Centre; it was designated as a delegated view. Once initial ethics approval was granted through the hospital, an administrative review was completed through the Office of Research Ethics with the University of Toronto. Both research ethics boards adhere to principles outlined in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, 2nd Edition (TCPS2).

I obtained initial ethics approval from the Research Ethics Board of the Level I Trauma Centre in February 2016 and through the University of Toronto in March 2016. Ethics approval
was submitted and approved for each change required at the research site, including attending the critical care and intensive care units, when changing various consent forms, and for approval for the focus group. In accordance with the research requirements at the hospital site, a primary investigator needed to be designated at the Level I Trauma Centre; this individual had a leadership role in one of the units involved in the study. However, this individual did not have access to any data from the study, nor were they aware of informants specifically involved in the study.

4.4 Study Informants

Admitting individuals into the study involved recruiting (1) patient and family informants and (2) hospital informants. Patients were admitted to the study on the basis of a diagnosis of a severe traumatic brain injury, defined as having sustained a score on the GCS of eight or below. This score was readily available on the medical charts and communicated to this researcher by health professionals assisting with recruitment of patients and their families for interviews. The individuals with sTBI varied in age between 17 and 87 years of age. Twenty-one patient/family interviews were completed. A family member provided consent as a substitute decision maker and described the work they completed with the individual with sTBI. If able, individuals with sTBI described their own healthwork in recovering from their injuries. Patient and family informants involved in the study were connected to the individual with sTBI as spouses and partners, adult children, parents, step-parents, siblings, step-siblings, grandparents, grandchildren, in-laws, and friends. One patient was observed for an initial observation period of 90 minutes as the family member indicated that they would prefer to complete an interview afterwards. However, this family member later decided they did not wish to complete an interview.

Three patients with sTBI were more actively involved in interviews as they were able to discuss the healthwork they performed as they recovered; one was quite talkative throughout the interview. These individuals had faster recoveries with imminent planned admission to inpatient rehabilitation or discharge home. These three individuals had impaired awareness and were not able to identify various safety risks, including fall risks or the extent of their cognitive impairments. Other individuals with sTBI participated to varying degrees but could mainly communicate immediate needs, such as needing a glass of water or talking to a nearby family
member or health professional. Some of the patients had facial injuries and/or facial fractures and were not able to speak due to these injuries. Three of the patients were in disorders of consciousness and were unable to communicate.

Interviews with patients and families were often a very dynamic process as many of these interviews occurred in the patients’ rooms. This was the preference of the family members as they wished to provide care to the individual with sTBI while participating in the interview. These interviews also served as periods of observation of the individual with sTBI and their caregivers. During these interviews, various nurses, laboratory technicians, physicians, and rehabilitation professionals entered the room and performed a multitude of tasks with patients or addressed family members. All individuals entering the room during interviews were informed of the audio recording occurring at that time. When one therapy session spontaneously started during an interview, these rehabilitation professionals were provided with consent forms to complete, acknowledging consent for participation in the study. Some patient/family interviews were completed off the trauma ward in a private room. This space allowed family informants to communicate in a confidential manner during interviews. I met the individual with sTBI and the family member beforehand in inviting them to participate in the study. I had often interacted with the patient and family while being present on the trauma ward while meeting with other families, or as they had been on the trauma ward for some time and had expressed interest in the study. Consent forms were signed for all interviews and periods of observation.

Hospital informants participated in the study by completing one of more of the following: (1) an interview, (2) participant observation (3), and/or a focus group. Several hospital informants participated in all three data collection methods. Seventeen hospital informants were observed for periods of observation and 26 hospital informants were interviewed, including 13 who had been previously observed. Hospital informants included physicians, nurses, advanced practical nurses, nurse team leaders, unit managers, discharge coordinators, financial administrators, and various rehabilitation professionals who worked in the trauma units. To maintain the anonymity of the hospital informants, I have not disclosed the type of physicians or specific health professionals involved in the study, as there are limited numbers of some types of professionals in this hospital. Consent forms were signed for participant observation, interviews, and the focus group.
4.5 Recruitment

Recruitment was initiated in this study as I attended multidisciplinary rounds and introduced the study to the hospital staff participating in these rounds. Multidisciplinary rounds are completed on the trauma ward in a large central room twice per week, near the beginning and end of the week. These rounds are attended by nurses, the unit manager, care coordinators, rehabilitation professionals, and various physicians. Rounds are normally one to two hours in duration. Each nurse is assigned three to four patients on the trauma ward. Each nurse enters the room and reviews the salient issues regarding their patients with the remainder of the team.

During rounds, other health professionals addressed pertinent healthcare or discharge issues, including: medical complications, progress in therapy, anticipated admission to inpatient rehabilitation or other facilities such as repatriation hospitals, and issues with discharge destinations or plans. Generally, health professionals reviewed salient issues and developed a treatment plan for the patient to facilitate discharge. Components of these treatment plans included: providing further medical care or follow up, communicating with families, developing team and/or nursing plans to address certain care issues such as toileting, and providing therapy and equipment. I completed field notes during trauma ward rounds, focusing on the language employed, including recurrent words and issues, and identified possible patients for family interviews. I also invited health professionals to participate in periods of observation and interviews.

4.6 Data Collection Methods

Sequence of methods

I started attending multidisciplinary rounds on the trauma ward in March 2016 and attended twice per week until March 2017. From March 2017 to June 2017, I attended multidisciplinary rounds on the trauma ward once per week. I also attended rounds at a nearby unit for one month that would sometimes take additional trauma cases; there were no individuals with sTBI at that time, and I ceased attending this unit soon thereafter. I attended medical rounds on the critical care and intensive care units once weekly from September to December 2016; no interviews were conducted with families while patients were on these units. I
completed a focus group with health professionals on the trauma ward in March 2017. Observation occurred on the trauma ward, and critical care and intensive care units. Interviews with hospital staff were conducted in a private room near the trauma ward and in hospital staff offices. Interviews with family and patients occurred either: (1) in a private room near the trauma ward when the patient was not present; or (2) in the patient’s room with various family members present in the room or with family members taking turns participating in the interview.

I attended multidisciplinary rounds on the trauma ward twice weekly and became acquainted with the health professionals on the trauma ward, introducing the study, and providing information sheets for hospital employees (see Appendix A). I asked health professionals on the trauma ward if I would be able to observe them during their work duties. Many of the health professionals who worked on the trauma ward initially indicated they were too busy for an interview and were too unfamiliar with the study to assist to recruit patients and families. Normally, after I had completed a period of observation with the health professionals, I invited them to participate in an interview; they usually agreed. When I was on the trauma ward at other times, waiting to secure interviews, or to observe health professionals performing their duties, I often waited in the large room where bi-weekly rounds were conducted. This room serves as the computer room for many of the staff accessing patient data systems and completing electronic documentation. Most documentation for health professionals is in electronic format, so various health professionals were seated at numerous computer desks in this room. Many of the health professionals were quite comfortable discussing various issues on the trauma ward in this room as they completed their routine work duties.

As time progressed and I spent more time on the trauma ward, many of the health professionals appeared increasingly interested in participating in the study and expressed interest with recruiting for patient/family interviews. A number of the health professionals on the trauma ward were aware I also worked as an occupational therapist in a different practice context. I frequently reiterated that I had not worked on a neuro trauma unit without clinical expertise in this area. I clarified that periods of observation and interviews were intended to explore their work and the issues encountered by individuals with sTBI in accessing rehabilitation as opposed to engaging in any evaluation of their work duties. Many of the health professionals on the trauma ward agreed to an observation period while they performed their work duties. These work duties were novel to me as I did not have work experience in this area; health professionals
appeared quite engaged in describing specific duties and challenges in their work in ethnomethodological detail (D. E. Smith, 2005).

Approximately one month elapsed between the first period of observation and the first interview with a health professional. Health professionals who volunteered for initial interviews acted as social gatekeepers for other health professionals on the trauma ward, signaling their acceptance of the study (Watts, 2006). I normally observed the health professional performing their work duties and then completed an interview with the individual afterwards. During interviews, I requested these individuals identify other individuals, including patient/family informants and hospital informants to interview through snowball sampling (Noy, 2008). I requested informants to identify pertinent documents in their work and to provide these documents; document collection continued for the remainder of the study (D. E. Smith, 2005). I also completed several interviews with individuals in managerial and administrative positions in the Level I Trauma Centre.

As I started interviewing health professionals on the trauma ward, these health professionals assisted to recruit patients’ families of patients with sTBI, providing them with an information sheet regarding the study (see Appendix B). I was not able to approach patients and families directly due to restrictions through the Research Ethics Board, circumventing direct initial contact between patients/families and researchers. Most health professionals on the trauma ward, including rehabilitation professionals and nurses, became actively involved in recruiting patients and their families into the study. Health professionals on the trauma ward explained the study to these families, frequently referencing my insider position as a former caregiver for an individual with sTBI (Watts, 2006). Identifying my experience from an insider position was an effective technique of recruitment; many families referenced this point as I introduced myself to them and discussed their participation in the study.

If the family was agreeable to participate in the study, I attended the patient’s room to inquire if they would complete an interview. Interviews were completed at that time, or later that day or week, depending on the schedules of the family members attending the hospital. In some instances, interviews were completed weeks or months later if the patient experienced critical medical events on the trauma ward. In these circumstances, these patients were often transferred to the critical care and intensive care units or other units to address urgent medical issues,
including complications requiring surgery or they required intensive medical management. These interviews were completed once the patients’ medical condition stabilized and they returned to the trauma ward. In some instances, interviews occurred quite some time after the initial invitation as the family was still adjusting to the seriousness of injuries to the individual with sTBI; they were not prepared to participate in an interview until a later date.

During patient and family interviews, family members identified the critical care and intensive care units as important sites of investigation, as these sites were initial points of entry into the Level I Trauma Centre. Family members often contrasted the intensity of nursing care on these units and high degree of surveillance with the lower nursing ratios and decreased observation level on the trauma ward. Family members of individuals with sTBI designated critical care and intensive care units as meaningful as (1) these were sites of significant upheaval whereby many urgent medical events occurred; and (2) the close, intense proximity of many physicians, nurses, and other health professionals, which many family members described as reassuring in the initial stages of injury after sTBI.

I completed three months of observation once weekly at medical rounds in the critical care unit and intensive care units. Medical rounds occur on a daily basis on each of these units. The same attending physician is in charge of the medical rounds on both units on any particular day; there are specific rounds for patients with critical neurological injuries. These rounds are normally three to four hours in duration between the two units. As I attended medical rounds, I invited physicians to participate in the study. After I had interviewed a number of health professionals and physicians on all three units, I interviewed more individuals in managerial and administrative roles. I completed a focus group with the health professionals working on the trauma ward three months prior to the conclusion of the study and continued to complete staff and patient/family interviews. I concluded the study with an interview with an individual in an administrative position addressing the intricacies of healthcare funding.

**Participant observation**

One method of data collection in this study included participant observation, foundational to many studies in IE. Diamond (2006) addresses what participant observation offers to IE from a methodological perspective, as it has the “potential to refine our appreciations of at least the following dimensions of the craft: stories, authors, bodies, place, time, motion, how ruling
relations work, and particular ways for seeing the social organization in the local” (p. 58).

Stories that are seen, struggles that occur, and descriptions rendered in IE are deeply rooted in the originally formulated problematic (Diamond, 2006). Diamond’s (1992, 2006) method of observational analysis, drawing on the performance of work tasks, was employed in this study to draw out aspects of the guiding local and translocal influences that shaped work in this context. Diamond suggests that one’s own body is integral to the research process in understanding observed bodies, reflecting upon his own work as a personal care worker in nursing homes:

Its specific aches and pains, its emotions, the messiness of the flesh and blood events—these provide a corporeal, incarnate base with which to ground the author’s and other bodies in action and coordination. In the work reported here, I wrote about the smells that seemed to linger in my consciousness long after shift and shower were over, or of the hunger in the middle of the night experienced by both resident and worker, or the boredom of routines or the challenges of the close-up bodily contact—all provided grist for analysis and for organizational and policy critique (Diamond, 2006, p. 59).

The social organization of rehabilitation work is the main focus of this dissertation; participation observation focused on how people involved in the study do this type of work. D. E. Smith (2005) conceptualized work and work knowledge as something that extends well beyond paid work, and focuses on the individual’s experience of their work, including what they do, how they think and feel about their work, and how their work is coordinated implicitly or explicitly with the work of others. D. E. Smith described work in a generous sense, meaning that it would include “anything done by people that takes time and effort that they mean to do, that is done under definite conditions and with whatever means and tools, and that they may have to think about” (2005, p. 151-152). D. E. Smith (2005) has drawn this notion of work from a feminist perspective highlighting the importance of women’s work, for example, the unpaid work of being a mother or a caregiver. “The concept of work and work knowledge as they are conceived in institutional ethnography orients the researcher to learn from people’s experiences regarding what they actually do, how their work is organized, and how they feel about doing it” (p. 155).

A total of 17 periods of observation with health professionals were completed during this study. Observation periods occurred on the trauma ward with health professionals as they completed their work shift. Periods of observation of health professionals lasted between one and five hours; informants were provided with a consent form to complete prior to participation,
outlining the purpose, risks and benefits of the study (see Appendix C). Periods of observation involved observing health professionals reading paper and computer hospital records, completing computer reports, completing rehabilitation work with patients, and talking to families and other health professionals. These professionals described their main work duties and what their work priorities were on the day of observation. One family member and patient were observed for a period of 90 minutes after signing the consent for observation (see Appendix D), as the family member was not ready for an interview. This family member later decided they did not wish to complete an interview.

**Interviews**

Three pilot interviews were completed prior to the study. I completed two interviews with health professionals who had worked on neuro trauma units, including a physiotherapist and an intensive care nurse. I was also interviewed by a fellow graduate student regarding my experiences as a former caregiver for an individual with sTBI. During this study, I completed 21 interviews with patient/family interviews and 26 hospital informant interviews. Fifteen patient/family interviews occurred in the patients’ rooms and six interviews occurred in private meeting rooms. Family members served as the substitute decision makers for all of these interviews; the patients themselves signed the consent form when they were able to do so. In patient/family member interviews where several family members were interviewed, family members alternated their participation in the interviews as other family members went for a break. Various family members and hospital staff also entered the patient’s room as interviews occurred. Interviews for hospital employees and patients/families were between 20 minutes and 2 hours and 10 minutes in duration. All informants signed a consent form outlining the purpose, risks, and benefits of the study (see Appendix E, F).

Interview questions and probes used during all interviews are listed in the Interview Guide (see Appendix G). Questions and probes varied for the hospital employee informants (hospital medical, nursing and rehabilitation employees, and hospital administrators) and family informants (individuals with sTBI, family members, and friends). Questions for hospital employees targeted their paid work and issues related to the provision of rehabilitation for individuals with sTBI, and issues their families faced. These questions were adapted from Kvale and Brinkmann (2009) and Aronson Fontes (2008). It was reiterated to family members and
caregivers for individuals with sTBI, as stated in the consent form (see Appendix F), their responses would not affect the services for the individual with sTBI. Paterson and Scott-Findlay (2002) cautioned that family members can at times confuse researchers with health professionals and may frame their answers to ensure that they will receive services. Health professionals did not only recruit patients and families with positive experiences of medical care and rehabilitation at the Level I Trauma Centre. These health professionals also recruited family members with concerns regarding the care and rehabilitation provided.

The period when data collection was completed for this study was a particularly intensive time on the trauma ward; data collection started in March 2016. Generally, ‘trauma season’ starts annually on Victoria Day in May and ends on Labour Day in September; this is the most abundant time for traumatic injuries to occur. Many of these injuries are traffic injuries, but recreational accidents and violent assaults are quite common this time of year. The period of data collection marked an intensive trauma season whereby almost one third of the beds on the trauma ward were filled with individuals with sTBI near the end of 2016. Many of these individuals were in lower levels of consciousness, some with quite slow recoveries, and no imminent discharge location.

Several research probes were included in the Interview Guide (Appendix G) for the instances whereby patients were able to actively participate in interviews. Paterson and Scott-Findlay (2002) suggested researchers often do not interview individuals with cognitive impairments due to their communication impairments and ethical issues in obtaining appropriate consent. Paterson and Scott-Findlay (2002) offered salient advice for conducting these types of interviews, including: monitoring an intolerance to stimuli, using simplified questions, and being conscious of image management attempts by individuals with TBI. Three patients with sTBI were better able to address the healthwork they did in recovering from sTBI during the 21 patient/family interviews. This low level of patient participation during interviews was due to the significant severity of their injuries. As many patients with sTBI were either in prolonged lower levels of consciousness; were disoriented, confused, or agitated; or they had mouth/face injuries, many were not able to answer interview questions.

Interviews in IE are intended to discover ‘how things work’, leading to and drawing upon other types of analysis, including document analysis and participant observation (DeVault &
McCoy, 2006). DeVault and McCoy (2006) described the work of sociologist Eric Mykhalovskiy, as he indicated participating in interviews is more than just asking questions and listening for answers:

Describing interviews as a set of questions doesn’t get at the actual work involved. For me, analytic thinking begins in the interview. It’s like an analytic rehearsal. I’m checking my understanding as it develops; I offer it up to the informant for confirmation or correction (p. 23).

As interviews progressed, new interview questions were added to the original interview guide. In interviews with individuals in managerial or administrative positions, which differed from the interviews with frontline health professionals, questions focused on particular policies or documents related to sTBI rehabilitation or those related to trauma care. I prepared for these interviews by researching relevant healthcare policies and funding structures in Ontario. I also met briefly with individuals employed in administrative positions at the trauma centre to discuss relevant documents and policies.

**Focus group**

Near the conclusion of the study in March 2017, I completed a focus group with health professionals on the trauma ward. I conducted this focus group as I sought to generate a variety of perspectives regarding some of the issues I had observed and discussed with various health professionals and patient/family informants over the previous year (Kvale & Brinkmann, 2009). “The aim of the focus group is not to reach consensus about, or solutions to the issues discussed, but to bring forth different viewpoints on an issue” (Kvale & Brinkmann, 2009, p. 150). Focus groups can “provide access to forms of data that are not obtained easily” (Morgan, 1997, p. 8) during participant observation or interviews. In this research study, I wanted to expand on topics discussed in individual interviews with informants and to address issues of relevance in the past year of data collection.

Topics addressed in the focus group were related to events that had occurred in the previous year as I attended biweekly rounds and during formal and informal periods of observation on the trauma units. I frequently observed interactions with the health professionals and the patients and their families as I moved about the trauma ward. The trauma ward becomes a ‘pressure cooker’ at times when there are many seriously injured patients with insufficient
human resources to address the extensive needs of the patients and families. Stressful events occurred that I either witnessed or were discussed afterwards when I was present on the trauma ward. These events included: patient or family outbursts, very tense family meetings, medical complications, deaths of patients, and frustrated families and staff on the trauma ward. The nature of trauma itself, due to the extreme nature of the injuries, generates intense emotional consequences that affect patients, families, and health professionals, all inhabiting the same liminal space.

A focus group was the most appropriate method to discuss some of these issues I had observed in the trauma units. I also sought to explore pertinent topics in more depth, such as challenges in working with individuals with sTBI, who were conceptualized as two different groups—those patients who recover more quickly and others with much slower or very limited recoveries. We also discussed the challenges of the layout of the space on the trauma ward and how the space of the ward could be redesigned. Nine informants attended the group and signed the consent form for this focus group (see Appendix H). Please see Appendix I for the Interview Guide for the Focus Group.

Transcription

All the interviews and the focus group were digitally recorded, and these audio files stored on an encrypted computer. Informants were dissuaded from using specific personal identifiers during interviews and the focus group. Most of the audio recordings were transcribed by professional transcriptionists; I completed the remainder of the transcripts. Audio recordings were assigned a number and no identifying information was provided to the transcriptionists. These transcriptionists signed a confidentially agreement prior to receiving the audio recordings (see Appendix J). Transcriptionists were instructed to eliminate identifying personal information in the transcripts during the transcription process, such as names of individuals or facilities. I listened to all of the audio recordings of the interviews and the focus group after receiving the transcription to remove any remaining personal information and to verify the accuracy of the transcripts.
Examining texts

During the interviews with informants, these individuals identified policies, forms, and applications instrumental in shaping the work they performed in this context. In *Texts, Facts and Femininity*, D. E. Smith (1990) suggested texts are ubiquitous in modern life; we take texts for granted in the same manner that we would the ground that we walk on, as they are so pervasive throughout contemporary society. D. E. Smith (1990) described these texts as an omnipotent presence in our lives, through written or printed text, in addition to various textual forms generated by computers. “Incorporating texts into ethnographic practice is essential to institutional ethnography. It is what enables it to reach beyond the locally observable and discoverable into the translocal social relations and organization that permeate and control the local” (D. E. Smith, 2006, p. 65).

D. E. Smith (2005) emphasized that texts, particularly those in a written format, permeate institutions, generating particular sequences of action, in addition to generalizing and standardizing modes of action. In *Writing the Social*, D. E. Smith (1999) proposed texts coordinate subjectivities into an objectified form of consciousness through their universalizing discourse, repressing the naturally occurring diversity of views, experiences, and perspectives. Rankin and Campbell (2014), who examined how institutional managerial procedures affected nursing practice, extend this notion of the repressing influences of text through computer software technologies, which regulate and organize nursing work in disquieting ways. Nursing managerial software presupposes institutional priorities for nursing care, displacing client-centered interactions between nurses and patients. This software prioritizes admissions, transfers, and discharge—with its institutional allegiance to employing bed maps, figuratively placing ‘three in a bed’ to improve nursing workforce efficiency—rather than patient care (Rankin & Campbell, 2014).

Institutional discourse promoting efficiency over care has also been described in emergency work performed by nurses and paramedics. Corman and Melon (2014) recount how reformed nursing and paramedic work procedures and policies restructure their practice through institutional demands for efficiency, effectiveness and quality of care, sometimes obscuring the actualities and contingencies of practice. Electronic accounts of patients, The Canadian Triage and Acuity Scale (CTAS), provide depictions of the acuity of the individual’s injuries or
illnesses, which are subject to being plotted visually in computer representations in order to find space for and electronically move patients prior to actually doing so.

Daily actualities of textually mediated social relations within hospitals bear particular relevance to this dissertation as this study occurred in a similar context. Computerized textualized relations mapped many patients to the hallways of the trauma ward as the locale of choice for extra patients when the trauma centre was overcapacity. Numerous forms, such as specific brain injury protocols for critical care, various nursing and rehabilitation assessments and forms, and visitor and overnight policies, were collected during this study. Computerized textualized relations of admission forms for local inpatient rehabilitation facilities were collected; their requirements dominated discussion in multidisciplinary rounds. The institutional discourse in these admission forms also swept through all facets of rehabilitation work with individuals with sTBI on the trauma ward. These documents will be addressed in detail in Chapter 6 and Chapter 7.

4.7 Confidentiality

Confidentially was maintained for informants involved in the study through a variety of means. No names of informants were provided to the transcriptionists during the study. Any identifying information was later removed as I reviewed transcripts completed by the transcriptionists. I maintained the anonymity of informants and any information discussed, though I acknowledge that informants may have disclosed their participation to one another and discussed their responses amongst themselves without my knowledge. The digital recordings of the interviews were stored and transferred to transcriptionists through secured websites with only the assigned numbers, not the informants’ names.

I managed maintaining anonymity through a variety of different methods in presenting data in this dissertation for the concealment of the identities of the informants in this study. I used certain terms to define many of the hospital employees in this study. I used the term ‘health professional’ to refer to physicians, nurses, and rehabilitation professionals, signifying these individuals are frontline workers providing direct patient care. I referred to nurses as nurses; there are hundreds of nurses at the research site on the units where I conducted the study. I interviewed a number of physicians in this study and I have purposely not included their specialties throughout the entirety of this dissertation.
In employing quotes and describing instances described by particular rehabilitation professionals, I have employed the term ‘rehabilitation professional’ throughout the dissertation, rather than identify the individual as belonging to a specific profession, such as a physiotherapist. I have used more generic quotes from many of the rehabilitation professionals with ambiguous descriptions of their duties. I interviewed various non-frontline hospital staff such as unit managers or managers in other positions, applied practical nurses, various care coordinators, and financial administrators. I have used the term ‘administrator’ for these individuals to maintain their anonymity. In some instances, these individuals did not have direct caseloads, but they interacted with patients and families through hospital initiatives or their duties necessitated direct patient contact. Direct patient care is not one of their main duties and they perform more communicative functions with patients and families. Some individuals I have referred to as ‘administrators’ have no patient/family contact. Anonymity of the informants has been maintained by replacing the informants’ names with pseudonyms in the transcripts and changing or concealing various personal attributes.

At times I changed the gender of the patient and particular identifying relationships of family informants in the transcripts, given the limited numbers of individuals with sTBI and DOC and the possibility of these individuals being identified through their commentary (Saunders, Kitzinger, & Kitzinger, 2015). In several of the chapters, I have employed vignettes as opposed to using extensive quotes from patients and families as they expressed a desire to keep their personal circumstances private. These vignettes meld together many circumstances of patients and their families into fictionalized characters. These characters also harbor resemblances to individuals in my own personal life. Any future publications with parts of these transcripts will employ similar methods of maintaining anonymity. Only this researcher and one of her thesis supervisors had access to the transcripts. These transcripts were provided to the supervisor in an electronic format after all identifying information had been removed. Electronic transcripts were stored on the encrypted computer of the researcher and her supervisor.

4.8 Avoiding Institutional Capture

D. E. Smith (2005) acknowledged there can be challenges in decoding and uncovering the details of individuals’ daily lives related to the language or lexicon of everyday life. D. E. Smith (2005) explored the challenges of institutional capture, whereby both the informant and
the researcher are familiar with institutional discourse, when the researcher has intimate
knowledge of the topic. When a researcher is working from an insider position, given the
researcher’s inherent familiarity with institutional discourse, they may not recognize that they are
taking for granted meanings and knowledge. In this way, the researcher may not sufficiently
explore these details with research informants: “This is a barrier created by the ways in which
institutional discourse may enter into and, from the point of view of the ethnographer, pervert the
dialogue that produces work knowledge” (D. E. Smith, 2005, p. 155). Throughout my fieldwork,
I was attentive to this institutional capture and employed strategies to circumvent this issue
through extended participation observation, and in requesting familiar and unfamiliar terms be
unpack by informants during observation and interviews.

D. E. Smith (2005) has offered strategies in the interview process for decoding
institutional discourses deployed by research informants. She suggested individuals within a
shared context speak to one another in ‘shells’ or in terms that may not be understood by
individuals outside of this context. For the institutional ethnographer, D. E. Smith has stressed
the importance of uncovering meaning within the social, institutional, and management
discourses in unpacking the shells inherent in institutional language, which can be ambiguous to
the researcher or casual observer:

There is a type of noun that lacks specific content—for example, thing, fact, case, reason,
and so on (Schmid, 2000). Schmid calls them “shells”. They do not stand alone but
remain filled with substance by clauses that usually follow directly or are part of the same
text— “The reason I was late for dinner was that my car ran out of gas” where reason is
the shell term. Linguists in general adhere to the status of the text, and readers are
generally absent in this analysis (D. E. Smith, 2005, p. 112).

During my fieldwork and in interviews, I employed strategies to unpack these shells
inherent in people’s language about their work and work knowledge, as I will discuss in Chapter
5. These shells were evident in the language of the physicians as they discussed terms that I was
unfamiliar with; these terms were an inherent part of their institutional discourse. During
interviews with rehabilitation professionals, it was evident they were talking in shells as they
would deploy terms they assumed I was familiar with. I would request further explanation when
I was unfamiliar with these terms and I would request that they unpack the term through the
particular informants’ understanding of it.
In collecting interview data from informants, I considered how institutional discourse affected individuals’ responses discourse as they talked about their work. D. E. Smith (2005) suggested: “Institutional discourse swallows perspective, the local, the particular, and the subjective experience of workers” (p. 156). D. E. Smith (2005) described the dialogic interactions of people’s doings in coordination with institutional discourses:

So rather than view institutional discourses as prescribing actions, we might see them as providing terms under which what people do becomes institutionally accountable. They are distinctive in that they displace and subdue the presence of agents and subjects other than as institutional categories; they lack perspective; they subsume the particularities of everyday lived experience (p. 113).

D. E. Smith (2005) has drawn from the work of Garfinkel (1967) in rejecting a paradigm that accepts the patterning, typicality, or repetitiveness of social activities that are simply responding to and conforming to social norms or rules. Garfinkel suggested people act in ways that they themselves see as rational or objective in response to the presented environmental conditions (D. E. Smith, 2005). As I discuss in Chapter 6, health professionals on the trauma ward displayed these dialogic interactions with institutional discourses in prescribing which individuals with sTBI were considered suitable inpatient rehabilitation candidates, based on their rates of recovery. Health professionals developed an intensive ideological code of addressing the needs of patients with sTBI with differently paced recoveries. These professionals acknowledged institutional and managerial discourses pushed for the most intensive work with individuals with sTBI with faster recoveries, as they were likely to be admitted to healthcare facilities designated for rehabilitation. I also needed to account for how my own background as an occupational therapist led me to take up institutional discourses during the research process. Incorporating reflexivity strategies allowed me to gain greater understanding of the translocal institutional relations shaping activities in the research context and resist institutional capture.

4.9 Reflexivity

Reflexivity is a qualitative research strategy used to improve the quality of the research through identifying the researcher’s position in relation to the informants and as a method to convey the researcher’s background to the reader (Primeau, 2003). Reflexive thinking allows researchers to turn inward while synthesizing and theorizing data and to consider, as part of critical analysis, how our personal, political and academic lives shape our position in relation to
our informants (Doucet, 2008; Edwards & Ribbens, 1998). An extensive typology of reflexivity exists in qualitative research, with reflexivity being described as embodied, narcissistic, endogenous, referential, indexical, constitutive, and even epistemic (Maton, 2003; Kinsella & Whiteford, 2009; Pagis, 2009). England (1994) advocated for the incorporation of reflexivity as an integral part of fieldwork, discounting claims that this methodological approach consists of salacious indiscretions or mere navel gazing. She described reflexivity as “self-critical sympathetic introspection and the self-conscious analytical scrutiny of the self as researcher dismissing more neopositivist notions of researcher distance and impartiality” (England, 1994, p. 244).

Reflexivity is integral to IE given the characteristically reflexive musings of D. E. Smith (1990, 2005), and “lies at the heart of feminist research” (Edwards & Ribbens, 1998, p. 3). Reflexivity surfaces throughout D. E. Smith’s writings, which transport readers into her everyday doings at the moment she is producing her own written text. She has written about the experience of waiting in line, attending a conference, correcting papers, and even connects readers to her travels from Fredericton, New Brunswick, Canada to Eugene, Oregon (D. E. Smith, 1999). D. E. Smith has intentionally connected readers with her activities and her interactions with others as she has written about her own life as a single mother and an academic, and in her discussions with Alison Griffith regarding the mothering discourse (Griffith & Smith, 2005). She has referenced her own activities and her reflections on these happenings to explain certain methodological and theoretical aspects of IE in conveying a particular concept or idea central to her ‘sociology for people.’

Highlighting reflexive contributions to our research, Doucet (2008) has suggested we consider our own personal or political motivations in conducting research and that we practice sensitivity to our own hidden motives. Doucet (2008) has suggested the importance of incorporating relational knowing into the reflexive research process to detail how our own interpretations and experiences nuance our research analysis. Doucet has drawn on the work of Clive Seale, who has linked the use of reflexivity as means of creating an audit trail of “underlying epistemological assumptions and methodological procedures” (Doucet, 2008, p. 83-84) as a part of the research process. In Chapter 8, I consider my own experiences as a former caregiver of an individual with sTBI and my work experience as an occupational therapist, which shaped this analysis.
Doucet (2008) has described reflexivity as three gossamer walls researchers employ to construct knowledge based on: (1) relationships with oneself (and the ghosts that haunt us); (2) relationships with the research participants; and (3) relationships with readers, audiences and epistemological communities. In the first gossamer wall, Doucet (2008) suggested the ghosts of our own past and experiences, such as childhood memories or figures from our past, work their way ever so subtly into our written research. Doucet (2008) suggested developing an awareness of these ghosts within ourselves in our research analysis. The second gossamer wall exists between the informants and the researcher. Doucet (2008) suggested employing a method of analysis such as the Listening Guide to assist in data analysis; a strategy I have used in this dissertation. The Listening Guide is a feminist approach that uses multiple, structured, and in-depth readings of the transcripts to listen to what the participants are saying through directed readings, rather than pre-determined categories and concepts (Brown & Gillian, 1992; Doucet, 2008; Gilligan et al., 2003). The third gossamer wall exists between researchers and their audiences, and considers how our research may be taken up within epistemic and theoretical communities. How research is taken up can be to the surprise of the researcher, as Doucet discovered following dissemination of her own research, which asks: Do men mother? (Doucet, 2006).

Engaging in reflexive practice allows us as researchers to consider how our own beliefs, prior knowledge, and assumptions contribute to formulation of the final research study. D. E. Smith suggested that the researchers’ original concerns need to be “transcended or set aside in formulating the research problematic. Institutional ethnography is essentially a work of inquiry and discovery; it must move beyond what the ethnographer already knows or thinks she or he knows” (Smith, 2005, p. 207). G. W. Smith (1990) expands upon the generation of empirical IE research through the process of bracketing, a term usually applied in phenomological research. G. W. Smith suggested his own prior research in IE had involved “the necessity of bracketing ordinary political explanations – the technique of the materialist epoché, as I call it – in order to provide a scientific account of the social organization of a ruling régime” (G. W. Smith, 1990, p. 630).

I needed to bracket knowledge from my own insider position as a prior caregiver in formulating the problematic of the study. I had been a caregiver for someone with sTBI who improved quickly and attended inpatient rehabilitation. I was able to expand the focus of the
study beyond this prior knowledge to identify important institutional relations in the Level I Trauma Centre through the bracketing of this prior knowledge, with prolonged engagement in the field, and in using extensive methods of data collection. These ruling relations marginalized individuals with sTBI who were recovering slowly as these individuals had restricted access to rehabilitation. My prior caregiver insider position would have occluded my view to these important findings. One of my co-supervisors read the transcripts and the other co-supervisor was instrumental in focusing the analysis using fundamental tenets of IE.

4.10 Strategies for Data Analysis

Data analysis in this research project was informed through a variety of analytic methods. I considered analytic discussion regarding institutional ethnography (IE) by Campbell and Gregor (2002), analytic strategies described by D. E. Smith (2005) in reviewing texts, strategies used by Bisaillon (2012, 2013) in conceptualizing data collection and analysis as a fluid process, and use of the Listening Guide for structured readings of the transcripts (Brown & Gillian, 1992; Doucet, 2008; Gilligan et al., 2003; Walby, 2013). In addressing data analysis in IE, Campbell and Gregor (2002) stressed that analyzing social relations to explicate social organization is at the heart of this type of research. Rather than using anthropological techniques focusing on description (Fetterman, 1989) or grounded theory to generate factual accounts as informants understand them, IE seeks to analyze how individuals’ activities locally are tied to the extralocal (Campbell & Gregor, 2002). As the end product of the analysis is different, the process of analysis differs from other research methods by honoring materialist, empirical, and reflexive ontological commitments of IE (Campbell & Gregor, 2002). Institutional ethnographers readily concede that individuals, in talking about their daily life and their activities, are not likely to recognize or describe the inner workings of social organization; thus analytic responsibility remains with the researcher (Campbell & Gregor, 2002).

Strategies from Bisaillon

Bisaillon (2012, 2013) has offered tangible strategies in data analysis, which I employed both in the process of data collection and analysis. Bisaillon (2013) has differentiated ‘indexing’ from ‘theming’ in institutional ethnography (IE), which are both activities used by social scientists in organizing data. Theming presupposes that data has been identified as
interpretations of dominant or recurring themes (Bisaillon, 2013). Indexing reflects the ontological commitments of IE, in that “data are materially occurring happenings” (Bisaillon, 2013, p. 2); activities occurring in the material conditions of people’s lives, rather interpretations of data by the researcher.

Bisaillon’s doctoral dissertation explicated the social relations of mandatory HIV testing of immigrants in Canada using three phrases of data analysis. Bisaillon (2012) described data analysis as an intertwined and iterative process, including reading data, marking data, and writing about data. Bisaillon (2012) has recommended data analysis techniques previously described by D. E. Smith (2005) in successive re-readings of the data, with a focus on analyzing what is occurring in the described settings and presenting tangible arguments of these happenings. Bisaillon (2012) suggested this earlier phase of data analysis involves “identifying and examining taken-for-granted practices; considering contradictions or tensions these posed for the informants; and identifying clues about the social organization of these contradictions” (p. 141).

Bisaillon (2013) described the approach she used in the completion of her doctoral dissertation during data analysis, after performing successive readings of the transcripts and field notes; a fundamental part of data analysis in IE. She colour-coded this textual data according to five categories: work, talk, text, people, and institutions. She also placed dialogue boxes in the margins of these field notes and transcripts and then created five Word files with the five categories and then sub-files, based on topics emerging from the descriptions by the informants of the material conditions of their lives (Bisaillon, 2013). Colour-coded descriptions in the transcripts were copied and pasted into the file, and sub-files were created in the course of data analysis (Bisaillon, 2013).

Bisaillon (2012) indicated informants described problems during their day-to-day activities related to HIV testing upon entering Canada. Bisaillon used clues to connect these activities to social processes, including drawing on the coordination of people’s activities through text, specifically medical eligibility forms. This process of analysis allowed Bisaillon (2012) to conceptualize the larger puzzle that these individuals’ activities were tied into. The use of analytic mapping from a visuospatial as opposed to linguistic perspective, as in memo writing, allowed Bisaillon (2012) to see these connections in a different way. Bisaillon (2012) used these
techniques to create a historical and successive mapping of the activities of immigrants as they proceeded through the process of HIV testing in Canada. Bisaillon (2012) used a number of analytic strategies to chart important social relations, including category (talk, text, people, institutions, and work) files and topic files for informants’ statements, in addition to recognizing pivotal institutions coordinating forces in people’s talk.

Campbell and Gregor (2002) dissuaded researchers from using computer programs designed to manage data in IE through categorization, as these programs obscure the meaning of the data; “the meaning of the data is in their setting of use as they arise there” (p. 208). Given the popularity of computer programs such as NVivo and post-positivist notions associated with their use, due consideration is warranted in reference to their use. Bisaillon’s (2012, 2013) use of the computer is a more flexible, iterative process through the organizing properties of similar contextualized data located in one place. Having access to the computer search functions is a pragmatic, useful solution to the management of textual data. These were strategies I employed during data analysis, as I will expand upon later in this chapter.

The Listening Guide

Walby (2013) considered data analysis in institutional ethnography (IE), drawing upon two established forms of data analysis from the social sciences, including the Listening Guide (voice-centred relational method) (Doucet & Mauthner, 2008, Gilligan et al., 2003) and interpretative phenomenological analysis (IPA) (Brocki & Wearden, 2006). IPA seeks to undercover “the process through which participants made sense of their own experiences, by looking at the respondents’ accounts of the processes they have been through and seeking to utilize an assumed existing universal inclination towards self-reflection” (Brocki & Wearden, 2006, p. 88). The Listening Guide “highlights the importance of narrative in constructing the self and how the narrated self is shaped by social and cultural forces” (Walby, 2013, p. 142) while IPA “focuses on stories that people tell about themselves” (Walby, 2013, p. 142). Walby (2013) has drawn out the main theoretical differences between the two approaches, noting theoretical and ontological coherence with IE. Walby (2013) claimed IPA is situated at the individual level, lacking the capacity to extend to the level of the analysis of organizations or institutions to reflect socially organized knowledges.
Doucet and Mauthner (2008) and Gilligan et al. (1992) have discussed the use of the Listening Guide in doing data analysis to understand the narrated self in relation to others across ontological, epistemological, methodological, and theoretical dimensions. In this method, it is assumed that as people narrate themselves, their stories are expressed in relation to more pervasive cultural and social contexts (Doucet & Mauthner, 2008). This technique specifically addresses the analysis of research transcripts as opposed to other types of textual data, such as field notes or documents (Doucet & Mauthner, 2008).

The Listening Guide employs a four-step process in analysis through successive readings of the transcripts. The first step in these readings includes an initial reflexive reading of the narratives, tracing for central storylines, plots, and characters, in addition to identifying the researcher’s reaction to the plot (Doucet & Mauthner, 2008; Gilligan et al., 2003). The second step involves tracing narrated subjects, specifically attending to how the individual speaks about themselves within the parameters of the social world (Doucet & Mauthner, 2008; Gilligan et al., 2003). This step involves reading for ‘I poems’, in listening to the manner in which individuals talk about themselves (Gilligan et al., 2003). This reading can also involve identifying places whereby the informant shifts between the pronouns of ‘I’, ‘we’ or ‘it’. These shifts can indicate when informants see and present themselves with varied perceptions and how they fit into a given narrative (Doucet & Mauthner, 2008).

In the third step of these readings, the researcher reads for close relations and social networks, adhering to feminist critiques of individual agency versus how people are relational (Doucet & Mauthner, 2008; Gilligan et al., 2003). In these readings, the researcher looks for instances whereby the informant talks with contrapuntal or opposing voices (Doucet & Mauthner, 2008; Gilligan et al., 2003). Informants may make comments that coincide with their previous talk or voices per se and then proceed to talk in opposing voices to prior discourse (Gilligan et al., 2003). In the fourth reading, the researcher focuses on identifying dominant ideologies and discourses, and overarching power relations, linking these micro level narratives to macro level structures and processes (Doucet & Mauthner, 2008; Gilligan et al., 2003).

Data analysis process

Critique exists within the institutional ethnography (IE) literature regarding the process of data analysis, as many studies do not explicitly identify how researchers arrived at their
conclusions (Walby, 2007). I will reflect on the process of analysis using both the Listening Guide and strategies from Bisaillon (2012, 2013) during data analysis. Prior to fieldwork at the research site, I completed three pilot interviews while completing an IE course with Mykhalovskiy. Two interviews were completed with health professionals who had experience working in a Level I Trauma Centre. The third interview was completed by another student with myself, addressing the work I performed as a caregiver to a friend with sTBI. I have included a detailed analysis of pilot interviews in Appendix K to add transparency to my analysis. Ethics approval was received through the Research Ethics Boards at York University and the University of Toronto for the completion of these pilot interviews.

I performed 47 interviews and three pilot interviews during fieldwork for this study, in addition to completing one year and three months of observation. I also collected numerous documents at the research site. Initial overall analysis of data incorporated techniques from Bisaillon (2012, 2013) for organizing data into topics relevant to IE, specifically: work, people, talk, institutions, and text. Analysis was completed using these topics to organize the information collected during fieldwork. I then used the Listening Guide (Doucet & Mauthner, 2008; Gilligan, 2003) for a deeper and more structured analysis of the interview transcripts. I have expanded upon the use of the Listening Guide (Doucet & Mauthner, 2008; Gilligan, 2003) in the pilot interviews of an intensive care nurse in Appendix K. It should be noted that Bisaillon’s techniques apply to all types of data, while the Listening Guide applies specifically to the analysis of transcripts.

4.11 Chapter Summary

In this chapter, I have addressed the use of social relations as a methodological injunction; social relations are what are used to look for social organization. In this dissertation, by looking at social relations, I was able to explicate the social organization of rehabilitation for individuals with sTBI in a trauma centre. The focus of this dissertation included rehabilitation work performed in a trauma centre for individuals with sTBI, looking at both paid and unpaid work with these individuals to promote rehabilitation. I referenced the influence of institutional capture in the research process, delineating the importance of unpacking shells (Smith, 2005) during ethnographic fieldwork, in defining terms specific to the lexicon of research site.
I have described the setting, ethics approval process, recruitment procedures, and how confidentiality was maintained. I have also described the methods of this study, which included observation, interviews, a focus group, and documentary analysis. I have chosen a reflexive stance in this dissertation as suggested by Doucet (2008), who described three gossamer walls in the research process, involving reflecting on personal experiences, the experiences of the participants, and the audience at large. Doucet’s (2008) conceptualization of reflexivity coincided with her use of the Listening Guide (Doucet, 2008). I have expanded on these reflexive strategies in reviewing the findings of this study in Chapter 8. In terms of data analysis techniques, I incorporate analytic strategies from both Bisaillon (2012, 2013) and the Listening Guide (Doucet & Mauthner, 2008; Gilligan, 2003). I have analyzed portions of interviews that I collected during coursework with these two methods of analysis in Appendix K.
Chapter 5

The Brain is Hidden from View

5.1 Chapter Outline

In this chapter, I argue that it is the complexity of sTBI itself that complicates early brain injury rehabilitation for these individuals in a Level I Trauma Centre. From the very beginning, as individuals with sTBI enter the liminal spaces of the trauma centre, the outcome—if they will live or die, or what quality of life they will have—is unknown. Acute care trauma work starts in the emergency trauma room of hospitals, and continues in the critical and intensive care units, focusing on life-saving procedures and life sustaining medical interventions. Some individuals with sTBI will die, others recover to variable degrees, and the remainder will spend the rest of their lives receiving extensive medical and nursing care due to severity of their injuries. I also argue in this chapter that the brain can be hidden from view for physicians, despite access to advanced technology; this medical discourse hooks families into the enigma of sTBI. The hidden nature of the brain shapes the work of physicians, other health professionals, and the work of families of individuals with sTBI from the initial stages of entry into the liminal spaces of the trauma centre.

As I interviewed families of individuals with sTBI, their narratives frequently returned to the initial days, weeks, or months spent in critical and intensive care units, recalling the shock and the uncertainty of this time. Families described intense emotional experiences in these units, as the extensiveness of the damage to the brain and body of their loved one revealed itself. Their narratives prompted me to follow medical rounds in the critical care and intensive care units for three months with the physicians. These physicians were often trauma surgeons and intensivists, specialized in intensive care medicine; medical residents and students also attended these rounds. During rounds, I listened as medical residents and physicians summarized the circumstances that led to the initial injury, what they knew to date about the medical status of these patients, and medical intervention plans.

The medical discourse of physicians during rounds often focused on when to increase or decrease sedation administered after sTBI as a part of the TBI Protocol, an internationally recognized series of emergent medical procedures. They hypothesized about other substances
that the person may have ingested, such as drugs or alcohol just prior to the injury; their medical work took into account the effects of these other substances with the medications they administered. While the physicians had access to extensive medical imaging, including X-rays, CT scans, MRIs, EEGs, and even Intracranial Pressure Monitors (ICP monitors) inserted into the brain to monitor internal cerebral pressure, they could not always predict the outcome as they reduced sedation. As I will discuss in this chapter, physicians also indicated that important aspects of their work with individuals with sTBI included managing medical complications after brain injury and communicating with the families of the individual with sTBI.

I have included a vignette about Hailey in this chapter, who was introduced in Chapter 1, to describe the integrated sequence of trauma work in the initial stages after injury. This vignette starts as an ambulance with Hailey is headed towards a major trauma centre, highlighting how trauma work is coordinated by different individuals at many sites, both locally and translocally. Paramedics contact the receiving trauma centre ahead of time to ensure adequate preparation for their arrival. Trauma surgeons contact other vital healthcare services within the hospital to ensure emergent medical needs are met. The intense coordination of this trauma work by the trauma team reflects the medical directive in trauma centres to save lives, but what happens afterwards can be a mystery.

I have chosen to abide by the ethnographic tradition of storytelling through vignettes (Diamond, 1992, 2006) to describe many experiences conveyed to me during fieldwork by patients, families, and health professionals, rather than use extensive quotes from patient/family interviews. Many families wished to remain anonymous as the details of the accidents, assaults, and suicide attempts were intensely personal. Hailey and her family, as described in the vignettes in this dissertation, are not any particular individuals or families I observed during my fieldwork; all of the characters are fictionalized. These vignettes include stories and reflections of patients, family members, and health professionals recounted and observed during fieldwork. These fictionalized accounts were also drawn from observation field notes during trauma ward multi-disciplinary rounds and medical rounds in the critical care and intensive care units.

This vignette starts at the end of the first vignette in Chapter 1. Hailey’s twin sister Shailene called 911 after a horseback riding accident; an ambulance is speeding to the riding stables to prepare and transport Hailey to the nearest trauma centre. Hailey was fortunate as her
riding stables were located very close to a world-class trauma centre. Mere minutes can mean the difference between life and death immediately following sTBI. The coordination of hospital trauma work starts from the scene of the accident. I will recount the experiences of Hailey, her twin sister Shailene, her brother Parker, and her parents in the very initial stages of the trauma, from the scene of the accident and the trauma room, to the critical care unit, where the most intensive care in the hospital is provided. Many families told me stories much like this one—memories of trauma etched irrevocably into their minds that they were unlikely to forget.

5.2 Hailey’s Arrival at the Level I Trauma Centre

Advanced practice lead paramedic Jim Keenan radioed the Level I Trauma Centre from the ambulance as they approached the riding stables. “Dr. Willow, it sounds like it’s a really bad head trauma, bleeding extensively from the left side and back of the head. I’d say a GCS of 3 from the sister’s description—no verbal response, no eye movement, and most importantly, no motor movement at all. We should be at the trauma room in less than 10 minutes.” Dr. Willow, one of the trauma team leaders for the past decade, knew just what to do. “Page the neurosurgeon on call, Dr. Watson, who isn’t supposed to be in surgery.” Dr. Willow picked up the line for diagnostic imaging. “Make sure the CT scan is ready to roll; we have a young woman coming in momentarily with a major head trauma. We need to know what we’re dealing with ASAP.”

Dr. Willow gathered her trauma team together: another experienced trauma surgeon, the anesthesiologist, three general surgery residents, one orthopedic surgery resident, two trauma nurses, and two respiratory therapists—an impressive team of 10 people. Dr. Willow briefed her trauma team with all the details that she knew so far. The trauma team gathered their equipment and readied themselves. Depending on how bad the trauma was, they may only have a few minutes to save the patient’s life. In the worst-case scenario, as happens approximately half the time after serious traumatic injuries, it will be too late already.

The paramedics raced into the trauma room with Hailey strapped onto a stretcher. The paramedics had bandaged her head in the ambulance; the blood soaked the winter white bandages in a vermilion shade of red. Shailene ran in behind the stretcher but was deftly caught by one of the trauma nurses. “Hey girl” the trauma nurse crooned softly after having seen many devastating head traumas and distraught family members, “you come with me to the waiting
room, it’s just around the corner. Are your parents on the way?” Their voices faded as they walked quickly away from the trauma room with Shailene crying softly, trying to explain what happened.

The doctors, medical residents, nurses, and respiratory therapists in the trauma team worked quickly and steadily on Hailey, hooking up blood pressure machines and an IV, pumping saline and blood pressure medications into her body. They worked together seamlessly in this coordinated ballet they had danced together many times. “Prep her for the CT scan,” called Dr. Willow, “We need to get her up there right now.” “Yes doctor,” replied the medical resident, “someone is just coming out of the CT scan this very minute. Let’s go!” Hailey was rushed off to the CT scan at lightning speed as the trauma team leader had all of her ducks in a row.

As Hailey slid under the iridescent lights of the rounded CT scan, the radiologist riled off the extensive list of brain injuries “Left parietal intracranial hemorrhage, left frontal and temporal subdural hemorrhage, rear left basal skull fracture and growing left cerebral artery dissection through the midbrain.” Dr. Willow, rapidly banged in the number for the neurosurgeon on call. “We have an active bleeder; we need you right now or we might lose her.” The neurosurgeon would head to the operating room to complete the craniotomy and surgical resection of Hailey’s damaged brain and arterial injuries.

The next day, Shailene sat on the edge of the hospital bed beside Hailey, staring in fear and horror at her twin sister. Usually mirror images of one another, the sisters bore little resemblance to one another on this day. Hailey’s head was swollen to three times its normal size. There was extensive dark red and purple bruising under her eyes and across her cheeks and a massive clean white bandage around her head. If Shailene did not know this was her sister, she was not sure if she would have recognized her, save for the blonde, wavy hair peeking out on one side. Hailey’s shoulder-length, thick wavy hair had been shaved off on the entire left side of her head in order to perform extensive neurosurgery the previous day.

An Intracranial Monitor, otherwise known as an ICP monitor, bobbed out of the visible right side of her head, in her long blonde hair, like a wayward fishing hook and fishing line. She was hooked up to a series of machines for blood pressure, blood gases, heart rate, and oxygen saturation; all of these machines beeped at an alarmingly regular rate, filling Shailene with rising panic each time as another set of beeping began. An IV snaked out of Hailey’s left
foreground; its long, thin, translucent tube carried saline, medicine, and other nutrients to her body from yet another machine next to her bed. A ventilator exited out through her mouth, allowing her to breathe; this machine kept her alive. The rhythmic rustling of air in and out of this machine beat slowly like an air drum, prophetically announcing the liminal, transitional quality of this space.

An NG tube coiled around Hailey’s head and into her nose to provide her with nutrition, as she could not eat. A Foley catheter, collecting her urine, appeared from beneath the bedsheets and was attached to a bag on yet another medical pole. She was not conscious; her only visible corporal sign of life included the slow rising and falling of her chest, wrapped in a light blue hospital gown. Her other sign of life, technological in nature, was evidenced by the blood pressure machine, which displayed her heart rate, systolic and diastolic blood pressure, and oxygen saturation. This machine, mercifully, was not in a state of alarm.

Shailene had just left the critical care unit waiting room, a large open room above the hospital’s very noisy cafeteria. There were no other rooms for families to wait in or rest near the critical care unit. Shailene had been up since the wee hours of the morning, catching a few minutes of broken sleep in the 70s-style plastic lime green chairs and recliners in the waiting room. All the while, the hospital staff wandered into and out of the cafeteria below, chatting nonchalantly, all night long. Her parents had left for one of the many restaurants in the large labyrinth of the trauma centre, in search of coffee and to talk privately.

The girls’ 20-year-old brother Parker sat in the plastic Geri chair beside Hailey’s bed. Shailene and Parker were dazed as they looked around the panoptical critical care unit, with its many beds in open spaces and one complete wall of glassed-in rooms. Hailey’s bed was in the middle of the enormous open room with no walls; there were only curtains to shield the bed and its patient from view. A nurse sat at a desk at the end of the bed and jumped up frequently to turn off the machines attached to Hailey—one round of beeping would stop briefly and then another would start. Shailene nodded at the nurse and whispered that the siblings needed a minute alone. Shailene pulled the curtain around Hailey’s bed so that the three siblings could have some privacy in this new, foreign, and very frightening liminal space. Parker and Shailene could hear the doctors, medical residents, health professionals, and nurses gathering noisily at the nurse’s station just in front of Hailey’s bed. The doctors, medical residents, and other health
professionals were preparing for the daily morning rounds, amicably discussing the remainder of their Thanksgiving holiday weekend plans.

Hidden behind the curtain around Hailey’s bed, Shailene crawled into the single automated hospital bed with her twin sister, as she had many times since their childhood. They had been in the habit of sharing their super single beds, growing up on a farm in southwestern Ontario. It was their solution to the frigid temperatures in their childhood home, dovetailing with their parents’ plaintive complaints about the high Hydro bills for their hobby farm. Shailene sighed heavily as the machines beeped noisily around them, but her sister Hailey said nothing and did not stir. Parker, home for Thanksgiving weekend from university, looked at his sisters jammed together in the narrow hospital bed and did his best not to cry.

Shailene and Parker stared at one another as they heard the physicians and medical residents at one of the other hospital beds nearby, talking about the patient. Shailene and Parker were dead silent, listening when they knew that they should not be. They wanted to prepare themselves for what they would possibly hear soon from the physicians in this scary new medical landscape. The resident in charge at the other patient’s bed briskly listed off this patient’s extensive injuries, finishing in saying that the patient was brain dead. They were waiting for the patient’s family to arrive to deliver the news. They would see if the family wanted to speak to the organ donation coordinator afterwards. The attending physician explained to the medical residents that they would do their best to keep the patient comfortable as they waited for the family to arrive. Comfort and quality of life would come first, and any discussion of organ donation would come later.

Shailene, exhausted and distraught after yesterday’s tragic events and in having almost no sleep in the waiting room, looked plaintively at her brother Parker. She huddled closer to her twin sister’s muscular yet lifeless body. Shailene’s eyes filled with tears, which overflowed across her bottom eyelids, and finally spilled down her pale cheeks in torrents. She started to sob noiselessly, not wanting the doctors and medical residents so close by to hear her. Sobs racked Shailene’s thin frame in a silent, almost cyclical rhythm. They had no idea what was coming and what the physicians would say during rounds when they arrived to discuss Hailey’s case. Parker was almost completely at a loss. Big brothers, even 20-year-old ones, are not equipped for this.
Finally, Parker said: “Hey, the social worker who was here earlier this morning said we should squeeze her hand, talk to her, tell her where she is, and tell her what happened to her. The social worker said that we should do the things that make her feel comfortable, do the things that she is used to, as much as we can. The social worker said people that are like this, with head injuries, might like to hear music,” he hastened to add. Parker flipped through the playlist on his Samsung 7, trying desperately to think of something that would distract terrified Shailene and possibly revive his silent sister Hailey. Their parents, Alton and Isabelle, Generation Xers who grew up going to concerts in Canada’s music scene in their late teens and early 20s, were huge Canadian music fans. *They* had been playing the Tragically Hip constantly in the household since Gord Downie’s diagnosis of terminal brain cancer. *Parker* settled on one of Hailey’s favourite tunes, and clicked play, hoping for the best:

- Sun down in the Paris of the prairies
- Wheat kings have all their treasures buried
- All you hear are the rusty breezes
- Pushing around the weather vane Jesus

### 5.3 Early Trauma Work Saves Lives after sTBI

In order to understand the work performed by physicians and other health professionals when patients with sTBI such as Hailey arrive at a Level I Trauma Centre, I interviewed physicians and other health professionals about this work. During these interviews, I needed to discern between institutional discourse, organizational accounts, and the actual work duties of physicians, as terms they used or the manner in which they used them, were unclear to me. D. E. Smith (2005) highlighted the importance of unpacking the content of ‘shells’—nouns that lack specific content and are descriptively empty. D. E. Smith (2005) laced together shells, or words without a clear meaning, and institutional capture, whereby the researcher and the speaker understand the same terms through familiarity with the same context—both leaving inadequate detail in research transcripts. D. E. Smith (2005) warned that organizational accounts and institutional discourse can easily fill transcripts but leave the ethnographer with little concrete description of the person’s work.

Understanding the daily work of the physicians involved moving beyond taken-for granted understandings we shared, as I also work in healthcare. Physicians’ narratives aligned
with the institutional discourse of ‘prevention is the best medicine’, such as avoiding drinking and driving and the use of seatbelts. Dr. Sorensen described the ideal treatment: “Well, the ideal treatment is prevention. But once it happens, you can’t take it back.” In re-reading their transcripts, I recognized the dual nature of the word ‘prevention’, which meant both preventing injury by avoiding dangerous activities and also preventing further damage to the brain by ensuring adequate blood supply through targeted medical intervention. Their work duties as physicians—what went well, what did not go well, and what their work looked like—were the accounts I sought to uncover.

I asked the physicians to unpack terms or experiences I did not know or understand; other times they quickly understood what was unfamiliar to me. One vital term I did not understand was the ‘trauma room’; one physician unpacked this shell for me. The trauma room is near the Emergency Department but is not somewhere we normally see in attending a hospital, unless someone we know is involved in a major trauma. This is a liminal space where I have never been, nor did I visit this space during ethnographic fieldwork. The trauma room is crucial for individuals with sTBI arriving to hospital for urgent care, as it is where the trauma team performs critical and emergent life-saving work. One physician, Dr. Pascale, described this crucial work in the trauma room:

Dr. Pascale: It’s part of the emergency department. It’s just for trauma patients. When there’s an accident, let’s say the patient is shot in the head, that patient doesn’t go to the emergency department. He goes straight to the trauma room because it’s a trauma patient. It’s different. If you have appendicitis, you’re having abdominal pain, and you go to the regular emerg, and the emerg physician examines you. The trauma patients go to the trauma room in a Level I Trauma Centre. This is a Level I Trauma Centre. There’s an entire team that goes in the trauma room to assess and manage the patient. The trauma team leader is the boss that coordinates the team. You’re going to have probably 9 or 10 people. You have the anesthesiologist who’s going to take care of the airway of the patient. You’re going to have a couple of general surgery residents. They’re going to do some procedures if it’s needed. You have the orthopedic surgery resident. You have the respiratory therapist, the RTs. You have two nurses. What else? That’s it. And the TTL (Trauma Team Leader) is the one who coordinates. Because if the patient is dying, you have priorities. For example, if the patient has a severe TBI and is not breathing, if you do not give patent airways, a way for the patient to breathe, they’re going to die in minutes. It has to be quick. The TTL is going to say, “Well, I need you to intubate the patient right now” to the anesthesiologist.

As described above and in the vignette at the beginning of this chapter, physicians need to act very quickly to save a life after sTBI. Physicians examine various integral aspects of
human functioning like blood pressure, using them as landmarks on the road map of saving a human life. They easily recite the complex facets of trauma work in a trauma centre; well-worn work patterns, like Hebb’s synapses—the reinforced synaptic connections in the brain (Ledoux, 1996). Another physician, Dr. Reed, highlighted the significance of monitoring blood pressure, as low pressure can signify different critical conditions in the investigative work of the trauma team:

Dr. Reed: With blood pressure, there are different types of problems. In trauma, low blood pressure ultimately means bleeding. Someone is bleeding, so you can give fluid. And the fluid can be crystalloid, normal saline, or there’s lactate, and it also can be blood, and blood transfusions. Those are the main ways that you resuscitate. But 10% of the patients have different kinds of shock. When I say shock, I mean the low blood pressure. This might be related to a spinal cord injury. It might be because of a severe traumatic brain injury that’s in a very, very advanced stage, and is compressing the brain stem. And they do have blood pressure changes because of the central nervous system, not because of blood loss. In this case, like you use pressors, vasoressors keep the blood pressure up. The same medication that people use in the ICU. And of course, there are the cases of shock in trauma that are related to sepsis when someone takes a long time to get to the hospital. There is a bowel injury, for example, and the blood pressure is low because of the infection. Not because of bleeding, not because of spinal cord injury, not because of traumatic brain injury, but because of infection. That’s it very briefly.

Another physician, Dr. Sorensen described the priorities of the trauma team as revolving around assessing the status of the brain and avoiding further cerebral injury. Blood pressure and blood flow are telltale indicators of what to do next in trauma work. Keeping blood pressure down and maintaining adequate blood flow prevents further injury to the brain after sTBI; this trauma work was described as a main priority with individuals with sTBI. The trauma team seeks to provide the brain with an ideal, balanced environment after the initial trauma of the injury; finding this balance is monumental to survival and future functioning. Dr. Sorensen described this priority in preventing secondary injury to the brain as a unified goal of the work of the trauma team immediately after sTBI:

Dr. Sorensen: What we do, the ICU does, the emerg docs do, the trauma team does, is to try to prevent a secondary injury. That could be because of increased pressure, that could be because of lack of blood flow, because of low blood pressure, and that can be because of many reasons. The only thing we do to actually help is to try to keep these people stable and try to prevent the brain from injuring again a second time. That’s why we struggle to control the pressure in the head and keep the profusion to the brain.

Lynn: And keep the swelling down?
Dr. Sorensen: Yes, keep the swelling down. It’s all geared towards keeping the brain happy with the amount of blood that’s in there—not too much, not too little—to prevent a secondary injury.

The trauma team works within the known parameters of brain functioning, using a TBI Protocol in the critical care unit, drawn from international guidelines for trauma care. This evidence-based knowledge applied by the trauma team involves giving sedation after sTBI to stabilize blood pressure and various insults to the brain, like internal bleeding. Dr. Pascale describes how a physician’s work knowledge is complex in trauma care and incorporates knowledge of these various physiological aspects of brain functioning. Dr. Pascale addressed the complexity of the brain itself and how little is known about the brain in modern medicine:

Dr. Pascale: When the patient has a brain injury, let’s say the patient is too agitated, he’s releasing lots of adrenaline. Adrenaline is good for your body. But when the patient has a brain injury: it’s a huge topic and we know 10% of it. But what we know is that when the patient is agitated, the blood pressure keeps oscillating, and the oxygenation is oscillating, the rationale is to give sedation to make things become more stable.

Lynn: For their respiration?

Dr. Pascale: Yes. If you’re too agitated and you’re breathing fast, you’re going to alter your oxygenation. If you’re too agitated and you have lots of adrenaline, your blood pressure goes up. You don’t want high blood pressure in a patient who has a bleed in the head.

Working in a trauma centre in the critical care of patients means that seeing individuals with devastating sTBI is commonplace. Dr. Sorensen described physicians’ work in a Level I Trauma Centre: “That’s what happens here every day. Everybody knows what they have to do. Even if it’s very unusual, eventually you get used to it because it happens often.” Even Dr. Sorensen acknowledged the shifting sands of medical certainty in working in a trauma centre when unexpected outcomes occur. This physician described an instance whereby it was thought that a patient with sTBI would not survive: “Because of the brain injury and her presentation in emerg, [it was thought] she didn’t need an operation because she wouldn't survive. She went to ICU, they treated her for a few hours, and she got better. [She had an operation.] She’s walking around now.”
5.4 The Brain is Hidden from View Early after Trauma

Physicians described the various medical tests, such as diagnostic MRIs and CT scans, they completed to reveal the inner sanctums of the brain as a part of their work. They performed physical tests, such as looking for any eye movement and physical limb movement or waiting for a word to be spoken or a sound to be uttered. Physicians addressed invasive procedures they did to gain a view of the inner workings of the brain, inserting probes into the brain, specifically intracranial pressure monitors. They added and took away medications to raise or lower blood pressure, to provide an optimal environment for the brain to heal. They drained cerebrospinal fluid to reduce hydrocephalus; swelling of the brain caused by excessive cerebrospinal fluid. Physicians waited and watched to see what the brain would do.

The particularities of the brain\(^3\), even in the advent of modern technological, diagnostic and neurobehavioral testing, can be hidden from view. The physicians frequently described the brain with a sense of humility. They described carefully laid plans to bring the severely injured brain and body into view, through series of carefully coordinated activities by the trauma team, like the inner workings of a Swiss clock. The physicians spoke about the unpredictability of emergent care and the likelihood of death, describing intense efforts to gain control of the emergent care process to save a life. Physicians acknowledged the brain’s contribution to

\(^3\) Throughout this chapter, it is difficult to describe the brain and its injuries without descending into Cartesian dualism, often critiqued by D. E. Smith (1999, 2005). In some instances, I have referenced the connection between mind and body, as severe traumatic brain injuries often result in infections of the body and contribute to overall susceptibility to other complications, such a pneumonia or meningitis. In some instances, certain individuals refer specifically to the brain and thus this separation is warranted, given that the injuries have been primarily to the brain as an organ, just as the heart is an organ. D. E. Smith’s primary concern regarding the separation of mind and body was that the mind becomes separated from the doings of the body. She intimated a sense of the femaleness of the body as opposed to the maleness of the conceptualization of the mind in modern science and sociology. She described Descartes’ separation as follows: “The separation of mind and body for which Descartes wrote the constitutional conventions is perpetuated in a separation of the regions of thought and mind from people’s doings and, most strikingly, from the social. With the notable exceptions of George Herbert Mead, V. I. Voloshinov, and the tradition of psychological theory descending from Lev Vygotsky to Alexander R. Luria, the lexicons of consciousness and subjectivity give us no sense of the social; not only are consciousness and subjectivity represented as if they existed outside time and place, but they also appear as if they were not implicated in how people’s doings are coordinated” (D. E. Smith, 2005, p. 75).
personhood, to the self, to being human; sometimes the brain itself seemed to coordinate the
activities of the physicians rather than the reverse. Dennett, a philosopher and cognitive
scientist, offered insight into the language the physicians and family members use about the
brain and the body:

Do brains think? Do eyes see? Or do people see with their eyes and think with their
brains? Is there a difference? Is this just a trivial point of “grammar” or does it reveal a
major source of confusion? The idea that a self (or a person, or for that matter, a soul) is
distinct from the brain or a body is deeply rooted in our ways of speaking, and hence in
our ways of thinking. I have a brain. This seems to be a perfectly uncontroversial thing
to say. And it does not seem to mean just the body has a brain (and a heart, and two
lungs, etc.). Or this brain has itself. It is quite natural to think of the “the self and its
brain” (Popper and Eccles, 1977) as two distinct things, with different properties, no
matter how closely they depend on each other. If the self is distinct from the brain, it
seems that it must be made of mind stuff (Dennett, 1991, p. 29).

This is not to say that the physicians did not understand how to interact with the brain and
the body—they clearly did. They monitored the brain and the body, they did tests on the
individual, they did surgery, or they waited to see what would happen next. But the brain and
the body are hidden from view. These are contradictions in the way we see physicians and
modern medicine: holding a scalpel, having a plethora of powerful medications and tools at their
disposal, with extensive technological implements to predict future functioning. A mother of
one of the patients reproduced the medical discourse of the physicians in discussing her son’s
condition:

Mother: I think at this point the hardest thing is just not knowing, just not being able to
understand where he’s at. The fact that it is anatomy versus function. The brain is not,
you can’t look at a CT scan, you can’t look at all the information and be able to predict
what he’s going to be like, what we’re looking at in terms of recovery and how long it
will be. So that’s difficult because every day is like another whirlwind of emotions
because you’ll have one day where he seems to be doing okay and then you’ll have
another day where he’s may be not as responsive or his fever is going up or [he has]
swelling or something like that. And then it just sort of all cycles. The medical team
doesn’t want to give you false hope, so they prepare you for the baseline. He could
potentially never recover from this state and that’s hard to hear. It’s also hard because
you don’t know that for sure, so it’s not like we can just give up and stop trying.

This mother also reproduced the medical discourse of the physicians that the brain is hidden
from view and that knowledge regarding promoting future functioning is elusive:
Mother: There’s no sort of idea of how to make him progress. And that’s the other thing; they’ve done what they can do for him, which is because the brain is so unknown. There’s not a lot of therapies you can do to try to help recover. It’s kind of just leave it up to whatever will happen.

The concept of the brain being hidden from view in the trauma centre foretells the future in social life of the outside world with TBI: “Unless a head injury resulted in obvious surgery, facial alteration, or physical impairment, most brain dysfunctions were invisible to others” (Sullivan, 2008, p. vii). The person with a less devastating TBI after the initial trauma is walking and talking—the prerequisites for fully functioning personhood. However, TBI deficits, even subtle ones like impaired memory or organization, can be quite disabling in daily life. People with TBI sometimes choose not to reveal this injury to others, keeping it hidden from view, fearing the experience of stigma of this disability.

The hiddenness of TBI parallels the hiddenness of individuals with sTBI in healthcare institutions and in social life, juxtaposing with other disabling conditions described in the media. The story of Christopher Reeve, who played Superman in numerous movies, after a life-altering spinal cord injury, was broadcast on television and recorded in magazines and newspapers. In contrast, Formula One racer, Michael Schumacher, who sustained a sTBI while skiing when a GoPro on his helmet lodged into his brain in a fall, has been shielded from public view. Any mention of his current health status by former employees or newspapers is quashed by his family’s legal team. By the few available accounts of his injury, the consequences of this injury have had a profound, disabling impact on his life, but his altered life has been largely hidden from our view.

Physicians, health professionals and the families themselves related incredible narratives of the unpredictability and uncertainty of the brain during the interviews. I have included some of these details in the vignettes that appear in the Preface and Chapters 1, 5, and 6 of this dissertation. Narratives recounted by physicians and other health professionals revolved around individuals with sTBI whom it appeared would not survive. Families also talked about these incredible circumstances, desperate moments after accidents and falls, whereby people with sTBI eventually experienced notable recovery after catastrophic injuries. Amazing narratives were recounted of how these individuals did indeed wake up, were able to walk or talk, and continue in their lives as parents, spouses, athletes, and valued members of society.
Dr. Pascale described the challenges in early prognostication and the landmarks of functioning used by physicians to determine who will improve and who will not recover after sTBI. He addresses the responsibilities of the physicians as they communicate with families in the midst of these uncertainties. While expectations of recovery are more easily discerned in the best and worst case scenarios, extensive middle terrain exists in terms of predicting outcomes and uncertainty can rule. Physicians pull families into the work of waiting with the individual with sTBI, as they await for outcomes to unfold:

Dr. Pascale: Prognostication is something where you have the signs in the beginning after an accident, in looking at the level of consciousness, the amount of bleeding, and how the patient is responding. In my role as the trauma team leader, you have this initial impression but things may change. That’s why always when I talk to families about prognosis… you have the extremes. You have a very bad one where patient is going to die in the next few minutes. And you have the opposite, where things are okay. It’s a young patient. There’s a small bleed in the brain. So the patient is going to be admitted. We’re going to just monitor the neurological status. In 12 hours, we’re going to repeat the CT scan. It’s probably going to be the same. The body is going to take care of the bleeding. The patient is going to go home. So we have the two extremes. And you have the middle, which is a large population. In this middle population, our role as a trauma team leader is to initiate the conversation with the family. When the patient goes to the ICU or gets admitted, you’re going to have the neurosurgeon and [others] assessing the patient. At that point, they are going to have a better impression because it changes. Sometimes you have a patient that goes to the ICU intubated, with a low level of consciousness, and 3 days after, the patient is talking. So you can’t… my assessment is limited to that moment. You can communicate, not with 100% of certainty, but with a higher percentage of certainty, if the patient is about to die or if it’s a very small bleed. With the middle population, it’s more difficult. So you just initiate [the conversation] and say, well, we’re going to need to wait. There is an evolution.

Physicians contend with these uncertainties through examining the results of medical tests and explaining these results to families, who are new to this unfamiliar medical liminal landscape.

Another physician, Dr. Oliveri describes accounting for unpredictable outcomes after sTBI through investigative medical work to deduce further functioning. Dr. Oliveri outlined how to look for definitive clues about the brain and recovery. Predicting outcomes hinged on differentiating categories of individuals with sTBI: 1) those who would not survive; 2) those who would survive and thrive; and 3) and the ‘in-betweener’ as what happens next is anybody’s guess. Physicians are tasked with managing medical intervention for these individuals. Physicians were also responsible for explaining these different types of injuries and outcomes to families.
5.5 Physicians’ Work with Families after sTBI

Part of the daily work of the physicians involves talking to families regarding the impact sTBI, the possibility of recovery, and long-term prognosis. Attending physicians in the critical and intensive care units were often observed to meet with and talk to families during medical rounds. Physicians were observed to spend significant time talking to these families. The attending physician waved the other physicians onto the next patient during rounds to talk to the family in private. As medical rounds occur in the critical care and intensive care units at consistent times, family members learned this routine and were often present for rounds.

As I was not present during these conversations between the attending physician and the family members, I asked about this work during interviews with the physicians. They acknowledged this could be difficult work, but that it was also necessary and an important part of the physician’s role to explain these injuries and possible outcomes to families. Physicians described different aspects of this role, including helping the family to understand what sTBI is, and its possible consequences:

Dr. Oliveri: So, helping them understand what a brain injury is, that there’s no specific treatment for it. All the operations and everything we do after is to try to prevent further damage. I spend a lot of time talking about uncertainty around prognostication. So, I tell patients like there’s basically three flavours. One is the patient looks…they’re fine, and we know they’re going to do well. One is they’re in a profound coma, and they do absolutely nothing. Those patients tend to do quite poorly. Most patients are somewhere in between where they’re clearly not normal when they come in but they’re doing some things. Those are really hard to prognosticate. The ones where they’re doing something, they’re not clearly GCS 3, and not the ones who are GCS 15. It’s the ones that do a little bit of something.

Narratives of physicians, other health professionals, and families suggest three categories of sTBI in their stories about recovery or death after sTBI. The first group includes people with sTBI who do not survive the initial stages of care. Life support is withdrawn with no clear signs of brain activity. The second group involves people with sTBI with significant initial injuries, but they survive, move through various stages of consciousness, and experience clear recovery. The third group includes patients who survive the initial presenting injuries, but experience limited or slow recovery afterwards, hovering in lower levels of consciousness with seemingly
limited interaction with the world around them.\textsuperscript{4} The brain can be hidden from view and the medical gaze in these more ambiguous cases, as described by Dr. Oliveri:

Dr. Oliveri: The in-betweeners, it’s very hard to predict. Here are people where more junior residents would say: “Why are we doing this? We should withdraw life support” and they [the patients] come back in three months, and they’re walking and talking. It’s a very humbling thing to make recommendations. It’s hard to say at the beginning how it’s going to go. But you know, even months... We know that the changes continue for about a year at least. Even then there can be changes that we don’t see. But I do suspect that a lot of these patients never make what we would call a meaningful recovery.

As I have described above, a plethora of medical tests and indicators were threaded together to weave a more extensive picture of future functioning. Physicians drew on other demographic factors such as age and accepted notions of brain neuroplasticity to predict recovery as they talked to families. But the guessing game of early sTBI described by physicians and families supports the notion that the brain is hidden from view in brain injury rehabilitation. Dr. Oliveri summarized these conversations of uncertainty with families after sTBI:

Dr. Oliveri: We can say, overall if you’re older, you’ll do worse. But the question that families just want to know is: “Are they going to wake up, and what are they going to look like when they wake up?” No one can tell them that. Not for their specific person. It’s more around saying the truth, which is no one knows. Don’t give up hope. Know that it might go really well; it might go really poorly. We’re here to support you. And also know that the timeframe is really long. For a young person, they can keep changing for months and months and months. Just setting that expectation of what it might look like with the best case and worst case scenarios, and what the timeline might be. The other thing people often ask is about imaging. Should we get another MRI, should we get another CT? It’s really helping them understand that the most important thing is what the person can do. CTs and MRIs are important for specific questions around treatment or to see if there’s something that can be intervened with, for example, like another bleed. But it’s not going to tell us if mom is going to wake up.

\textsuperscript{4} Throughout this chapter, there is also the interesting interplay between consciousness as a social percept and consciousness as constitutive of selfhood. Consciousness is usually described by D. E. Smith as “concepts, beliefs, ideas, knowledge, and so on (what Marxists know as consciousness) [which] are included in this ontology of the social...as practices that are integral to the concerting and coordinating of people’s activities” (1999, p. 75). D. E. Smith is also preoccupied with how people’s consciousness is revealed through talk and text as living, breathing iterations of the social (1999, 2005). For the sake of clarity of the argument that the brain is hidden from view, I have kept these descriptions out of the main text of the chapter. D. E. Smith’s fascination with language also foretells how improving levels of consciousness intersect with societal views of what is selfhood during recovery—that is, the time when people first start to speak. As Dennett indicates in this chapter, the self and brain are very difficult to conceptualize separately as they are so intertwined—language is integral to this perception of the self.
Dr. Oliveri described the fabric of the social world in this medical work as families’ expectations of modern medicine show a line of fault in terms of what physicians can do to assist individuals with sTBI after the initial medical treatment. Dr. Oliveri addressed how families’ expectations regarding the clinical utility of modern diagnostic brain imaging tests exceed what these tests can accomplish in actuality. Dr. Oliveri explicated the difficulties in physicians’ work when medical technological implements have a limited capability to predict future functioning:

Dr. Oliveri: People have this reliance on technology. Where [they think] an EEG is going to tell us, or an MRI is better than a CT. But the truth is with brain injury, the physical exam still is the most important. We have to focus on what he can do. That’s the best predictor. A neurosurgeon might say something more sophisticated. But what we really are looking for is purposeful movement. Obeying ideally or localizing. If they can do that, the CT is not that helpful.

Dr. Oliveri referenced commonalities within the fabric of daily life, as many people would not have a frame of reference for understanding the consequences of sTBI. Prior to the injury, families would be unlikely to know what physicians could do to remediate this condition, or if diagnostic tests could predict recovery. Dr. Oliveri has outlined above how many questions remain unanswered for families initially after the injury and perhaps for months or years afterwards. As I interviewed one family member regarding what they expected after learning their family member had sustained a sTBI, they replied that they did not know what to expect. Their narrative hooks them into the social in relating their experience with their family member with what they saw on television, which was not helpful:

Lynn: You weren’t familiar with brain injury before or very familiar?

Son: No. I was not familiar with brain injury at all. I mean beyond ER and Grey’s Anatomy and those are not always realistic.

As physicians have access to numerous technological advances, including CT scans, MRIs, and intracranial pressure monitors, as I have described above, families may assume physicians can predict future functioning. Questions from families can also centre on consciousness: In terms of the level of consciousness, personhood or the self, what will the person be like? But if the person with sTBI is unresponsive, physicians have not had the benefit of being able to assess their behavior—an introspective look into the patient’s brain. Cohen, a British journalist, addressed previous historical efforts by scientists to ‘see’ into the brain. Cohen (1996) drew a similar conclusion regarding the clinical utility of diagnostic tests as Dr.
Oliveri above. Cohen (1996) framed his historical analysis of the development of brain imaging tests in terms of their inability to adequately access consciousness and represent being human:

Since the 1960s, there has been a new interest in investigating consciousness, as psychologists realised that their science had to account for the subtleties of being human. At the same time, technology has been catching up with psychology’s desire for the quantitative investigations of consciousness. First developed in the 1920s and since refined, EEGs sensitively measure electrical activity in the brain, although many time-consuming baseline studies must be made before any interpretation is possible. Functional MRIs and PET scans can illustrate graphically levels of activity in the brain. These techniques can elicit the sort of objective information that even the most skilled introspection could never hope to achieve—but without some very human, subjective thought, the meaning of the scans remains obscure (p. 77).

In addition to discussing the results of the various diagnostic tests after sTBI with family members, physicians also addressed other bodily injuries and infections that commonly develop after sTBI. One family member discussed his frustration as physicians tried to identify the source of infection for his father after sTBI: “I was talking to a doctor and I was freaking out. And he started giving me this story: ‘we do our best to, do everything we can to the patient, but sometimes, the longer they’re in the hospital, they’re susceptible to other risks and sometimes they can be life-threatening’.” This family member described how difficult it was to locate and identify this infection, as these infections can also be hidden from view.

Dr. Reed addressed how the physician’s work with the brain occurs in tandem with trauma work for the body of the individuals with sTBI in determining what needs to be addressed medically: “They do have a lot of complications, almost always managed by the ICU, which are medical complications or complications from other injuries they have. They often have spine fractures, they have chest problems, and other traumas.” The consequence of these injuries themselves—open skulls and/or body orifices at the time of injury—are bound to invite infection. Dr. Oliveri explained how so many open sites of entry to the body with various lines and tubes could invite infection. As described by the family member above and by Dr. Oliveri, physicians engage in the quest to locate, identify, and quell these infections.

Family members are drawn into observing this series of medical procedures and the often disappointing ups and downs of medical treatment with chronic infections in individuals with sTBI. Rather than invoke knowledge claims of effective evidence-based practice in modern medicine’s trauma care, Dr. Reed refers to finding and eliminating the source of these infections
Dr. Oliveri: In the ICU, I end up seeing a lot of those patients coming in and out. And that’s what we try to explain to families in terms of making goals of care. There is suffering associated with living with this really profound head injury. Naturally we cough and move and walk. That prevents pressure ulcers, and it clears our lungs. They’re not able to do any of those things. All the housekeeping of the body is profoundly deranged with bad head injuries. They have central lines; they have trachs. The body’s natural defenses are breached. So, it’s almost inevitable. A lot of them need complex continuing care and those beds are scarce and far between.

The changes in states of consciousness and in medical states by individuals with sTBI create a sense that they are liminal entities. Van Gennep, an anthropologist who studied rites of passage, described liminal phases, which were “rites which accompany every change of space, state, social position, and age” (Turner, 1969, p. 94). Turner expanded on these concepts of liminality as: “The attributes of liminality or of liminal personae (“threshold people”) are necessarily ambiguous, since this condition and these persons elude or slip through the network of classifications that normally locate states and positions in cultural space” (1969, p. 95).

Individually with sTBI represent this liminality, as they may move up or down in levels of consciousness quickly or unpredictably and recovery can be uncertain. “Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arranged by law, custom, convention, and ceremonial” (Turner, 1969, p. 95). Turner (1967, 1969) has defined this lack of belonging to specific social categories for liminal entities as marginalizing as they lack clear structural definition. This marginalization applies to those individuals with sTBI who remained in lowered levels of consciousness, existing as liminal entities, with obstructed access to various healthcare liminal spaces, such as inpatient rehabilitation, in the absence of clear recovery.

The liminality of these individuals in indeterminate states of being—the hiddenness of their infections, the brain/body and its secrets—contrasted with the open visual spaces of the critical care and intensive units. Many of the beds in these units are in large open rooms, and the remainder of the rooms on these units are glassed-in. Family members often sat beside the person with sTBI in these units, with many nurses nearby, in plain view. Systems of ventilation,
blood pressure monitoring, oxygenation, and nutrition were hooked into these bodies, chugging away, blipping issues and concerns.

As patients recover and no longer need ventilation, they move to the intensive care unit from the critical care unit. Nursing care is decreased from nearly one-to-one patient-to-nurse ratios to two patients to one nurse. As individuals with sTBI rely less on nursing care, they move to the trauma ward. Nursing care on this unit included patient-to-nurse ratios of three to four patients to one nurse in the daytime and six to seven patients to one nurse at night. Once on the trauma ward, individuals with sTBI attained a functional recovery that created dividing lines in terms of the rehabilitation they received, as I will argue in Chapter 6.

5.6 Chapter Summary

In this chapter, I argue that the physician’s work after sTBI is centred around lifesaving procedures, promoting medical improvement from these injuries, and also assisting families to understand the implications of sTBI on the individual’s future functioning. I have continued the vignette regarding Hailey that I initially presented in Chapter 1. Hailey is an 18-year-old woman who sustains a sTBI following a horseback riding accident. In the vignette in this chapter, I discuss the initial stages of Hailey’s medical treatment upon entering a Level I Trauma Centre trauma room and critical care unit. I also discuss the adjustment of her family members to these new circumstances.

In this chapter, in reflecting on their daily work, physicians describe this work as complex and intensified as they engage in the mandate of a Level I Trauma Centre—to save lives. I argue that a notable analytic point became apparent as the physicians talked about the brain, and even the body itself, as being hidden from view. Physicians describe various initial procedures required, such as intervening with blood pressure and blood flow, and performing neurosurgery when needed. Physicians complete many medical procedures and diagnostic tests to predict the future functioning of an individual with sTBI. However, these tests sometimes offer few clues into what the person’s recovery from sTBI will look like.

Families reproduced this medical discourse as they learn there can be limited information regarding their family members’ future functioning based on various diagnostic tests. Some individuals with sTBI will die after the initial injury and some individuals with sTBI will have
recoveries, even quite surprising ones. Others with sTBI will show limited recovery, remain in lower levels of consciousness, and experience numerous complications with chronic sTBI, remaining in healthcare facilities in need of extensive care. However, these individuals are unaccounted for in acute care liminal spaces with very limited access to rehabilitation to move them onto other modes of care.
Chapter 6
The Paradox of sTBI Rehabilitation in Acute Care

6.1 Chapter Outline

I argue in this chapter that early rehabilitation for individuals with sTBI presents a paradox in the social organization of rehabilitation work practices in trauma care, as the timing and intensity of rehabilitation required far exceeds available resources. The paradox of acute care is that this is the time when rehabilitation is significantly required, but daily rehabilitation is unavailable due to funding restrictions. I begin this chapter describing the movement of individuals with sTBI through the liminal spaces in a Level Trauma 1 Centre where medical care and rehabilitation occur. Rehabilitation work required to move individuals with sTBI to other healthcare spaces is labour intensive with complex work sequences, beginning with movement across the liminal spaces of the trauma centre. This work with individuals with sTBI becomes bifurcated early in the process of rehabilitation, as health professionals must quickly decide which individuals will satisfy entry requirements for inpatient rehabilitation and which individuals are recovering too slowly to meet these requirements. Rehabilitation work is shaped by textually mediated translocal relations outside of the trauma centre, organized through admission policies mediated by the Toronto ABI Network and restraint minimization policies, both policies set through the Ministry of Health and Long-Term Care (MOHLTC).

Individuals with sTBI unlikely to gain admission to inpatient rehabilitation are ideologically moved to the outer margins of responsibility of health professionals from a managerial perspective. However, these individuals with sTBI may still need to meet admission requirements for other facilities, including repatriation hospitals and complex continuing care (CCC). Rehabilitation work with these individuals requires labour intensive work sequences involving a series of intricate steps, such as removing tracheostomies to prepare them for other healthcare spaces. This intensive work with individuals with sTBI who show limited recovery remains hidden from view and unaccounted for, as it is ideologically incongruent with economic contingencies in acute care. Health professionals working in trauma care develop an extensive ideological code to address these complex work sequences.
I also argue in this chapter that family members of individuals with sTBI are recruited into rehabilitation work in light of limited healthcare resources on the trauma ward. Families, accustomed to high nurse-to-patient ratios in critical and intensive care, can develop extensive visiting schedules to account for far fewer nurses on the trauma ward and limited rehabilitation. Families may develop comprehensive and even around-the-clock schedules to monitor and care for individuals with sTBI. While visitor and overnight policies exist, they are infrequently discursively invoked by hospital staff. Families become mobilized to provide numerous aspects of care for the individual with sTBI, from nursing care to rehabilitation. I include two additional vignettes regarding Hailey and her family in this chapter to portray her family’s involvement in her care. I argue that the work of families is unaccounted for and hidden from view in acute care liminal spaces.

6.2 Transition across the Liminal Spaces of the Trauma Centre

As individuals with sTBI stabilize in terms of their medical condition, they move beyond the boundaries of the critical care and intensive care units to the trauma ward. This movement through the liminal spaces of the trauma centre is not only a geographic change, but also an ideological one, symbolizing moving on within acute care from one form to another. Physicians, mainly surgeons and intensivists, and numerous medical residents are frequently visible in the critical care and intensive care units. Physicians and residents perform medical rounds in the critical care and intensive care units on a daily basis at the same time. Physiotherapists, respiratory therapists, dieticians, speech language pathologists, pharmacists, occupational therapist, spiritual care, and social workers also occupy these spaces. Families of individuals with sTBI are in frequent contact with these health professionals, who are clearly visible in the critical care and intensive care units.

The critical care unit is a very visually open space, with many patients residing in the same enormous rooms, or in rooms walled with glass. In the critical care unit, patients normally have ventilators, one clear signifier that they need to be in that unit—they cannot breathe on their own. Individuals with sTBI normally have a tracheostomy, a hole in their neck to breathe, and the ventilator is attached to their tracheostomy. These patients have many other technological implements, such as ICP monitors, IVs, blood pressure monitors, Foley catheters, and various types of feeding tubes attached to their nose, mouth or stomach. Patients on the critical care unit
are monitored through constant surveillance via the close proximity of many health professionals, with numerous technological devices hooked into their various bodily systems and through the visually open space of the critical care unit.

Individuals with sTBI in the critical care unit have intense care needs as they are often unable to cough or move. They need to have fluid suctioned from their mouth and the air passageways of their lungs, accessed through the open tracheostomy in their necks, as they do not have the capacity to move these fluids on their own. These fluids are referred to as secretions and these secretions need to be frequently suctioned out of air passageways. Without frequent suctioning, these individuals would aspirate and their lungs would fill with fluid, which can be a fatal complication of sTBI. Nurses, respiratory therapists, and physiotherapists perform this frequent suctioning. Rehabilitation professionals and nurses mobilize patients with sTBI into sitting positions to assist them to cough and move these secretions on their own, and to move the rest of their body.

In the critical care unit, there is a staffing complement of almost one nurse to one patient. The almost one nurse occurred as an economic contingency after the financial crash in 2008 when hospital revenues decreased. Previously, it was one nurse to one patient. The critical care unit moved in 2008 via this economic contingency to reduce the number of nurses on the unit, hence the ‘almost one nurse’. As patients with sTBI are able to breathe on their own and ventilators are removed, they move to the intensive care unit, where the nursing complement is one nurse to two patients. If their condition improves significantly while in critical care, they may transfer directly to the trauma ward and bypass admission to intensive care.

In rare cases, patients with sTBI may also have ventilators in intensive care, whereby the ventilator has become chronic, but their other care needs do not warrant critical care. Open surveillance remains in the intensive care unit with high nursing complements and many doctors in plain sight. Rehabilitation professionals are also present and clearly visible in the open format of the unit. Fewer technological devices are required as a consequence of having fewer medical needs. Many individuals with sTBI still need to be suctioned frequently; these high-suctioning needs are a barrier to being transferred to the trauma ward. Eva, a rehabilitation professional who works on all of the trauma units, differentiated the goals of care for individuals with sTBI in different trauma units:
Eva: In the intensive care unit, often for the people who have a neurological or traumatic brain injury, they, we're more worried about their ABCs (airway, breathing, circulation). We’re more dealing with making sure that their airway is patent and they’re clearing their secretions. And if they’re not, then we’re assisting them with clearing their secretions. In a less acute setting than ICU, on the ward, at that point hopefully they’re much more stable in terms of maintaining their airway and so on. We’re focusing now on their neurological injury and helping to start training, in more general terms, training the brain back into functional activities and mobility.

As individuals with sTBI demonstrate further improvement and require less medical and nursing care, they are normally transferred to the trauma ward in preparation for their discharge to other healthcare spaces or to their home. The trauma ward represents a very different work and ideological space than the critical care and intensive care units. Nursing complements are much lower, with three to four patients to one nurse during the day and six or seven patients to one nurse at night. During hospital breaks for nurses when they leave the unit, nursing complements are divided by two. For example, at night, there is one nurse to 12 or 14 patients when a nurse is absent from the ward.

The goal of the trauma ward is to transition patients out of the hospital, as these individuals are more medically stable and able to tolerate various therapies. Similar rehabilitation professionals work on the trauma ward as the critical care and intensive care units, including occupational therapy, physiotherapy, social work, dietetics, speech language pathology and spiritual care, but these professionals are more visible. Respiratory therapists are less visible on the trauma ward as patients have decreased suctioning needs; suctioning is managed by nurses. Hospitalists were added in the trauma ward midway through my ethnographic fieldwork; their addition was to improve communication and provide consistent medical monitoring for patients. Hospitalists are hospital physicians; they work solely in the hospital, in the trauma ward and other areas of the hospital.

Provincial bed designations remain the same for individuals with sTBI on the trauma floor as they are in critical and intensive care; all are acute care beds. No TBI rehab beds are designated in acute care in Ontario, even though individuals with sTBI have varied needs as they move through acute care liminal spaces. Physically, the appearance of the trauma ward is dramatically different from critical care and intensive care units. Several rooms with a single glass wall are located in front of the large nursing station in the centre of the trauma ward. The
remainder of the rooms on the trauma ward have fully encapsulated walls with one to several patients in each room; the doorways are the only way to see in or out.

The trauma ward represents a very different ideological space than the intensive care and critical care units. Arrival on this ward signifies a new phase in medical care and rehabilitation. Transition out of this space is intended to be elsewhere outside of the trauma centre—another hospital, a rehabilitation facility, complex continuing care, a person’s home, and occasionally long-term care. Some patients on the ward are improving quickly and need rehabilitation to progress. They may need adaptive equipment, such as walkers or wheelchairs to mobilize, or require the implementation of services at home; their needs are primarily physical. More physically mobile patients are placed in beds in the hallways of the trauma ward when the hospital is overcapacity; a common sight in Ontario’s hospitals.

Transitions across spaces within the trauma centre for individuals with sTBI draw our attention to the sense that these spaces are liminal in nature. Individuals move across the thresholds of the units of the trauma centre as their states of consciousness and their medical conditions change. The Latin root of the word ‘limen’ refers to a threshold: “Boundary or border may become a threshold, but only when it is transgressed. The limen suggests a space more explicitly understood as a site of transgressivity, a point of entry into another zone. Unlike the closed space or place given form by its perceived limits (limites), the liminal space or site of the limen is one of opening, unfolding, or becoming” (Tally, 2018, p. xi). “Liminal spaces are those which are simultaneously, place and space. They are familiar, yet known; they are secure, and yet intimidating” (Downey, Kinane, & Parker, 2018, p. 3).

People with sTBI move across these spaces depending on their medical needs and degree of improvement. Patients with less frequent suctioning needs, who can be managed with a lower nurse-to-patient ratio, are transferred to the trauma ward. Individuals with sTBI often still require IVs, Foley catheters, and types of feeding tubes. Some persons with sTBI are improving quickly and on the cusp of being ready for inpatient rehabilitation. Other patients with sTBI are improving and medically stable, but not ready for inpatient rehabilitation. They are discharged to repatriation hospitals or their own homes to wait for access to inpatient rehabilitation. Others with sTBI do not improve sufficiently to leave the trauma centre; they remain in a state of liminality as they ebb and flow through lower levels of consciousness due to extensive brain
trauma and frequent medical complications, oscillating back and forth across the liminal spaces of the trauma centre.

I have described a linear passage through the units from critical care, to intensive care to the trauma ward above for some individuals with sTBI, but this transition is convoluted when patients with sTBI develop serious medical complications. I observed numerous persons with sTBI leave the trauma ward for critical care and intensive care units due to illness over the course of my ethnographic fieldwork. Medical complications can include infections in the brain or body, pneumonia, or central nervous system and bodily fevers. Complications can also include hydrocephalus—swelling of the cerebrospinal fluid in the brain or spinal cord—or other medical conditions requiring increased medical surveillance and nursing care. Physicians often referred to patients with sTBI who develop long-standing complications as having chronic TBI. As discussed in Chapter 5, Dr. Oliveri indicated that living with a profound head injury involves suffering “as all the housekeeping of the body is profoundly deranged with bad head injuries” due to the extensive damage to the brain and body, and the breaching of the body’s defenses.

Patients with sTBI who develop medical complications can move repeatedly between various units as intensive hospital work is required to address these complications. This group of patients with sTBI has ongoing medical and nursing needs that are critical in nature. These patients cannot remain on the trauma ward or be transferred to most other healthcare facilities, with the exception of other tertiary hospitals able to manage these extensive medical needs. The progression of their traumatic injuries is unclear; they may never recover, or live with profound suffering, as described above by Dr. Oliveri. They may also eventually surpass these complications and show many improvements afterwards. Complications are common with sTBI, but the duration of time these complications are experienced can vary greatly from person to person.

To portray some of the details regarding individuals with sTBI who develop medical complications that hinder their ability to progress, I introduce a third vignette about Hailey and her family. The needs of a person with sTBI alternate back and forth between medical and intensive nursing care and intense rehabilitation as the course of their disease changes. However, as designated by MOHLTC, once a patient is in a bed, it remains the same: there are no rehabilitation beds for TBI in acute care. While this is a fictionalized account, events such as the
one described below occurred during my fieldwork. This vignette tells the story of some of Hailey’s experiences with hydrocephalus, a complication resulting from excessive cerebrospinal fluid in the brain and spinal cord. It also tells the story of other serious health circumstances another member of the family faces.

6.3 Hailey’s Movement across Acute Care Liminal Spaces

“Omigod,” exclaimed Shailene to her favourite nurse Tyra in the intensive care unit. “We are back again! Hailey was so much better after they put a shunt in her brain for hydrocephalus.” Hailey had been bouncing back and forth between the critical care unit, the intensive care unit, and the trauma ward since her admission in October 2017. It is now late February 2018. She had had infection after infection, numerous fevers, and pneumonia. However, the hydrocephalus had been the most difficult of all to manage. Several weeks before, the neurosurgical team had installed a shunt in Hailey’s brain to drain the excess cerebrospinal fluid in order to relieve swelling in her head.

“After surgery,” she told Tyra, “Hailey was doing great. You could really see the swelling on the left side of her forehead had gone down. She was sitting up comfortably in the wheelchair on the trauma ward. She was doing exercises with physiotherapy. Occupational therapists and physiotherapists were working with her on the side of the bed and she was saying some words. The speech language pathologist assessed her to see if her swallowing had improved. Then a week after surgery, everything went south—big time! See the swelling on the left side of her forehead again! The neurosurgeon explained it in detail, but it just sounded like something about a clogged drain to me.”

“I’m sorry to hear that,” said Tyra. “I know that you have all been through so much.” “I’m just going to suction Hailey’s trach since there are a lot of secretions today. The respiratory therapist is going to assess her later this afternoon to see if she is getting any better.” The nurse moved the long thin suction tube along the tracheostomy.” Shailene replied, “Oh, I can help you later with some of the light suctioning.” “Thanks,” replied Tyra. “I’m just going to do some of the deep suctioning inside first so that your sister can breathe better”. Tyra suctioned for several minutes with the long, thick, plastic suctioning tube, which looked and sounded like a mini-vacuum cleaner.
“Great.” exclaimed Shailene. “Now can you please help me comb out her hair? She has had this mess of half of a head of hair since the neurosurgery after the accident. I had it under control, but it’s a mess after she had a high fever again. She is pretty quiet today, so I’d like to get it cleaned up. She keeps nodding “no” every time I tell her I want to shave off the rest of her hair.” Tyra replied, “I can try and help you with combing out her hair. Do you have a really good comb?” Shailene rustled through Hailey’s things in the bedside table. “Found it!” she exclaimed as she pulled out the needle nose comb. Tyra announced to Shailene, “I’ll help you as much as I can, but I have to keep a close eye on my other patient today. I also need to keep on top of my nurses’ notes, keep up with her suctioning, and give out medications later this afternoon. Now let’s start cleaning your sister’s hair up!”

“Okay,” said Shailene as she gingerly pulled the comb through Hailey’s long tangled mess of blonde, wavy hair. Tyra showed her various tricks to comb out Hailey’s hair without hurting her. As Shailene worked patiently through Hailey’s hair with the comb, using the tricks that Tyra had shown her, she wondered where her parents were this afternoon. At the hospital, and at home, she noticed that they were always whispering to one another. Her mother seemed so tired all of the time and sometimes she stumbled when she walked.

Shailene was hoping that her mother was just feeling exhausted and worried like the rest of the family about Hailey. But as Hailey improved slowly, her mother still appeared tired all of the time. The neurosurgeon said that Hailey had a temporary setback and the shunt needed some adjustment. Why was her mother still so exhausted and unable to cope?

Just as Shailene had finally combed all the hair on the right side of Hailey’s head into an acceptable style, her father, Alton appeared. “Hi dad!” she exclaimed. “Where is mom?” Her father, a very tall slim man who was usually quite reserved, seemed to smile too brightly at her. “Oh, she went home. She had a long, tough day at work today.” Alton hoped that his sensitive and intuitive daughter Shailene would not pick up on his mood or be suspicious about Isabelle not being at the hospital today. Tyra, still standing at the bed, walked back to the nursing station to give them some privacy. She too had noticed Isabelle’s ataxic gait while on the unit.

Alton replayed the afternoon’s events in his mind of the neurologist’s appointment with his wife. His wife Isabelle had been feeling very tired, shaky, and off-balance for the past several months. Her family physician had sent her to a neurologist, who indicated that she
would need to complete a series of diagnostic tests before he could tell them anything conclusive. This afternoon, the neurologist did not waste any time and got straight to the point. “I’m afraid I have bad news,” said the neurologist. “Isabelle, I have reviewed all of your tests. You have an upper motor neuron disease called ALS or Lou Gehrig’s disease. Unfortunately, the symptoms that you’re having are just the beginning. The course of this disease is very serious.” Isabelle’s face dropped as she heard the news. “Doesn’t Stephen Hawking have ALS? He’s still alive,” she chirped. “Yes,” said the neurologist, “but his condition has been a very rare case. I do not know what your progression will be like or how long you will be able to function. It is too early to tell. As I said, this disease is very serious and usually fatal.”

Recalling these events this afternoon, Alton looked at his twin 18-year-old daughters. Hailey, who was lying in the hospital bed, stirred quietly and waved halfheartedly to him. Shailene was peering at him suspiciously. Averting her gaze, Alton thought he would try to change the subject. He winked at Hailey in her bed. “So Shailene, why don’t you tell us what went on at school today and what is new at Hartdale High?” Shailene looked unconvincing at her father’s performance. But even as she felt anxiety flutter in her stomach regarding recent mysterious events in her family, Shailene did not want to tip off Hailey that something else might be terribly wrong in their household. At that same moment, Tyra walked over to the bed. “The neurosurgeon just called. He wants to do surgery today to fix the shunt.” Alton and Shailene clapped their hands in excitement. Hailey smiled and went back to sleep.

6.4 Translocal Textual Policies Shape sTBI Rehabilitation Work

In the vignette above, I recounted numerous issues individuals with sTBI face in acute care liminal spaces. I have framed Hailey’s functional recovery as that of an ‘in-betweener’ as described by Dr. Oliveri and Dr. Pascale in Chapter 5. Hailey is not improving quickly enough post-sTBI to be considered a clear candidate for inpatient rehabilitation. However, after successful medical intervention following months of complications, she is improving slowly. She represents a state of liminality as she rests between determinate borders of functioning set by the rehabilitation world. Hailey’s liminality challenges textually mediated relations reproduced by the Toronto ABI Network, the organization that distributes admission forms and guidelines to enter inpatient rehabilitation. The rehabilitation facilities set these guidelines for entry. Hailey’s recovery straddles between being accepted into a rehabilitation facility and being sent to
complex continuing care (CCC) or to another hospital, based on her recovery in reference to these admission guidelines. Hailey’s possible lack of access to inpatient rehabilitation is hard to accept for her family as she is only 18 years old, and she is ‘doing something’ as Dr. Oliveri described in Chapter 5. This poignancy is purposeful on my part as these types of stories unfold on a daily basis in a Level I Trauma Centre.

During my ethnographic fieldwork, health professionals referenced admission guidelines and forms distributed by the Toronto ABI Network as important documents in their work. Health professionals complete these forms and abide by these guidelines to assist individuals with sTBI to gain access into local rehabilitation facilities. According to their website (http://www.abinetwork.ca/about-us), the Toronto Acquired Brain Injury Network assists hospitals and community-based programs to connect people with Acquired Brain Injury (ABI) with required services. Traumatic brain injury (TBI) includes a subset of these individuals. People with TBI have acquired a brain injury resulting from trauma, as opposed to other medical events, such as a stroke or a tumour.

Forms and guidelines reproduced by the Toronto ABI Network occur as “discreet forms or units of organization” (D. E. Smith, 1999, p. 157), creating ruling relations for inpatient rehabilitation. One specific form, the ABI Resource Tool (Figure 2), takes precedence over other forms and guidelines. D. E. Smith (2005) described the interaction of texts as interlocking or, alternatively, intertextual in a hierarchy of texts. The ABI Resource Tool is a hierarchical text that designates admission criteria for the three inpatient rehabilitation facilities in Toronto, Ontario, Canada. The ABI Rehab Resource Tool designates minimum textual requirements to enter inpatient rehabilitation, based on a widely used cognitive scale—the Rancho Los Amigos Levels of Cognitive Functioning Scale. There are eight levels to this scale, listed as follows:

<table>
<thead>
<tr>
<th>Level 1</th>
<th>No response</th>
<th>Level 5</th>
<th>Confused – inappropriate – Non-agitated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 2</td>
<td>Generalized response</td>
<td>Level 6</td>
<td>Confused – appropriate</td>
</tr>
<tr>
<td>Level 3</td>
<td>Localized response</td>
<td>Level 7</td>
<td>Automatic – appropriate</td>
</tr>
<tr>
<td>Level 4</td>
<td>Confused- Agitated</td>
<td>Level 8</td>
<td>Purposeful – appropriate</td>
</tr>
</tbody>
</table>
This document is meant to serve as an additional method of communication between acute care facilities upon repatriation of patients with an ABI, and to provide suggestions that will help facilitate the transfer to an inpatient ABI rehabilitation program.

This document includes a checklist (based on admission criteria for inpatient ABI rehab) and the following resources: Rancho Los Amigos Scale and Tips for Managing Challenging Behaviours in Inpatient Settings.

The checklist below indicates any outstanding items that need to achieved (unchecked boxes) for admission to Regular Stream inpatient ABI rehabilitation.

- **Medically Stable/No Acute Medical Issues:**
  - No ventilators
  - No acute psychiatric issues
  - No trach (exceptions may be made on case by case basis, please contact the ABI Network)
  - No restraints (1 to 1, physical or chemical for the past 48 hours)
  - No exit-seeking.

- **Rehab Ready**
  - Tolerance: 2 – 3 therapy sessions per day for 45 – 60 minutes each session, 5-6 days per week
  - Demonstrates daily motivation
  - Cognitively able to participate and progress in rehabilitation
    - Follows one to two step commands
    - Demonstrates potential for improvement (i.e. carryover of new learning)
    - Demonstrates sustained attention
    - Oriented x 2 (person & place – e.g. “hospital”, not necessarily the name)
    - Demonstrates some insight into reason for admission and deficits
    - Rancho Level 5 or higher on the Rancho Los Amigos Scale
  - Team can identify rehabilitation goals

- **Discharge Destination Discussion**
  - Discharge location in place
  - Support and resources at home discussed
  - Expectations from rehab discussed (patient’s expectations and rehab program’s expectations)
  - Consent obtained

- **Early Referral Notification** form submitted to the ABI Network *

*For information on Slow Stream rehabilitation or information on how to connect with your local ABI Provincial Navigator, please contact the ABI Network at 416-397-3057.

*Please make sure to submit an Early Referral Notification form when it is determined by the team that a patient will likely benefit from inpatient rehabilitation but the patient is not yet rehab ready. For more information or to download the form, visit [http://www.abinetwork.ca/inpatient-forms](http://www.abinetwork.ca/inpatient-forms)
Textually mediated relations for sTBI rehabilitation weave together in interlocking texts. Textual relations mediate the provision of rehabilitation for those individuals with sTBI likely to fit specific criteria, excluding those individuals who do not approximate admission criteria. One interlocking text with the ABI Resource Tool includes the Early Notification Form, used by acute care facilities to track possible rehabilitation candidates in the system—for example, prior to repatriation to a home hospital. There are two streams of inpatient rehabilitation programs: (1) regular stream, and (2) slow stream. Regular stream rehabilitation may be up to six to eight weeks or less and has the most beds available. Slow stream rehabilitation is for individuals with sTBI with slower recovery, up to 12 to 16 weeks, and has very limited beds available.

Two additional interlocking texts are used in coordination with the ABI Resource Tool: (1) High Intensity – General Admission Criteria, and (2) Low Intensity General Admission Criteria. These electronic texts further elaborate on guidelines to enter inpatient rehabilitation, providing guidance to assist patients to achieve these goals. To enter High Intensity regular stream inpatient rehabilitation, an individual with sTBI needs to meet the following criteria: Level RLA V or higher, medically stable, tolerance for several daily hour-long therapy sessions, age 18, potential for improvement, and clear rehabilitation goals. To enter slow-stream Low Intensity General Admission Criteria, individuals need to meet the following criteria: RLA Levels III to V, able to tolerate 10–15-minute sessions several times per day, and have a slower rate of recovery.

The language of the ABI Network discursively organizes conversations, priorities, and rehabilitation work of health professionals on the trauma ward in biweekly rounds and in their rehabilitation work. Admission criteria reproduced in the ABI Network guidelines constitute what is considered recovery from sTBI. Rehabilitation work is coordinated in relation to which individuals are most likely to approximate these admission criteria; these decisions happen quickly. As Ursula, one of rehabilitation professionals explained, the pace of decision making has become so fast with increased repatriation or movement to home hospitals, she makes decisions about discharge in one session or in a maximum of two sessions. Individuals with sTBI whose functioning does not approximate these rehabilitation admission criteria have no clear discharge destinations and face uncertain futures. For rehabilitation work on the trauma ward, individuals with sTBI who are most likely to move forward in the rehabilitation continuum have priority.
Coordination of rehabilitation work on the trauma ward occurs translocally through the texts and language of the ABI Resource Tool, which socially signifies which individuals with sTBI will receive the most concentrated rehabilitation work. In acute care, economic priorities governed by the MOHLTC focus on medical procedures, with limited resources for rehabilitation. D. E. Smith addressed the pervasiveness of texts within the social: 1) as a means to coordinate people’s activities and 2) as a means of repression—to suppress divergent perspectives through institutional discourse (1999, 2005). D. E. Smith (2005) described how texts act as a key juncture between people’s activities and the ruling relations within institutions:

Institutions exist in the strange realm in which social relations based on texts transform the local particularities of people, place, and time into standardized, generalized, and especially translocal forms of coordinating people’s activities. Texts perform at that key juncture between the local settings of people’s everyday worlds and the ruling relations (p. 101).

Wanda, one of the nurses, discussed how the daily work activities of health professionals on the trauma ward become socially organized in relation to inpatient rehabilitation admission guidelines. There are many steps involved in ensuring health professionals coordinate their work practices in accordance with these admission guidelines:

Wanda: So, it’s a collaborative team effort. We [the trauma team] make sure they’re [the patients] medically cleared and stable from either a TBI perspective or any other injuries they may have. OT [occupational therapy] will basically use the Rancho Scale. So, when they’re in the appropriate level, we’ll apply to rehab as well when physio thinks they’re appropriate. We just make sure they’re safe to go to rehab. So, if they had observers, we make sure they wean the observer and they’re managed without the observer. We ensure that the family is aware that they’re ready for rehab and we get buy-in from the family and then we apply.

The scenario described by Wanda is the ‘best-case scenario’: the individual with sTBI improves, the team works together, and the patient attends a rehabilitation facility. However, a number of other possibilities exist, including patients being sent to repatriation hospitals to wait for inpatient rehabilitation or returning home as they do not meet admission criteria but no longer want to stay in a hospital. There are also individuals with sTBI who do not meet the admission criteria for inpatient rehabilitation and are not accepted by any other healthcare facilities due to the seriousness of their medical condition or in not having access to provincial healthcare (e.g. OHIP funding). Individuals without OHIP funding cannot enter any other healthcare space aside from acute care; as one rehabilitation professional, Thelma, described: “acute care is mandatory,
but everything else [inpatient rehabilitation, complex continuing care, long-term care] is optional”.

Forms from the ABI Network regulate entry into inpatient rehabilitation through the reproduction of institutional discourse that define priorities across numerous healthcare locations and various sites, including peoples’ homes where someone with sTBI can be waiting for admission. D. E. Smith (2005) described texts as institutional coordinators: “Texts are key to institutional coordinating, regulating the concerting of people’s work in institutional settings in ways that impose an accountability to the terms they establish” (p. 118). D. E. Smith (2005) conceptualized texts as occurrences in the act-text-act sequence; texts are a part of ongoing activity and should be analyzed as abstract and separate, as they enter into and coordinate action sequences temporally. Summer, a rehabilitation professional on the trauma ward, outlined these act-text-act sequences in negotiating entry from the trauma ward to a rehab bed:

Summer: In rehab, they don’t take patients with observers or with behavioural issues that are unmanageable for them. So, we try and problem-solve those behavioural issues and try to negotiate creative solutions. You know, alternatives to observers. There’s a lot of back and forth. So, if the rehab centre says “okay, we can’t take them now because of X, Y and Z,” then we try and solve X and Y, and figure out a compromise on Z, and then re-advocate, and reapply. So, it’s a dialogue.

Beyond the specifics of the form, different facilities also have specific program properties (for example, two are locked units, one has a Watchmate system—a wrist-based security system to prevent escape, and one has a behavioral program). Health professionals on the trauma ward coordinate their rehabilitation work with individuals with sTBI through application of their work knowledge of the admission parameters of these inpatient rehabilitation programs and through discursive work with inpatient admission coordinators. To assist patients with sTBI to meet these established and negotiated parameters for entry, health professionals on the trauma ward perform intensive and complex work sequences with individuals with sTBI to assist them to gain entry into other healthcare spaces. I argue that health professionals on the trauma ward engage in an ideological code of their work practices to meet these varied and complex responsibilities.

6.5 The Ideological Code of the Trauma Ward

Once a person with sTBI is considered medically stable, then ideologically, they do not belong in acute care as they no longer require extensive medical procedures. Medical procedures
in Ontario’s hospital-based funding model garner the most funding; rehabilitation work is not a part of this funding model for TBI in acute care. I will discuss the specifics of this funding model in Chapter 7. I argue in this current chapter that the paradox of individuals with sTBI in acute care is that these individuals require intensive rehabilitation work at this time to move them to other healthcare spaces, with very limited resources to do so. Some of individuals with sTBI improve quickly, some improve slowly, and other individuals with sTBI experience numerous medical complications with little or no progress.

Health professionals on the trauma ward, working with patients with sTBI, in addition to numerous other individuals with complex injuries, develop an intensive work schedule and set of behaviors in the form of an ideological code (D. E. Smith, 1999). These work behaviours and schedules approximate those of the academic star (Solomon, 2008) described in Chapter 3. Being an ‘academic star’ shapes the work lives of those in the academy through discursive organizers such as having ‘star status’ or being among ‘those who rise to the top’, and through various material signifiers of academic stardom such as awards, grants, and publications. Health professionals on the trauma ward develop similar intensive work routines to those of the ideological code of the academic star (Solomon, 2008), as Ursula indicated: “We all work crazy work hours.”

The ideological code of working on the trauma ward meant rehabilitation professionals stacked their patient lists with sometimes upwards of 20 patients with varied and complex medical conditions. Rehabilitation professionals displayed onerous work routines and regiments to complete their corporately expected, fast-paced, acute care work and hidden rehabilitation work. They had numerous strategies to cope with these demands, including endless crib notes and task lists for each patient, comfortable running shoes and pedometers, commissural tête-à-têtes with the trauma ward team on particularly difficult days, skipped lunches, and evenings and days off at home in front of the computer completing their electronic documentation. The nurses reproduced similar behaviors, dashing from room to room, bed to bed, task to task, patient to patient, and chart to chart, with Voicera, their neck-bound paging system, simultaneously echoing further requests, questions, and demands, as they went about their daily work. Health professionals also had numerous other responsibilities such as charting, attending rounds, supervising students, teaching at the university, and professional meetings, in addition to seeing patients.
This ideological code of the trauma ward team formulates priorities for rehabilitation work for the health professionals on the ward—in essence, everything becomes a priority. While corporate hospital mandates press for moving patients out of the hospital quickly to make space for the next patient, rehabilitation work requires time-consuming and complex work sequences. I argue that these health professionals develop this ideological code of intensive work routines in response to their complex caseloads, including those individuals with sTBI. For example, Gabriela, one of the rehabilitation professionals on the trauma ward, described her priorities as follows: patients with serious respiratory issues such as those with spinal cord injury or sTBI, patients being prepared for imminent discharge, and persons with sTBI on the cusp of being ‘rehab ready’. Gabriela had 18 patients on her caseload. Thus, with time allocated for charting, meetings, and other responsibilities, she could spend approximately 20 minutes with each patient if seen daily.

Rehabilitation professionals described their work on the trauma ward and reflected on how, ideologically, they were not ‘supposed’ to do intensive rehabilitation. “It comes from corporate” was one of the many ways health professionals referred to corporate strategic direction. “It comes from corporate” was a discursively reproduced managerial perspective, meaning rehabilitation professionals were not intended to provide intensive rehabilitation—their role was consultative in nature. The following is a transcript excerpt from an interview with Gabriela as she described the actualities of her work. She had previously described a work sequence involving 1.5 hours with a patient, while simultaneously explaining the trauma centre was not funded for intensive rehabilitation:

Lynn: And where does that come from: “We’re not funded for rehabilitation?” Is that a policy?

Gabriela: That’s corporate.

Lynn: That’s their policy or that’s the province’s policy?

Gabriela: I think it’s the province. We are an acute care facility. We’re not funded to do that heavy, an hour a day patient rehab.

Lynn: But you just said that you spend an hour and a half…

Gabriela: But some of our patients can easily…I mean yesterday I spent an hour and a half with somebody, not necessarily particularly all doing rehab, but these people need things done for them. They need to be comfortable after you get them back to bed.
Health professionals grappled with the paradox of rehabilitation for individuals with sTBI as the trauma centre lacked sufficient resources (including staff, equipment, and space), or as some patients improve slowly. The Level I Trauma Centre was described throughout my ethnographic fieldwork as being at capacity, overcapacity, or well overcapacity, such as being at 105% capacity. Sophia, one of the rehabilitation professionals, indicated that when the trauma centre is well overcapacity “the hospital comes to a halt” with far too many patients and not enough beds. Gabriela addressed these contradictions in acute care with limited resources for rehabilitation and numerous time constraints, while individuals with sTBI can experience significant recovery in this acute phase. Rehabilitation work on the trauma floor becomes oriented towards assisting individuals with sTBI in accessing inpatient rehabilitation, as extensive rehabilitation cannot be provided in acute care:

Gabriela: Best practice is that most recovery occurs, if it’s going to, in the first six weeks. You’re better off putting your resources into that brain injury at that particular time. I think, though [pause], it is difficult…For instance, sometimes it is only a very fine minute time that you can work with somebody because that’s when they’re awake or that’s when they're cooperative. You don’t do things the same way as you would in rehab. You couldn’t spend a whole hour assessing somebody because they wouldn't tolerate that. Their injury is too acute. I think we work differently. I think our challenge is when somebody doesn’t go to rehab for whatever reason when they need it. Say we can’t get an observer off of a patient because they’re not quite…they’re still a fall risk, say, and they’re still impulsive. They show impulsivity; they’re a fall risk. So that’s our classic. We can’t discharge the observer. Other than that, they’re ‘rehab ready’. They would do well in rehab. That’s when we really need to put our resources in.

Gabriela’s comments echoed principles for early rehabilitation in a textbook on trauma rehabilitation: “Identify rehabilitation needs and develop a plan of care to address those needs; institute the plan as soon as [the] patient’s medical condition allows” (Robinson, 2006, p. 36). Contradictions in the work practices of health professionals were evident as strategic priorities appeared to fold unto themselves. Trauma is acute care and a strategic priority for the hospital. However, the concept of rehab as a place and not a practice in acute care becomes problematic in the liminal spaces of the trauma centre. Physicians reproduced this concept of rehabilitation as a place incongruent with a Level I Trauma Centre with statements including the following: “This is not a rehabilitation centre,” “We’re not a long-term hospital,” or “We just have resources for the initial stages of critical care.” Dr. Sorenson, however, nixed the paradox of non/rehabilitation in acute care, suggesting instituting a rehabilitation centre on-site:
Dr. Sorensen: So, if this is a big trauma, stroke, and cancer centre, rehabilitation is a given, right? Almost everybody needs it. If they had a rehabilitation for this hospital, a rehabilitation institute, we’ll just send them there and they will do it. And it’s just across the street. If there’s an issue, you [the physicians] could go there. They could go faster because we’re close. It’s not like they’re going to a different institution. They could go sooner. Because right now I have to wait until the guy’s completely well, so he can go. But if he’s just here [at a rehabilitation institute on site], he could go much sooner.

The physician above referring to ‘big trauma’ was referring to the types of patients who took up residence on the trauma ward. The sources of trauma were varied and indeed very traumatic: violent spousal, familial or gang-related physical/knife assaults or gunshot wounds; motor vehicle versus pedestrian or cyclist; motor vehicle accidents that involved large vehicles or occurred at exceedingly high rates of speed; and suicide attempts using guns or moving vehicles. There were patients in recreational accidents, including falls from heights; industrial accidents slicing off or crushing limbs or impaling heads; and work accidents involving falls off buildings or accidents with machinery. A surprising refrain I heard during rounds included: “How many gunshot wounds again?” The nurse for this patient counted through the pictogram with the circles representing gunshot wounds. “Eight, I think” she replied. Patients on the trauma floor had traumatic brain injuries, numerous arm and leg fractures, crush injuries, extensive internal injuries, collapsed lungs, complete and incomplete spinal cord injuries, arm and leg amputations, or recurrent and insidious infections related to the trauma.

6.6 Bifurcation of Rehabilitation Work with sTBI

Moving individuals with sTBI to other healthcare facilities from a trauma centre requires intensive rehabilitation work, organized to meet two different objectives: (1) meeting admission guidelines for local rehabilitation facilities; (2) preparing individuals with sTBI who are not improving for other healthcare spaces, such as: repatriation hospitals and complex continuing care (CCC). I argue that rehabilitation work becomes bifurcated on the trauma ward as the work of health professionals is organized in different forms to meet these varied objectives. Doing rehabilitation work to move persons with sTBI into inpatient rehabilitation involves managing significant physical risk as these individuals become more mobile. Preparing individuals with sTBI to live in chronic care facilities such as complex continuing care involves managing and reducing medical risks to allow them to live outside of liminal spaces of the trauma centre.
The language of the ABI Resource Tool, specifically being ‘rehab ready’, is a discursive organizer in the work with individuals with sTBI. Being ‘rehab ready’, as per the ABI Resource Tool, means having no restraints (one-to-one supervision, physical or chemical restraints), and no exit-seeking. Rehabilitation work to reduce restraints according to these admission guidelines dovetails with the Ontario Government’s patient restraint minimization policy (Patient Restraints Minimization Policy, 2001). Frequently, as individuals with sTBI improve and move from lower to higher levels of consciousness, they show agitation in Ranchos Los Amigos Level IV, just prior to being ‘rehab ready’. Addison, one of the health professionals on the trauma ward, described the process of removing these restraints:

Addison: At the hospital, we obviously try to abide by the least amount of restraint policy that we have in place. Which means that we need to constantly look at physical and chemical restraints that we might have in place and truly evaluate whether it is necessary—what we can do and when we can remove it.

Rehabilitation work on the trauma ward with individuals with sTBI showing agitation or confusion develops into very complex forms of work in trying to minimize restraints while maintaining safety. Chemical restraints are medications to decrease agitation. Physical restraints include two-point restraints—usually having two arms restrained to the bed—or in rare cases, four-point restraints—having all four limbs restrained to the bed. Freedom splints—full arm splints to prevent the elbows from bending—are used to circumvent patients from reaching to their head or body to pull out feeding tubes, parts of tracheostomies, IVs, catheters, or neck braces. Observers or sitters are considered one-to-one restraints; these observers can also be shared amongst several patients. Observers are intended to assist in preventing patients from pulling out tubes or escaping from the trauma ward.

The agitation phase of sTBI is a social signifier for health professionals on the trauma ward that intense rehabilitation work is required to: (1) prevent injury through falls or unplanned removal of technological devices; (2) increase surveillance of the individual; and (3) increase rehabilitation resources to transition the individual to Los Amigos Rancho Level V. Rehabilitation on the trauma ward addresses managing this agitation in trying to pull out lines and tubes; this phase usually means an individual with sTBI is recovering. Observers on the trauma ward have little or no training in sTBI; they are not licensed care professionals. As a
caregiver for someone with a sTBI, I also sought to manage this agitation through purposeful activity, as I described in a pilot interview for this dissertation:

Lynn: We had had a book where we would record what she had done that day, what we talked about, and we brought in pictures. I had brought in all sorts of basic occupational therapy objects that you would use, cones that you stacked one on top of the other for purposeful activity or cubes, or monkeys that you string one from the other—basic stuff I would have used in rehab years ago that we had at the office where I worked. I would give her things like cones and that would keep her entertained. It was purposeful activity that kept her hands away from trying to pull the tubes out all the time. She’s at the level where she knows it’s an object and she knows cause and effect. If she bangs those two objects together, they’ll make a noise. If she stacks one on top of the other, they fit together neatly and that she has two hands. I would loosen up the restraints so that she could manipulate things in her environment. At that point, that would be in the first ten days, she knew enough to know ‘Those are objects’. I would take my iPhone, play music, and then sing with the music. I would get her to try to mouth the words and she would love the iPhone. She’d shake the iPhone and make it change the noise and the music that was coming out. I did a lot of that, especially in the evenings when I would go. The other patients as well would want to hear the music and the sitter would too. Just anything to stimulate her. I brought different scents and I would have her smell these scents. Anything to stimulate the brain to say, all these things are available. There are sounds, there are scents, there are objects, there is talking, there is interaction, and there is movement.

Rehabilitation work is coordinated in meeting inpatient rehabilitation criteria, including reducing restraints. As I described earlier in this chapter, D. E. Smith suggested that texts work as (1) a means to coordinate people’s activities, and (2) a means of repression through institutional discourse. In meeting extensive caseload demands, other forms of rehabilitation, including the intense work with individuals with sTBI recovering very slowly, become repressed in the liminal spaces of the trauma centre. As Gabriela mentioned earlier in this chapter, health professionals putting their resources into preparing individuals with sTBI to be ‘rehab ready’ needed to be efficient in this work. Reducing confusion and promoting insight was addressed through repetition by the whole team, occurring in tandem with other goals, such as increasing mobility, as described by Vivian, one rehabilitation professional on the trauma ward:

Vivian: To promote insight? Writing things down on the board so that they know the date, they know what their injuries are, if we can jot them down for them. Again, for me it’s just the conversation and reiterating the same thing. Sometimes, you might even write things down on a piece of paper and post them in different spots in the room. We’ve done that before. So, the patient can look to one side and say, “Jim, you’re not supposed to get up on your own. Remember, use the call bell. Wait for your nurse,” whatever it may be. That’s a strategy we use often. Ultimately, it’s just the frequency of
visits and making sure you communicate with the rest of the team. We all have the same plan. This is what we’re working on with Jim, building his insight, reminding him that he shouldn't be getting up on his own, and reminding him that he can’t pull at this line or whatever it is. Whenever anyone goes into the room that’s part of the care team, we’re providing that same information to him. So hopefully with time and repetition, he will remember that he’s not supposed to be doing some of the risky behaviours that he might be doing.

In minimizing restraints and preparing individuals with sTBI for other healthcare spaces, bedrails were put down, beds were kept in lowered positions, and mats were placed on the floor. These interventions acknowledged that there is risk in less restraint and accommodated for these risks in case individuals with sTBI fell out of bed. One-on-one observers were decreased, and observers were hired by the trauma centre to supervise patients to prevent pulling out tubes or falling, rather than using physical and chemical restraints. Patients’ families were discouraged from providing constant 24-hour supervision or extensive supervision during this phase, as these were barriers to accessing inpatient rehabilitation. Placement of the patient in a particular room was a form of restraint, as rooms closer to the nursing station, rooms with multiple beds, or rooms with glass walls provided additional surveillance. Hospital bedrails served as a form of restraint as well.

Rehabilitation work aimed at reducing restraints in meeting inpatient admission policies formalized health professionals’ work practices on the trauma ward. Exit-seeking and the need for restraints were prohibitive to being admitted to inpatient rehabilitation. Not being able to speak or eat well would not prevent someone to being admitted to inpatient rehabilitation; these are not exclusion criteria listed on the ABI Referral Form. Ursula, a rehabilitation professional on the trauma ward, described a person with sTBI waiting to be accepted into inpatient rehabilitation. Limitations in oral movement and speaking were his ‘last horse’ in the horserace of improved functioning. But the risk for falling was the prohibitive factor in being admitted to inpatient rehabilitation:

Lynn: Why did you say he has newfound mobility?

Ursula: Oh, because he’s working a lot with the physio. The physio is progressing him and progressing him. Sometimes it’s like a horse race. You have your cognition, you have your function, and you have your mobility. And these are all head-to-head and neck-to-neck. And ideally, they’re all progressing well together. But his body is moving ahead of his head. His memory impairments, his problem-solving, his attention to detail, his judgment are still not as good as his physical walking. Which puts him at a risk to try
more, fall more, and do more dangerous things. Having said that, he also cannot speak. He has no voice. So that is the last horse right now. He can’t tell us what he needs right away. It takes him effort to speak. One, because he doesn’t have vocal sound; two, because he has motor planning issues and it makes it hard for him to move his lips. ENT is looking at that. Speech is looking at that. But that’s his last horse. It’s not coming along as quickly as we would like it to be. Probably part of the motor planning—it’s hard for him. He doesn’t want to eat. He looks very passive—his whole face. It’s effortful for him to smile, to open his mouth, do all those things. So that might be affecting his eating as well. That is what we’re pushing. But that’s not going to be a prohibitive factor for rehab.

Lynn: Is it typical that somebody starts walking before their judgment comes in, if they’re able to walk safely?

Ursula: I don’t think that there is a typical pattern. Because I see people who have great judgment and have great paralysis as well. And they work well. But their paralysis comes along slower. I don’t know that it necessarily always follows that physical comes first. I do have that category of people who are walking, talking, but they’re very unsafe. They’re trying to escape. Which is why the floor is alarmed.

Rehabilitation work in abiding by the least restraint policy has its downside on the trauma ward. Despite having wrist braces that activate the security system, patients with sTBI still occasionally manage to escape. As Ursula has pinpointed above, individuals with sTBI do not recognize the safety risks outside of the trauma ward and even the hospital. Extensive hospital resources and even police services are required when individuals with sTBI manage to evade surveillance systems put in place on the trauma ward, as Ursula explained:

Ursula: A couple of weeks ago, there was a woman who really was confabulating a lot and thought she was absolutely fine to go back to work and tried to escape. [Someone] spent a lot of time just capturing her, calling 911, and getting the police to bring her back. This was a woman physically well but not thinking well. But in this case, she’s just a little bit behind in her judgment. And it’s not malicious.

As I spent over a year performing participant observation on the trauma ward, I observed many patients wandering the trauma ward with little to occupy them. They moved well physically and were ambulatory but did not meet inpatient rehabilitation admission criteria. The trauma ward is locked if there is an individual with sTBI who is wandering and exit seeking. I asked Ursula why I often saw patients with sTBI wandering the halls without someone to work with them. She addressed the lack of budget for rehabilitation in the trauma centre:

Ursula: We don't have enough people to work with them. I could spend 20 minutes with you (as a patient) and that’s it. This morning in an hour, I saw three people, of which two
of them have cognition changes because of brain injury, and one of them has a cognition change because of delirium. Those three people split into one hour is 20 minutes each. I will not go back to them today because I haven’t even gotten to my other people.

Family members described their frustration with the paradox of limited rehabilitation in acute care, when this rehabilitation work would facilitate faster access to other healthcare spaces. Some families critiqued the infrequency of rehabilitation work and limitation in services available. The family member in the transcript excerpt below expressed his frustration with the lack of rehabilitation for his father. Economic contingencies mandating acute care as primarily medical are incongruent with rehabilitation requirements to assist patients to show improvement. This patient had had numerous medical complications due to his injuries and his family member had spent over a month at his bedside during this time. As these complications had resolved, the family member indicated his father needed daily therapy to improve:

Son: I freaked out last week. He was laying here. I have insurance. If you don’t want to do it, I’ll have my own people in here. But they don’t want to let your own people in here. Well now they say they’re going to let the massage therapist come in. He’s cramping up and, because he’s been lying around. It looks like they’re doing stuff think they make it look like it is happening but is not happening the way you want it to happen. Maybe my expectations are too high. Maybe it’s just me.

Lynn: I think going back to that ideal, so what’s the ideal of what happens? What would happen every day?

Son: Yes, they would come in, and they could shower him. It is work right, to take a shower. There should be an OT or a physiotherapist working with him. Ensure he does his exercises. Start somewhere and build on it. Because he could be walking I believe. He could be on his own. It’s just that it takes work.

While rehabilitation work with individuals with sTBI who were improving focused on meeting inpatient rehabilitation admission criteria, work with individuals unlikely to become ‘rehab ready’ focused on different goals. Rather than being concerned about their safety and risk management (such as avoiding falls or exit-seeking), rehabilitation work with individuals with sTBI who remain in hospital can be organized around diminishing medical risks associated with open body orifices, including tracheostomies. In these cases, rehabilitation work focuses on the slow process of tracheostomy removal. This process is referred to as corking, whereby the tracheostomy tube is gradually covered and no longer used; it then heals over. A tracheostomy team with various health professionals, including physicians, meets weekly to address removal of this medical implement through a series of graduated steps.
Many of the sTBI patients with tracheostomies also have diminished physical conditions and frequent medical complications, as described in Chapter 5, as their bodily systems are severely compromised after sTBI. Promoting decreased reliance on medical implements is achieved through rehabilitation work with these individuals with chronic sTBI, suspended at a critical nexus of human functioning—unable to breathe and clear their lungs and airways unassisted. Without rehabilitation work—a series of critically orchestrated plans and steps—these individuals would remain in acute care liminal spaces indefinitely. Addison, a health professional on the trauma ward, explains the purpose of corking. This process involves changing the cover over the tracheostomy by gradually closing it so individuals can eventually breathe on their own:

Addison: In order to actually cork someone, you need to have the right type of trach. So, there’s a couple of different types. There’s non-fenestrated trachs and fenestrated trachs. The fenestrations refer to little slits in the actual trach that allow mucus and air to pass through. When someone has a trach, if it’s a non-fenestrated trach and it has a cuff on it, which is like an inflatable little cuff that just keeps it in place in the trachea, then all of the patient’s air is going to go through the trach. Every time they breathe in and breathe out, it goes through the trach. They don’t use their upper airway at all. Their mouth and nose aren’t involved in the breathing process.

In interviews, during rounds and in conversations with health professions, I asked about the process of corking as it was unfamiliar to me. Discussions in rounds regarding individuals with chronic sTBI often focused on the process of corking. Talk also concentrated on managing other aspects of chronic sTBI, such as pressure ulcers, and contractures—rigid positions of the extremities that develop with limited neurological input to move these limbs. Having a tracheostomy and needing frequent suctioning is a barrier to entering other healthcare spaces, while pressure ulcers and contractures are not. Rehabilitation work to accomplish corking is complex and needs to be carefully coordinated. Eva, one rehabilitation professional, described the careful timing of this delicate process:

Eva: During the corking process, if at any time you need to open it to re-suction again, you’ve reset that timer. Because that means they cannot manage their secretions up through their mouth and cough it out. It means you have to go through there [the trach].

Part of the rehabilitation work of decreasing secretions involves sitting up patients on the side of the bed—dangling. This work often requires two health professionals to perform this task. Eva described the benefits of dangling with individuals with chronic sTBI:
Eva: On the ward, if they’re stable enough, I would want to mobilize them. And when I mobilize them, most of the time if they’re really low level, they do have secretions and they’re a trach—they do start to spontaneously cough. They cough and they drool. Lots of stuff comes out. I find that’s effective. That’s what my goal is.

Lynn: When you say you mobilize them, what do you mean?

Eva: Mobilization for someone who’s really low level. Say they’re hemiparetic or there’s no motor function of the lower extremities, just sitting at the edge of the bed is mobilization for me. Dangling them. We find that very effective in mobilizing secretions, meaning getting their spit to move around and come up.

Lynn: What else does dangling do? It helps with their secretions?

Eva: Yes. It helps with their circulation. It helps with their orientation and stimulation neurologically. Dangling, we can take that opportunity to allow them to weight bear through their arms. Even weight bear through their legs by putting the bed low enough that their feet are touching the ground. They get a sense of proprioception. We can also test righting reactions, which are more involuntary. We can do that in sitting as well. Even to let them fall to one side, and then see if they stick their arm out to save themselves. There are a lot of good benefits to dangling.

Implementation of physical strategies, including dangling, related to the goal of corking and being able to move individuals with chronic sTBI to other healthcare spaces. Other non-textually mediated rehabilitation work, such as working with cognition through sensory stimulation, had ambiguous support on the trauma ward. Celeste, one of the rehabilitation professionals on the trauma ward, discussed whether cognitive interventions with individuals in lower levels of consciousness are rooted in evidence-based practice. Celeste suggested evidence-based support is mixed for cognitive stimulation and not tied to any specific institutional relations related to discharge at lower levels of consciousness. Celeste described how this work was relegated to families to complete:

Celeste: At Rancho I, II, or III, how much sensory stimulation actually promotes recovery? I was just doing a lit review about it. And there was sort of mixed… There wasn’t a huge consensus on how well it promotes [recovery]. How much stimulation, what type of stimulation helps? But there’s literature on it. You say, if you have anything that you want to bring in [to families]: music and stuff like that and reading. I had somebody that would…he would read a book. Even though, the next day he would forget what chapter he was reading. But you’d give him a book to occupy his time and just keep him stimulated.

Zoe, another health professional on the trauma ward, questioned evidence-based support for cognitive stimulation strategies. She indicated that she would provide these stimulation
strategies to families to try, rather than institute them in practice due to time constraints. She compared past rehabilitation practice with current practice, in terms of evidence-based support for these strategies:

Zoe: I think in the past, OT and SLP used to do more focused stimulation with people with low-level brain injuries. But there's no evidence that it actually wakes the brain injury up. A lot of times I’ll give focused stimulation strategies to families for really low-level brain injured patients...

Lynn: And when you say low level, do you mean like...

Zoe: Rancho II, III.

Lynn: They’re not...Are they minimally conscious or they’re beyond that?

Zoe: Yes, they’re not consistently responding to their environment. They’re not following commands consistently.

Lynn: There’s just not a lot of evidence built around what’s helpful at those stages?

Zoe: No, there’s nothing you can really do to speed it up. To speed up progression to... There’s no evidence that focused stimulation works to speed up the progression of cognitive recovery.

6.7 Recruitment of Families into Rehabilitation Work

As both Celeste and Zoe have addressed above, families become quite involved in care on the trauma ward for individuals with sTBI. Rehabilitation professionals described their own efforts to recruit family members into rehabilitation work with individuals with sTBI due to limited resources. I also talked to many family members who stayed on the unit for many hours daily to assist the individual with sTBI in any way they could, including exercise routines or ensuring their family member was out in a wheelchair. I have included another vignette regarding Hailey and her family as they assist Hailey in her rehabilitation during her recovery:

One month later, Parker joined Shailene and Alton as they visited Hailey on the trauma ward. It was the last week of March, and Parker had come home for the weekend from university at Shailene’s request. They had marched in March for Our Lives, a protest march held in cities around the world after 17 people, including students and teachers, were killed in a school shooting in Parkland, Florida; numerous others were injured. Many of their friends had
marched with them to support stricter gun control laws in the United States and increased awareness of gun violence around the world.

Shailene, a senior in a high school in a major urban Canadian city, had lock down drills at her high school on a regular basis. From her time spent on the critical care and intensive care units, and on the trauma ward, Shailene had learned the seriousness of gun violence in her own city. Parker also wanted to see Hailey again as he was usually away at university. He decided to spend the day on the trauma ward with his sisters, and Alton had joined them. Isabelle worked as a teacher at a local middle school and was teaching class today. She would arrive later this afternoon to join the family.

Just as they arrived in Hailey’s room on the trauma ward, a crowded room with three other patients, the social worker also joined them. The family jostled around various medical poles, equipment and numerous chairs, and two other patients in hospital beds. Hailey looked toward the family as they entered the room and gave them a withering look. Seeing the mass of chairs, beds, equipment and people, the social worker suggested that she and Alton find another room to talk. They quickly found a quiet room outside of the unit.

The social worker gently queried if Alton and his wife Isabelle had considered any of the complex continuing care facilities they had previously discussed. “Hailey is stabilizing medically after her recent surgery. She has not improved enough to go to rehab and we do not see her being ‘rehab ready’ soon. She needs to be able to participate in therapy on a daily basis for several hours per day and she is not able to do so. If she is stable medically and she does not improve, she will need to go to complex continuing care. We need to apply now since the wait is quite long. She may also be transferred to a hospital close to your home as she waits. This is a trauma centre and we need to make room for other seriously injured patients.” “Okay,” said Alton. “Isabelle will be here later and we will look at these forms.”

Serendipitously, Alton asked the social worker: “How much rehab will she get in complex continuing care?” “I do not think she would have access to a lot of rehab unfortunately” replied the social worker. “Hmmm,” replied Alton, sounding annoyed. “Well, how about this other hospital?” asked Alton. The social worker tried to reply honestly. “Well, it depends on the size of the hospital. A larger one will have some rehab, perhaps not as much as this hospital. A small hospital would have limited rehabilitation,” answered the social worker.
Alton countered, “She sees a therapist two, occasionally three days per week here, and you are telling me she will have much less rehab when she is discharged?” The social worker, wanting to be transparent with Alton, glumly shook her head in agreement. The social worker offered: “Some patients’ families hire private therapists in acute care to supplement the hospital’s rehabilitation program. Unfortunately, as Hailey’s injuries are from a riding accident, she would not have access to the significant funding available through auto insurance benefits. That coverage is quite extensive, but unfortunately there are no similar public funds for TBI in acute care to allow for additional private rehabilitation.”

Meanwhile, in Hailey’s room, Shailene decided she and Parker had work to do. Shailene, well accustomed to being on the trauma floor and ‘working’ as a family rehabilitation assistant extraordinaire, showed Parker the ropes. “Okay Parker, the first thing we need to do is round up a tilt wheelchair and hope that we can actually find some leg rests. There are a lot of other patients on the trauma unit with serious injuries and not enough of these chairs. We might just need to steal one from another patient if we want to take Hailey for a walk outside. At least the hospital is downtown, so we can watch people going by from the coffee shop on the main floor. Are you up for it?” Parker, unaccustomed to seeing shy Shailene take charge so forcefully, aptly answered “Yes”.

“Okay,” said Shailene. “Let’s find our physiotherapist, Noah. He is the master of finding wheelchairs and all of the necessary parts!” Shailene and Parker headed off through the crowded hallways of the busy trauma ward. Parker looked in surprise at the sets of two police officers sitting at several of the doorways of patients’ rooms. “This hospital gets a ton of people with gunshot wounds or they have been violently assaulted with knives, crowbars, you name it,” Shailene explained rather nonchalantly for an 18-year-old. “This is where those patients come for medical treatment. It’s just part of being in a big city.”

“Noah” Shailene yelled as she trotted towards the tall Australian physiotherapist who worked full-time on the trauma ward. “Hey mate! Here to cause trouble again!” he said as he laughed. “Very funny” replied Shailene. “Listen, we need Hailey in one of those tilt chairs ASAP and we don’t see one anywhere!” “Ah,” replied Noah. “I think I can find one, I have the keys to the kingdom” he said, as he shook the keys for the equipment room in the air. Noah,
Shailene, and Parker headed down to the trauma ward equipment room, a tangled mess of wheelchair parts, wheelchairs, walkers, and various other rehab equipment paraphernalia.

Noah easily pulled out the tilt chair from the corner of the equipment room but finding the leg rests proved to be much more challenging. Parker, Shailene, and Noah spread out across the four corners of the equipment room, as though they were looking for a lost set of keys. “Okay, everyone focus!” said Noah, holding up one of the two required footrests. “It is silver and bent near the end with a black footplate.” “They all look like that” grumbled Parker. “I know!” replied Noah, as Hailey grinned and dashed into a pile of jumbled leg rests. “Found it!” “Why don’t they have more wheelchairs and leg rests?” asked a bewildered Parker to the other two. “This is Ontario healthcare,” Noah replied sardonically “we are lucky to have the equipment we do!”

As they headed back to the room, Noah called to Ananya, Hailey’s occupational therapist, to assist him to transfer Hailey into the wheelchair. Unfortunately, Hailey had not been overly responsive since the accident and during the many medical complications that she had experienced. Hailey was usually quite docile, speaking few words. However, she had been more interactive after her recent surgeries to correct hydrocephalus. The swelling gradually went down on the left side of her head and did not reappear after the second surgery. She had been free of fevers and infections for the past week; she was quite healthy compared to months past.

Her family and the health professionals had been noticing changes in her demeanor in the last several days. Lately, Hailey moved around in bed and eagerly accepted being placed in the wheelchair. She seemed bored and exasperated in bed. Shailene noticed that she frequently kicked her left leg out of the bed, lying it over the side of the bedrail. Hailey had started to be irritable when she spoke and she sometimes cursed profanities, which was unlike her. She had started to tug at her IV and feeding tube in annoyance.

There was an observer in the room who would dissuade her from tugging at her tubes. The observer also attended to the other patients in the room. Hailey looked at the rehabilitation professionals and her family. “Out of bed!” she exclaimed, as she rocked in the bed. “Okay,” said Ananya, “but you need to calm down or we cannot transfer you.” Hailey lay very still in the bed and looked up at Ananya with the most angelic look she could muster. “Okay, let’s pivot
transfer her” said Ananya. They stood her up, one rehabilitation professional in front of her and the other behind her. They moved her light frame easily into the chair. Hailey was normally quite muscular, but she had lost 20 pounds since the accident, and she could easily be transferred by two people.

Shailene reached towards Hailey to fix her pyjamas and to rearrange the feeding and IV tubes. Hailey quickly pushed her sister’s hands away, crying “Off!” She suddenly grabbed for the feeding tube with both hands. Ananya, like quicksilver, caught Hailey’s hands before they reached the feeding tube in her stomach. “Noah,” said Ananya, “I think we need the Freedom splints right away.” “What are those?” responded Shailene, Parker, and Alton in unison. “They are splints that we will strap to her arms that will not allow her to bend her elbows. They will help to prevent her from pulling out her tubes” replied Ananya. “Doesn’t sound like freedom to me” quipped Parker.

“We use Freedom splints so we do not have to use two-point restraints to tie someone’s arms if they are agitated and pulling at their tubes, or four-point restraints to tie someone’s arms and legs to the bed if they are really agitated and trying to get away. Otherwise, without the Freedom splints, she will try to pull out her tubes and even climb out of bed. We will also talk to the nurse in charge of the beds and have her moved closer to the nursing station where they can watch her more closely. We are going to put her in a low bed close to the floor with mats on the floor in case she does fall out of bed as she is moving a lot more. She will need an observer all to herself.” “Why is she being so difficult?” asked Parker. “I thought she was getting better.” “Agitation usually means she is getting better” replied Ananya excitedly. “However, we need to keep her safe in the meantime, so she does not pull out her tubes or fall and hurt herself.”

At times, as in the vignette above, family members and health professionals worked together in unison. Other times, rehabilitation professionals described significant stressors in working with families. Tensions and contradictions are evident in the following transcript excerpt regarding if there is reliance on families on the trauma ward, as described by Vivian:

Lynn: Is there very much reliance on families to help with care for people with acute severe TBI?

Vivian: It depends on the patient and the family’s presence. Some family members are here day in and day out. Recently we had a patient who did have some behavioural
issues but the family… We requested multiple times, knowing that, we can’t have an observer at [rehab]. We need to try and discharge the observer before a patient goes to rehab. The family, regardless, kept staying overnight and were here most of the day. They weaned their daytime hours a little bit but not significantly. At some point, you have to respect the family’s choice, although it might not be what we would like in terms of being able to progress that patient. You have to work with each family individually. Some patients really thrive well when their families are present. Their families are very engaged in helping them to wash, feed, or get them set up with their meals, or whatever it may be. Other families are very hands-off. They want to be present, but in terms of being involved in their family member’s care per se, they’re less so. We take it case-by-case, and patient-by-patient, and try to work together and engage them as much as they feel comfortable. I wouldn’t say we rely on them. But at the same time, it’s definitely—when we can get them involved, a benefit to the patient usually.

Families described arranging shifts for supervision for individuals with sTBI, arranging these schedules in extended families and divorced families and stepfamilies, and with grandparents, cousins, and friends. Assorted familial and non-familial relations were engaged in the delicate coordination of care and rehabilitation for their family member, assigning themselves to this vital, hidden work. At times family members challenged and confronted health professionals involved in the trauma care of individuals with sTBI. Other times, they shared deep bonds with health professionals in liminal spaces of the Level I Trauma Centre in their shared work. Families appeared to attend the hospital for various reasons, as described by Sophia, one health professional: 1) the situation was a crisis; 2) they thought their family member may die; 3) to make sure things were done properly; or 4) they thought that it was their job to do this work.

Families embarked on the work of early brain injury rehabilitation with seriousness, vigour, and humility in difficult circumstances. Families trained themselves in the physical aspects of rehabilitation work, giving massages to paretic limbs and bodies, and introducing aromatherapy treatment to awaken individuals with sTBI in lower levels of consciousness. They would accompany the individuals with sTBI for walks with their walkers or canes or in their wheelchairs on the trauma ward, in the hospital, and outside on the hospital grounds for a breath of fresh air and change of scenery. They would suction out tracheostomies superficially, and ensure that medical devices such as neck collars, arm and leg splints, and body braces remained in place and functioned properly. They would do a range of motion exercises, even making up interesting games for their family member, like stretching out their leg to push the pedal of an imaginary bicycle, to encourage them to participate in rehabilitation.
For some individuals with chronic sTBI who experienced multiple medical issues, such as a tracheostomy needing intermittent suctioning, or numerous infections, families arranged 24-hour supervision schedules. One family member described why their family started a 24-hour schedule once on the trauma ward: “It seems like they’re understaffed to me; it’s not really fair for them to have so many patients. I guess they think that most are sleeping at night.” Many families did not fault the quality of work or interaction with health professionals, but rather described the nursing ratios as insufficient. Some family members who spent many hours at the hospital described a deep connection with the health professionals. One family member describing their 24-hour supervision schedule on the trauma ward, also highlighted the connections made with nurses through prayer:

Family member: Not just the doctors but the nurses, they’re the first-line staff. They’ve all been so amazing; they go above and beyond. That’s why we feel bad if they’re understaffed and overworked but they try to do so much. They do more than they’re supposed to, I feel. They go out of their way to make her feel better, to talk to her. Even in the beginning, they’d talk to her, even when she was unconscious, tell her what she was doing. They’re really good and they take really good care of her. They’re just all kind and gentle and tender. In the beginning a lot of them would come and pray for her. They’d say, “Did you want me to pray?” “Yes please.” And they would do that. That’s not in their job description, but then they would come and, when we were in critical care, they would come and find us when they weren’t our nurse because they switch all the time. They would say, “You know I’ve been praying for you; I’ve been thinking of you guys.” Our first nurse—the first one, you always have a special connection with—we bumped into her in the cafeteria earlier. We were so thrilled to see her. She was asking about her. We were telling her about all the improvements; she was just so over the moon for us, you know? She’s just so happy for us. But they all go above and beyond; I think they’re amazing. It makes a big difference.

Family members were involved in the physical aspects of care: changing diapers, emptying urinals, taking the person with sTBI to the washroom, changing their clothes, and bathing them. Parents connected to their injured adult children by reminding them of games they played when they were young children, repeating these games on the trauma ward to encourage their children to perform exercises or activities of daily living. Family members performed oral care to remove layers of oral and dental residue and soothe dried and cracked lips. They brushed, washed, and styled tangled hair, even when the individuals with sTBI had limited hair remaining after extensive brain surgeries. The rest of their hair had been shaved off when portions of their skulls were removed during emergency neurosurgery, as I described with Hailey in the vignettes in this chapter. Family members removed wrist or arm restraints and Freedom
splints to encourage the individuals with sTBI to participate in daily self-care tasks. They reattached these restraints and splints afterwards to ensure their family members’ safety.

Family members mobilized to perform a plethora of nursing and rehabilitation duties as a part of this hidden hospital work. They checked on medication schedules, ensured medications were ingested after being provided, and monitored medication effects. They conferred with doctors, nurses, and rehabilitation professionals on the next steps of rehabilitation. Family members ensured proper inpatient rehabilitation and complex continuing care forms were completed and sent, or verified the status of medical procedures. They hired lawyers to deal with auto insurance benefits and additional rehabilitation staff to supplement available rehabilitation on the trauma ward. They advocated for the individual with sTBI in meetings, frequent communication with staff, and letters to ensure their needs were met.

Family members and friends engaged in nutritional work, often after seeing the individual with sTBI lose dozens of pounds during their acute care hospitalization. Family caregivers became the unacknowledged experts in the operation of various feeding machines: G-tubes, NG tubes, PEG machines, and J-Tubes—all providing liquid nutrition to the person with sTBI. These family members could spot a malfunctioning, crooked, or bent feeding tube from across the room, or by simply listening to identify the erroneous operation of these complex, technological machines. Family members participated in feeding regimens with individuals with sTBI, providing different types of food in chopped up, puréed, and thin liquid forms. Family members withheld water from the person with sTBI when this water would have caused them to choke due to swallowing deficits, even when the patient repeatedly asked for water.

Familial relations stood sentry at the bed to keep the individuals with sTBI from pulling out the lines and tubes, recognizing the craftiness of the patient in their quest to remove these foreign objects from their body. Family members also monitored observers, untrained in TBI rehabilitation, and stood watch as paid observers slept peacefully. Families did the cognitive work of brain injury rehabilitation, while observers, hired from an agency, were not usually tasked with this rehabilitation work. Family caregivers were taught cognitive stimulation techniques at the onset in critical care, pulling them into their hidden rehabilitation work from the very first devastating days of injury. Family members practiced language, orientation, and
communication with individuals with sTBI. They repeated where patients were, what happened to them, and what they would do next, over and over and over again.

Family members read books, stories, newspaper articles, and online articles to familiarize the individual with sTBI with language once again. Families also wanted to connect them with the happenings of the outside world. They brought in pictures, stuffed toys, and clothing from home to reconnect them with their previous lives. Family members left notes, iPads, cell phones, letters, and cards for the patients with sTBI, to connect them with family who were away from the trauma centre. Family members called, texted, What’s App’d, and most likely Snapchatted, Facetimed, Skyped, and used a myriad of other cell phone and tablet applications to remain deeply connected across time and space.

Family caregivers engaged in the complex work of developing optimal conditions for the healing brain of the person with sTBI, even though the environmental confines of the trauma ward were at times structured against this work. They restricted noise and stimulation by limiting the number of visitors and closing hospital room doors to the ever-present, resounding ruckus at the large centralized nursing station on the trauma ward. Family members transported patients outside to the hospital gardens, and to cafeterias and communal spaces on the hospital grounds to show patients the liminal spaces existing outside of the four walls of their small, crowded, enclosed hospital room. Family members mirrored what the staff taught them—they opened the curtains of the hospital room during the day and closed them at night, encouraging wakefulness during the day and somnolence at night. Many individuals with sTBI lose their sense of circadian rhythm—when it is day and when it is night—and family members sought to correct this disrupted rhythm.

Family members engaged in the deep emotional work of helping the person with sTBI recover from their injuries and adjust to their circumstances of pain, confinement, and confusion. Family caregivers would squeeze patients’ hands over and over again to let them know that they were there, and that they cared for them. Family members would put a damp cloth on their head to soothe them when they were sick, had a fever or headache, or were upset. When the person with sTBI was agitated, anxious, or angry, family caregivers would try to calm them down, talk to them, and keep them from hurting themselves. They played music to the individual with sTBI to soothe or reorient them, and even sang to them and encouraged them to sing along. Family
members brought in their young children, parents, siblings, grandmothers, grandfathers, extended families, step families, and friends to see them, talk to them, and remind them of who they were, where they were, and of their life prior to injury.

Families themselves at times created significant additional work for health professionals as these family members coped with the challenging, devastating, and uncertain circumstances of sustaining a sTBI. Families had endless questions for staff about what would happen to the individual with sTBI. They wanted to know if they would get better, when they would recover, what would they look like with recovery, or when they would leave the hospital. The work that family members did with the person with sTBI became marred at times, as the caregivers’ needs loomed large over the staff. Family support groups have long since been axed from the trauma centre. In a pilot interview with a nurse on the intensive unit, Leslie identified the collateral damage to family members when someone sustains a sTBI and how she needed to learn communication skills to address these emotional exchanges:

Leslie: I had to learn many technological skills, physical assessment skills, and communication skills. Those [communication skills] are actually very important in the sense that, sometimes in very tense exchanges with family members and emotional experiences with them, helping them tolerate the environment and the shock.

Health professionals recognized this collateral damage extended beyond the emotional trauma of the injury to the economic viability and operation of the family unit. Parents’, older children’s’ and spouses’ functional abilities were instantaneously changed as a consequence of sTBI. Families grappled to cope with these new emotional and economic circumstances, in addition to providing care for the individual with sTBI and the remaining children or elderly parents in the family. Health professionals reflected on difficult decisions made by families about end-of-life decisions for the person with sTBI, when medical care was withdrawn early or when caregiver burdens and the patient’s suffering were too considerable for families to bear.

Health professionals and family members stood in opposition to one another at times in making decisions and providing care for the individual with sTBI. Individuals with both standpoints described how communication could be muted, unclear, confrontational, unreasonable, or consist of mixed messages. Health professionals acknowledged that the individuals with sTBI needed intense rehabilitation, but they themselves were consistently overwhelmed by heavy caseloads and corporately mandated priorities, textually mediated by the
MOHLTC. Other patients with acute injuries needed to be moved swiftly out of the hospital to free up beds; corporate priorities and hierarchical translocal texts rule institutional relations. Some families recognized the fast-paced, heavy workload of the hospital staff and mobilized themselves to fill in with their own hidden and unaccounted rehabilitation work. However, some family members considered a daily bath or shower, a consistent feeding routine, or daily therapy, as non-negotiable requirements to be provided through the institution within the liminal spaces of the trauma centre.

6.8 Chapter Summary

In this chapter, I argue that early rehabilitation with individuals with sTBI presents as a paradox in the liminal spaces of a Level I Trauma Centre, as economic healthcare contingencies do not support this intensive work. Rehabilitation decisions on the trauma ward regarding which individuals with sTBI are likely to qualify for inpatient rehabilitation are mediated through the discursive organization of admission forms distributed through the ABI Network. Rehabilitation work with individuals with sTBI is coordinated through textually mediated relations in forms reproduced by the ABI Network and through restraint minimization policies governed by the MOHLTC. These guidelines coordinate the focus in rehabilitation work on preparing persons with sTBI to be ‘rehab ready’.

Individuals with sTBI who are not likely to become ‘rehab ready’ remain transfixed in the liminal spaces of the trauma centre, as they can transition repeatedly through critical care and intensive care units, and the trauma ward as they develop numerous medical complications. Health professionals frequently referred to these individuals as being in lower levels of consciousness, referring to either lower levels of the Ranchos Los Amigos Scale or Glasgow Coma Scale. Physicians usually described individuals with sTBI coping with multiple infections and complications as having chronic sTBI. I included vignettes in this chapter regarding Hailey and her family to address the sites of struggle for patients and families in adapting to someone with chronic sTBI and the work families do to assist with their recovery.

I explore how families become inducted into rehabilitation work in light of lower nursing ratios on the trauma ward and limited access to rehabilitation. Families were visible in critical care and intensive care, but their constant presence was the most evident on the trauma ward, as
they mobilized themselves to engage in the hidden and unaccounted work of caring for their family member with sTBI. They were suspended in the liminal spaces of the trauma ward, in silent resistance against overnight and two-visitor-per-patient hospital policies. The overnight policy in particular was rarely enacted in the absence of sufficient human resources on the trauma ward. In Chapter 7, I argue that the work of individuals from multiple standpoints, including health professionals and families, is mediated translocally by the ruling regime of the MOHLTC. The MOHLTC prioritizes medical procedures and nursing work in acute care liminal spaces, with limited economic provision for rehabilitation.
Chapter 7
Social Relations are Mediated by Talk and Text

7.1 Chapter Outline

I argue in this chapter that language in ABI Network forms and guidelines prioritizes early rehabilitation for the individuals with sTBI with the fastest recoveries in acute care. Language in the ABI Rehab Resource Tool, specifically the term ‘rehab ready’ shapes the daily work of health professionals on the trauma ward in a Level I Trauma Centre. Individuals with sTBI likely to meet inpatient rehabilitation admission criteria take precedence; those with sTBI with slower or limited recovery remain unaccounted for in the liminal spaces of the trauma centre. Arrival of these individuals with sTBI at trauma centres is textually mediated through Ontario’s Life or Limb Policy, designating trauma centres as the destination of choice for life-threatening injuries. These centres deploy expert life-saving medical interventions, but rehabilitation work is rationalized in favor of medical care through acute care funding formulas from the Ministry of Health and Long-Term Care (MOHLTC).

I argue that the absence of a TBI strategy in Ontario reflects material relations favoring other diagnostic and demographic groups, such as individuals with stroke, as reflected in the Ontario Stroke Strategy. Provincial and national healthcare strategies deploy funding and resources for diagnostic conditions, socially signifying their importance as healthcare priorities. TBI is labeled the ‘poor cousin’ as compared to other diagnostic groups, such as stroke and cancer, by many TBI advocates in terms of the MOHLTC’s strategic priorities. Individuals with stroke signify a demographically older, politically more powerful group than typically younger TBI patients, just entering the economy. Neurological complexities and rehabilitation needs of both groups are similar; however, rehabilitation beds are designated for stroke in acute care, but not TBI.

7.2 Winner Takes It All: Being ‘Rehab Ready’

During ethnographic fieldwork, the term ‘rehab ready’ was the defining term determining which individuals with sTBI would receive the highest intensity of rehabilitation. I was attentive to this term as it is a discursive organizer of rehabilitation activities on the trauma ward: “It is in
language that people’s ideas, concepts, theories, beliefs and so on become integral to the ongoing coordination of people’s doings” (D. E. Smith, 2005, p. 56). The term ‘rehab ready’ initiates text-reader conversations of health professionals in an ongoing dialogue with the ABI Referral Form in terms of how their work activities are organized. D. E. Smith identified language as a primary coordinator of our consciousness and subjectivities, drawing on the work of philosopher George Mead, neuropsychologist Alexander Luria, and linguist Valetin Vološinov. Through text-reader conversations with D. E. Smith, I re-read some of Luria’s writings to understand how language, even specific words or phrases, shape our consciousness. Luria has drawn our attention to the sensuousness of words, as he described his well-studied patient named S, who had a photographic memory:

I recognize a word not only by the images it evokes but by a whole complex of feelings that image arouses. It’s hard to express…it’s not a vision or hearing but some overall sense I get. Usually I experience a word’s taste and weight, and I don’t have to make an effort to remember it—the word seems to recall itself. But it’s difficult to describe. What I sense is something oily slipping through my hand…or I’m aware of a slight tickling in my left hand caused by a mass of tiny, lightweight points. When that happens, I simply remember, without having to make an attempt (Luria, 1987, p. 28).

Certain words or phrases pervade our consciousness, monopolizing our activities through their coordination, pushing away other words, ideas, or concepts. Being ‘rehab ready’ intersects across planes of human existence after a TBI: knowing who you are, where you are, your state of confusion and agitation, and most importantly, your ability to rapidly improve. Time allotted for inpatient rehabilitation is usually four to six weeks; individuals are to be discharged home after their stay. In the transcript excerpt below, Celeste, a rehabilitation professional, described a sequence of events when a particular patient on the trauma ward was not ‘rehab ready’.

Becoming ‘rehab ready’ can involve a circuitous route of being in a trauma centre, being sent home, and then attending inpatient rehabilitation, in preparation for living at home:

Celeste: Waiting until he’s ‘rehab ready’. Because at that point, he wouldn't have been ‘rehab ready’. He would have likely had to wait here until he potentially can progress to be ‘rehab ready’. At that point he would have had at least four weeks in rehab if he were to be ‘rehab ready’. So, without this, the family said: “He’s up early, we’re happy with how much he’s doing. He doesn’t want to be here. He has talked about going home. I think it’s best for him if we find a plan to go home.” He was in a motor vehicle accident. We looked at that service and what can we get him, so he can at least live with some sort of a quality of life at home. He might not have felt the same way if he were to be waiting in hospital until he’s ‘rehab ready’.
Lynn: For four more weeks?

Celeste: At least. Because we don't know how well he’s going to progress. Because at that point, he still had 24-hour supervision with a sitter because he wasn’t insightful, and he was very impulsive.

Lynn: Was he going to get 24-hour supervision at home?

Celeste: Yes, the family was going to put in 24-hour supervision for him.

The work of health professionals on the trauma ward includes evaluative work to determine which patients are likely to become ‘rehab ready’, as noted in the excerpt above. These determinations, mediated during interdisciplinary rounds on the ward, shape health professionals’ practices towards more intensive work with sTBI patients with the fastest recoveries. Health professionals’ work involves invoking these discursive organizers with families, conveying when an individual with sTBI is unaccounted for by inpatient rehabilitation criteria. Thelma, a rehabilitation professional, discussed the reactions of families when they learn the person with sTBI will not have access to inpatient rehabilitation:

Lynn: The rehab entry guidelines are restrictive enough that if you don’t do well, you’re not going to go to rehab?

Thelma: You’ll never make it in if you can’t get to the point that you’re using the call bell and you’re demonstrating that you’re making gains over a period of time. You’re participating and following through. If you’re not demonstrating that, you’re not going to be a rehab candidate. And people say “Well just send them anyway. I want them to go. I want them to get better. They deserve this chance. You pay taxes for how many years. He deserves this. This isn’t fair.” People are not getting it just in terms of how the system works. In order to go, this is where he needs to be. I’m not saying it will never happen, but right now is not the time.

Lynn: You have to reach a certain sort of higher-level functioning per se to fit into what can be rehabbed?

Thelma: I think part of it’s also the acceptance as well because if we’re saying this person’s not going to reach… is not ‘rehab ready’, that also means that they may not recover to what the person’s expecting them to recover back to. And that’s hard too—a hard pill to swallow.

Being ‘rehab ready’ signifies reaching a level of functioning that will lead to access into more advanced rehabilitation facilities and preferable modes of care. Rehab readiness signifies sentient personhood—understanding the world around you and having some ability to act on that world. Reaching this stage of personhood in recovery means the individual is ready to go to
designated rehabilitation spaces. Inpatient rehabilitation provides steady, consistent, daily rehabilitation to prepare individuals with sTBI to live in the community. Individuals who are close to being ‘rehab ready’ may also temporarily stay in repatriation hospitals as they wait for inpatient rehabilitation.

This state of being ‘rehab ready’ signifies the movement of bodies across liminal spaces within the healthcare continuum. Being ‘rehab ready’ means that the individual has attained what is deemed a desirable status in the rehabilitation world, representing access to resources that can materially change their lives. They have met the appropriate cognitive and behavioural levels to move on to this preferred stage of rehabilitation. They have passed all the checks and balances of the rehabilitation world, and they have a place to go. In the interconnected web of hospitals, trauma centres, rehabilitation centres, complex continuing care facilities, alternate levels of care, and long-term care facilities, their movement in the healthcare system is defined.

The omnipresent use of the phrase ‘rehab ready’ assigns these individuals with sTBI into a distinct group and connotes a particular meaning. This meaning is that they will get better, they will recover (to some extent), they have a place to go, and that they belong. They are moving forwards instead of backwards. They have been accounted for in the twisted labyrinth of Ontario’s healthcare system because of their belonging in this denizened group. Rehab beds have been definitively carved out for them in this convoluted system of healthcare. The unyielding current of repatriation through trauma centres may sweep them away from these rehab beds without persistence on their family’s part, but at least they have options available to them.

7.3 Not ‘Rehab Ready’ = No Place to Go

The use of the term ‘rehab ready’ becomes problematic in its inclusiveness through the manner in which it also excludes, as language so powerfully does. The absence of language or a specific term for being non-rehab ready signals a set of non/circumstances, alerting us to important social and ruling relations organizing rehabilitation. During a focus group regarding individuals with sTBI, rehabilitation professionals brought the institution into view in discussing the provision of rehabilitation services:
Zoe: I think for the… We’ve sort of already touched on this. But the patients that are here for a long time that are waiting for something, like complex continuing care, and who aren’t progressing, who have sort of plateaued, we can’t…we’re so stretched already. This is in terms of the therapy team and the therapy we can provide. We’re so stretched already. For patients that are plateaued and are waiting, they’re less of a priority to see for reassessment and therapy. Families get really frustrated because they feel like while they’re waiting, we should be providing rehab. But it doesn’t work that way. So, they just get more…

Summer: They feel abandoned.

Zoe: Yeah, they feel abandoned for sure.

Gabriela: I can add to that. I agree with all the other speakers. I think there’s a little bit of a hole in the system regarding that piece. They wait a long, long time to go to an alternate level of care. And the expectations remain set from the first time they come here. So, everybody’s still—this patient might get better, we have to give them the chance. And I’m not sure that the steps of withdrawing…well, not withdrawing but how can I explain?

Summer: Diminishing?

Gabriela: Yes. As a patient doesn’t get better, how we deal with that. What the steps are, what the resources are. And maybe it is better that we outline it right from the get-go. So, you say, okay, if your relative hasn’t made any progress in a month then this will go down to such and such. And maybe that would work better.

Once medically stable, social signifiers such as the term ‘rehab ready’ constitute an important common ideological touchstone for individuals with sTBI in acute neuro trauma. In the excerpt above, language conveys place, belonging, and meaning. Alternatively, lack of language, or the lack of a specific term, unveils ideological non/circumstances and non/belonging of individuals with sTBI who recover slowly. G. W. Smith (1990) suggested ideology consists of a “set of conceptually ordered practices and procedures dialogically coordinated through speech or in writing. These ideological speech activities organize consciousness” (p. 313). The language of inclusion for individuals with sTBI likely to be ‘rehab ready’ denotes the exclusion of others with sTBI in lower levels of consciousness, illuminating the disjuncture in their experiences of acute care. Being on one particular side of the dividing line of rehab readiness determines greater access to acute care rehabilitation, while there is little to no rehabilitation on the other side of the dividing line.

As I discussed in Chapter 5, the brain can be hidden from view, and predicting final outcomes for individuals with sTBI can be a nebulous process. No one, even the physicians, are
able to clearly project all of these final outcomes. This liminality is an integral part of the transitions for individuals with sTBI, with surprising recoveries occurring, as I saw in my fieldwork. The liminality in moving through lowered states of consciousness can be a mysterious process. However, institutional discourse favours definitive outcomes and clear trajectories directed toward moving patients out of acute care liminal spaces. Institutional relations guide work practices of health professionals to prioritize those patients likely to improve, assisting to transition their movement to other institutions or to their communities. As Zoe describes above, rehabilitation resources become rationalized most towards those likely to improve—not the unknowns.

Individuals with sTBI with slower recoveries offer a living, breathing contradiction within acute care liminal spaces and healthcare rhetoric. These individuals are going backwards instead of forwards, progressing infinitesimally slowly, or just staying still. These are individuals in coma-like states, such as persistent vegetative states or minimally conscious—the very early stages of consciousness not defined by inpatient rehabilitation admission guidelines. They are designated by the healthcare system as being in states of consciousness falling well below the border of full personhood—they are not walking, talking, or consciously acting in the world. For individuals with sTBI who do not recover or recover very slowly, with no politically powerful name like ‘rehab ready’—not belonging means having no place to go in the unyielding world of healthcare language politics.

The most consistent term for these individuals with sTBI who were unlikely to become ‘rehab ready’ was used by the physicians. They would describe these individuals as having chronic traumatic brain injuries. These descriptions arose in reference to their own work duties, as the physicians more frequently treated individuals with acute sTBI by providing life-saving medical procedures. Physicians treated individuals with chronic TBI, while they were still in hospital under their medical gaze, with no place to go and limited recovery to date. The term ‘chronic’ conveys their lack of inclusion in the places and spaces where they live, exist, and even subsist on a daily basis—in acute care trauma hospitals. The juxtaposition of the meaning per se of their existence—having a chronic condition with an uncertain outcome—does not linguistically and ideologically belong in the fast-paced, liminal spaces of an acute care Level I Trauma Centre.
Being a member in this non-rehab ready group conveys a sense of not belonging, not having a place, and of not having a rehabilitation trajectory—of having an uncertain future. These aspects of their existence are parcelled out discursively, metaphorically, and most notably spatially, within the healthcare continuum. Individuals with sTBI who are non-rehab ready are patients who will remain in the trauma centre with an unpredictable course. They will live through the serious medical complications that accompany chronic sTBI. They may die of these complications directly, or eventually through the cessation of medical treatment, when families choose the right to die as the most favourable healthcare option.

People with chronic sTBI experience recurrent infections of the brain or the body, such as infections of their skull, hard to identify and treat infections within their injured bodies, or pneumonia. They can have long-term tracheotomies that become very difficult to remove. These tracheotomies promote their own continued use, as the patients become dependent on them. Survival through the advent of medicalized intervention with very limited access to rehabilitation keeps individuals with sTBI unaccounted for in the liminal spaces of the trauma centre. These individuals are not accepted or managed in the outside world beyond the walls of acute care institutions, unless other healthcare spaces such as complex continuing care (CCC) facilities have the required technology and training to address their needs—‘rare birds’ in the healthcare continuum.

Medical complications—the manifestations of being non-rehab ready with chronic sTBI—keep these individuals transfixed in a world where ideologically, they do not belong. There is nothing acute or fast-paced about their care. From a managerial perspective, they are supposed to be accounted for in other healthcare spaces, not in acute care. Rehabilitation resources to assist them toward the next level of care, in doing the work to remove the tracheostomy or diminish other physical or cognitive impairments, are scarce. This work is pushed to the margins of responsibility for health professionals, otherwise overburdened with extensive workloads of other acute care patients. Trauma centre rehabilitation resources are intended, through managerial and corporate control, to focus on moving the patients with the fastest recoveries out of hospitals. Health professionals are discursively organized through managerial discourse to free up beds quickly to decompress the eternally overflowing emergency departments of trauma centres.
Individuals with chronic TBI signify impediments in the cogwheel of a Level I Trauma Centre. They experience medical complications like hydrocephalus, which is excessive swelling and fluid in the brain, as I have discussed in some of the vignettes with Hailey. The presence of this hydrocephalus can be easily recognized with the distinct visual appearance of the enlargement of the head. Hydrocephalus functionally signals its presence by robbing the individual of many functional gains made, including their ability to speak, move or even know who or where they are. Complications such as this one will initiate bouncing through critical and intensive care units, operating theatres, and hospital wards, in an effort to stem the tide of rising cerebrospinal fluid. Decisions regarding the management of complex cranial conditions such as this one can set up silent battlegrounds within the hospital staff or between the staff and families, or simply erupt in uncertainty.

Families, following the individual with chronic TBI through the complex labyrinth of the trauma centre, can lose hope in bouncing erratically, unpredictably, and recursively from procedure to procedure, and unit to unit. Being non-rehab ready constitutes a very uncertain place in the medical and rehabilitation world. For the patient with chronic TBI, this means that you and your family do not belong; you have been collectively unaccounted for in the acute care world—but you have no other place to go. Your family will stay overnight with you to help suction fluids through your tracheotomy. They will soothe you during your fever from yet another infection. However, families have no bed to sleep in during their stay and very few rooms for privacy and comfort, or simply to subsist in the collateral damage of it all.

Having chronic sTBI is problematized within trauma centres due to the difficulty in finding other healthcare spaces for these patients. When a bed is finally found, some families may feel that they want to remain within the familiar confines of the trauma centre and decline transfer to another facility. Those with chronic TBI usually eventually go to complex continuing care (CCC). CCC beds are designated units or beds in healthcare where patients with more complex conditions can go, depending on the technical expertise of the specific CCC. However, the needs of individuals with chronic TBI can often be too complex to be admitted into a long-term care facility, such as a nursing home. Beds for individuals are CCC needs are dramatically limited with long wait times, as Etty, an administrator, described:
Etty: Is a huge wait for us and many of our patients again because we have done such a good job of saving them, [they] actually don’t meet criteria yet for long-term care. They don’t have rehab goals right now, and so actually do need complex continuing care and they wait...

Lynn: And they can’t get there?

Etty: Right. [Long pause.] They wait forever.

Lynn: So...

Etty: Well, not forever but...

The GTA Rehab Network, interconnected with the ABI Rehab Network, provides forms to gain admission to CCC. Patients with sTBI with chronic care needs sometimes access CCC beds through attrition, after someone in the bed with a complex medical condition dies, or if someone improves and attends another facility, such as long-term care. There are forms to apply for CCC beds. Usually, as mentioned above by Etty, wait times to access these beds are quite lengthy, and contribute to the long stay of individuals with chronic sTBI in acute care liminal spaces. At one point during my ethnographic fieldwork in early 2017, 27% of the beds in the trauma ward were occupied with individuals with sTBI who were recovering slowly; many were waiting for CCC beds.

Part of the investigative work in institutional ethnography involves tracing textually mediated institutional relations to determine how disjunctures in experience arise. In the previous section and chapter, I have discussed how certain individuals with sTBI, namely those individuals likely to be ‘rehab ready’, are recipients of more intensive rehabilitation work on the trauma ward. Ruling relations are perpetuated through the language of the ABI Resource Tool. The language of this text, specifically the term ‘rehab ready’, creates inequities in the rehabilitation services and support provided to individuals with sTBI and their families. Material signifiers of very severe brain injuries, such in-dwelling PEG stomach feeding tubes and long-standing tracheostomies, signal rehabilitation services will be curtailed. These inequities are visible and apparent within the liminal spaces of a trauma centre, whereby two patients with sTBI with differing outcomes can receive significantly different rehabilitation work. I wondered how so many individuals with sTBI could have ended up in the same liminal spaces of the trauma centre.
7.4 Ontario’s Life or Limb Policy

As I interviewed administrators in the trauma centre, I learned more regarding textually mediated ruling relations which led to so many individuals with sTBI in one healthcare liminal space, with discrepant rehabilitation services being provided between these individuals. I discovered that there had been a historical evolution of texts that resulted in situating individuals with very severe injuries into trauma centres. Sven, one of the administrators in the trauma centre, described the evolution of trauma services in Ontario in recent years. Prior to 2010, consistent 24 hour on-call neurosurgical services were not available in Ontario. Sven described institutional barriers in trying to access urgent trauma care, with paramedics calling tertiary care hospitals and trauma centres, and being turned away.

These work practices were placing the lives of individuals needing specialized neurosurgical care in peril. Neurosurgical cases, including those with TBI, who could not be seen in Ontario were sent to Buffalo, NY or elsewhere in the US to access critical trauma care. Sven described the genesis of the Life or Limb Policy through CritiCall Ontario:

Sven: You can imagine as a citizen, you wouldn't want to be shipped out. So, when there were no beds in the system, patients were shipped urgently to the US for care. So, the Ministry of Health, of course, said, “Well, that’s just not acceptable. We need to figure out a way to make this work.” And so, the genesis of life or limb in a very snapshot… You’ll get more detail in the critical care services but the neurosurgeons in the province…in the GTA, were asked to work together and work out a call schedule amongst them. This is probably half a dozen hospitals. They had to work out a call schedule so that a citizen wouldn't be turned away. So before, a peripheral hospital, say [name of peripheral hospital], would have to call four different facilities individually and say, “Can you take them?” “No, I can’t take them” [the hospitals would reply] and hang up.

Lynn: So now you can just take them?

Sven: So now you call one number. So, there's last call neurosurgery and then there's life or limb. So, the workload is distributed by CritiCall. They will look for a place that has a bed. But if nobody has a bed then [tertiary care hospital] tonight is on last call, we have to take the bed. Tomorrow night it’s [tertiary care hospital]. The next night it’s the [tertiary care hospital]. So that there’s a final stop. You don’t keep going around the circle. No matter how full you are, you get the patient. So, they’re identified as last call neurosurgery.
The Life or Limb Policy (MOHLTC, 2013) addresses urgent care needs for individuals with critical trauma care neurosurgical needs in Ontario. The Limb or Limb Policy is a regulatory text within the “intertextual hierarchy in which texts regulate other texts” (D. E. Smith, 2006, p. 79). This text does not regulate through its existence, but rather the organization CritiCall is responsible for mobilizing this text. Providing urgent critical care traumatic services is also a strategic priority for the MOHLTC. This regulatory text becomes active in the textual coordination of people’s activities as a part of the ruling relations of critical trauma care in Ontario. This policy, as a discursive organizer, acts translocally through relations of ruling to coordinate the activities of many individuals across multiple settings in Ontario.

Implementation of the Life or Limb Policy through CritiCall Ontario promoted specific forms of work for hospitals for patients in life- or limb-threatening scenarios. These textually mediated ruling relations nixed the ability of hospitals to deny access to critical care patients when these hospitals are overcapacity. The interlocking policies of Life or Limb and CritiCall were refined to ensure as many critical care patients as possible were brought to trauma centres in urgent crises, rather than being transferred to other less-equipped hospitals. The coordination of life-saving measures through rapid action as coordinated by these textual relations were evident as Etty, an administrator, described the increased number of patients they receive:

Etty: They changed the protocol such that it used to be when the medics got to a scene of a patient who qualified as a trauma patient, they would have 30 minutes from the time they got there to assess, treat, package, and get the patient to a Level I Trauma Centre. If they couldn’t do all of that within 30 minutes of getting to the scene then they took the patient to the closest hospital. Based on some literature that showed that with trauma patients, some trauma patients that are very ill are not getting to the Level I Trauma Centres fast enough, they changed the protocols such that when the medics get to the scene, they can assess and treat the patient and package them, ready for transport. From the time they are ready to go, they have 30 minutes to get to the trauma centre. So, of course, in the GTA, lights and sirens, you can get pretty well anywhere in 30 minutes. So it really increased the number of trauma patients that we’re getting.
A close reading of the priorities and stakeholders of Ontario’s Life or Limb Policy demonstrates both the means and intended agents of this text (MOHLTC, 2013). Numerous stakeholders within hospitals—boards of directors, physicians, nurses, patient coordinators, hospital clerks, repatriation coordinators, and representatives—are enumerated as responsible for mobilizing this text (MOHLTC, 2013). In addition to instituting a no-refusal option for hospitals in the care of critical care patients in Ontario, it also defines other guidelines. The policy sets out particular time guidelines for care, such as providing medical consultations or transfers to an appropriate point-of-care within a best-effort window of four hours. Critical Ontario expedites consultation with the most appropriate physician or service within 10 minutes for provisional life or limb cases (MOHLTC, 2013).

The Life or Limb Policy is a regulatory text in the hierarchy of texts that must be followed by healthcare facilities; it is non-negotiable. A very wide net has been cast in Ontario through critical care services to ensure that both life and limb are saved. While being structured to provide urgent, emergent care for the critically injured, the Life or Limb Policy creates a host of new problems by increasing the number of patients with complex and critical injuries in Level I Trauma Centres. This policy coordinated more very critical care patients being taken to trauma centres for life-saving measures, as well as greater numbers of less injured patients, transported to trauma centres as cautionary measures. From a managerial and institutional perspective, the implementation of the Life or Limb Policy is problematic in pulling so many trauma patients into Level I Trauma Centres, who will then need to be moved to other healthcare spaces.

The Life or Limb Policy intersects with other policies, including repatriation; patients deemed medically stable are to be repatriated elsewhere within 48 hours to decompress the large numbers of patients admitted to trauma centres. Textual relations enacted through the Repatriation Guide (Critical Care Services Ontario, 2014) are intended to move trauma patients from the liminal spaces of the trauma centre to a broad range of settings. Trauma patients, as described in this guide, are to be repatriated to the most appropriate home/repatriation hospitals that can manage their care, or transferred to appropriate rehabilitation centres, long-term care centre (LTC), or complex continuing care (CCC) facilities. However, attempts by the trauma centre to move patients to other healthcare spaces in enacting the Repatriation Guide can be difficult to accomplish in actual practice. Other healthcare facilities can be unable to manage the complexity of care once these individuals are medically stable, some families resist transfer to
other healthcare spaces, and the textually mediated entry requirements of other facilities themselves deny access to these acute care patients. A refrain made by several health professionals and administrators was “acute care is mandatory, but everything else (inpatient rehabilitation, CCC, LTC) is optional.”

Repatriation to other acute care spaces proves problematic due to the inequities in care and rehabilitation services provided between the trauma centre and repatriation hospitals. Frontline health professionals and administrators are the agents enacting textually mediated ruling relations of repatriation. These individuals mobilize this text into work sequences to move sTBI patients and other trauma patients to other healthcare institutional spaces. Entry into these spaces once patients are medically stable involves a very carefully negotiated series of steps for these professionals. These steps include the discursive work required to convince other facilities to accept patients, or families to agree to the transfer. One health professional, Sharon, described the uncertainty regarding the care provided at repatriation hospitals for patients with sTBI:

Lynn: What is one of the hardest things about your job?

Sharon: I would say in terms of people being angry because this has happened to their loved one. They’re grieving. Often the grieving they experience, they may take that out or lash out on staff. Or they’ve been here for a month, and they haven’t slept for a month. They’re here and they want to…they try to… Initially they didn’t know if the person was going to survive. And then they’re going to survive. And they have to be close. And they’re sleep-deprived; they’re in crisis. They have small kids. They have… Their life as they knew it is never going to be the same. And they don’t live in Toronto. That’s a big thing. A lot of these families, it’s not like they live down the street. They live two and three hours away. And then they’re worried about the rehab. And this goes back to repatriation as well. Around what kind of rehab, what kind of facilities they’re going to have, when they reach a point when they don’t require acute care. That can be really, really hard. Because I might know that they may not have that rehabilitation. The family is looking at me saying: “I’m so scared because I don’t think they can provide this for my loved one.” And I have to look at them and say they can, when in my heart I don’t necessarily believe that.

Lynn: So that’s the hardest thing.

Sharon: One of them. I would say… I don’t know if it’s one of the hardest, I think it’s just sort of altogether. Seeing someone, seeing that, it’s very hard. We deal with a lot of tragedy here. How that impacts the families can be very difficult to watch.

Sharon’s narrative leaves me with more questions regarding what will happen when sTBI patients are transferred to other hospitals and institutional settings after leaving the trauma
centre. Will there be resources for TBI rehabilitation services in these other settings? What will happen to these patients as they leave the trauma centre? Who will advocate for these individuals with sTBI at other hospitals, and CCC and LTC facilities? These questions will remain unanswered in this dissertation as these translocal settings are beyond the liminal spaces of the institution where I did this study. I will address how the ruling relations of the economy in healthcare, specifically the MOHLTC, influence rehabilitation services in a trauma centre and other similar acute care hospitals.

7.5 Procedures Matter: Healthcare Funding is a One-Trick Pony

Health System Funding Reform in Ontario has brought a series of changes in how funding is distributed to hospitals and healthcare facilities; these funding reforms have been initiated through the MOHLC in an effort to encourage hospitals to be more ‘efficient’. Hospitals in Ontario are moving away from global hospital funding, which distributed a lump sum to hospitals based on past budgets, to specific targeted funding for procedures. This targeted funding is based on medical work completed by the hospital, making visible an increased focus on the medicalization of acute care services. Rehabilitation services are paid for through the shrinking global hospital budget and are not accounted for within the textually mediated funding formulas from the MOHLTC. Hospitals select certain strategic directions, and use targeted funding and the global budget to support this strategic direction. Part of this strategic direction may include rehabilitation, as we have seen in this particular trauma centre.

While previous systems allowed hospitals to have up to 50% of their budget as a global budget, the current initiative, The Ontario Case Costing Initiative (OCCI) outlines a new funding formula in healthcare accountabilities. The expectation set by the MOHLTC is that funding will be distributed through a three-way split: 30% quality-based procedures, 40% Health-based Allocation Model (HBAM), and 30% global budget. Dorian, an administrator, explained the provincial funding formula for many hospitals:

Lynn: There’s quality-based procedures and then can you explain to me about the healthcare-based allocation model? Can you explain to me how that fits in?

Dorian: So typically, it’s… They’re trying to move away from it [the global budget], it’s a 40, 30, 30 split. So, they want 40% of your funding to come from this HBAM model
A population-based funding formula. What it does is it attempts to model what the Ministry expects for you, the cost for you to care for this patient type. And then it looks at how many they expect you to treat of this patient type. They multiply those two together to come up with your expected expenses. They do that for all hospitals that participate, and they calculate your share of total expected expenses. That percentage is how they allocate…They have designated funds that are for HBAM. So basically, we’re about [#] % of expected expenses in the whole province. We get [#] % of $5.15 billion. It’s purely a pie-sharing exercise and so it’s a zero-sum gain. So, if you treat fewer patients, you get less money. But that means someone else got more money because they ended up treating those patients that you didn’t treat.

Lynn: And then you said two things. You said there was a hope to move away from that.

Dorian: No, the hope is to move away from the global funding. They want to link it… They don’t want the funding to be tied to a specific hospital. They want it to be tied to the patients. And I think… I haven’t worked for the Ministry, so I can’t speak to what their intention was. But I think their intention is, regardless of where the patients choose, if you can say they choose where they go for healthcare, the funding is going to follow them.

As explained by Dorian above, each healthcare pot has a different set of terms and conditions. Quality-based procedures refer to the medical treatments that hospitals perform, such as total hip and knee replacements, cancer treatment, or stroke intervention. They are the ‘meat and potatoes’ of hospital acute care: emergency and elective surgeries, lifesaving treatments, and emergency surgery—in many cases, procedures that we literally could not live or function without. HBAM accounts for medical and nursing work as people remain in hospital through weighted cases; they are not discharged home right away after procedures, they have chronic health conditions, or are frail elderly. Weighted cases are based on medical resources that more complex patients consume. The global budget includes costs for non-direct patient care services such as administration, equipment, and patient care resources not accounted for by the other formulas, including rehabilitation. In the following transcript excerpt, Dorian explained how medical procedures, specifically what doctors do and document, are crucial in capturing healthcare funding:

Dorian: And it’s also important to know, and I guess this is what you’re trying to get at, is those weights are driven by what doctors’ document. And there’s a big push for doctors to create…to document as much as possible. There have been education sessions that
have gone on that say if this certain thing happened, this is what you need to document. Because those drive weights. There's out-of-hospital events where they get sent to another hospital for a procedure, and they come back. That drives up your weight. So, if they spend time in the ICU, we have that data internally, but that leads to a higher weight. Intervention events—paracentesis, pleuracentesis—if they had that type of activity, it will drive up their weight. And so, there’s been education at a lot of hospitals that has been going on about if these are the things that are very important, that you document. I know because doctors are busy, and they might not document everything. But there’s been a lot of education around these are things that it’s very important for you to document.

Hospital funding is also associated with the type of service provided, including: acute care, rehabilitation, mental health, or CCC, designating the type of healthcare bed. In addition to provincial funding, hospitals can also draw on federal funding, such as having beds designated for veterans. This is where things get tricky in the trajectory of patient recovery; healthcare funding coding is essentially a one-trick pony. Funding cannot switch from one type to another. Textually mediated coding for different types of beds occurs in completely different healthcare databases. Exceptions exist when the facility is able to designate both acute care and rehabilitation beds within its space—as spatially voluminous as these spaces have become in the flurry of modern-day hospital mergers. A notable exception exists with stroke care, as both acute care and rehabilitation beds are designated in acute care spaces.

When someone arrives at a trauma centre in desperate need of life-saving emergency neurosurgery and/or medical care after a sTBI, they are in an acute care bed. When many of their medical and nursing needs have resolved after several days, weeks, or months, and their needs transition to being rehabilitation-based—they are in the wrong ideologically and economically carved-out liminal space. Acute care funding is tied to medical procedures and nursing care, not rehabilitation. Acute care hospitals work around these funding formulas as needed for their patients, but risk being deemed as inefficient by the MOHLTC when their expenditures exceed the funding parsed out through textually mediated funding formulas.

In the transcript excerpt below, Dorian, an administrator, described how the MOHLTC does not recognize the complexity of trauma care. Complex cases become known as weighted cases, which enumerate primarily medical care into the intensity of the work required. If the hospital needs to devote additional resources to certain complex patients such as trauma patients, the hospital is viewed through the MOHLTC’s lens as inefficient:
Dorian: The funding model is very data-intensive. There’s always a two-year lag. So, things change so much in two years in the hospital sector that it’s hard to say, oh, this much should be for a hospitalist. Typically, what happens is you get your results, and they spit out your expected cost per weighted case. All you can really do is look at your actual cost per weighted case for the same time period to see where your actual cost per weighted case is higher than expected. And then dig around and look at the whole province to see for that patient type, who was able to provide it at a lower cost. And then do some benchmarking and see what they did. Is it a similar patient population? Are there differences? Is it justifiable? Because there can be justifiable differences. Because there are costs that it’s almost impossible for any sort of grouping or weighting methodology to capture. And that’s something…It just leads to more analysis, saying is it truly us being…the terminology the Ministry likes to use is inefficient. Are we truly inefficient or are we just treating a different population?

Lynn: Especially when you have trauma, it’s so complicated.

Dorian: Yes, exactly.

Lynn: This is different.

Dorian: It is a different population. So, it’s hard to compare us to people who don’t treat traumas.

As I have noted above in reference to the types of healthcare care beds designated in acute care, stroke is a contrasting example to TBI, as stroke rehab beds are designated within acute care hospitals. These beds are provided in addition to local rehabilitation facilities providing inpatient rehabilitation. For example, one healthcare corporation may have two separate hospitals. If an individual starts at hospital A with an acute stroke and shows enough improvement, they can be transferred to hospital B within the same healthcare corporation for additional rehabilitation. This hospital is not a locally-designated inpatient rehabilitation but has increased hospital resources to provide inpatient rehabilitation. They have moved from an acute care bed to a rehab bed in the same institutional healthcare space. Different material relations become evident as healthcare priorities favour those individuals with stroke over those with TBI in this change of institutional forms—an acute care bed becomes a rehab bed in the same healthcare liminal space.

7.6 Why is there No Ontario TBI Strategy?

In neurological rehabilitation in Ontario, there are frequent comparisons between stroke and TBI. These diagnostic groups appear materially different in terms of age and economic
position in the economy. Strokes tend to occur in older individuals and TBI tends to occur in young people. Of the identified 94,174 Ontarians who experienced a stroke and/or transient ischemic attack in 2010, the mean age of these individuals was 72.6 years old ±14.2 (Ng et al., 2015). By comparison, of the identified 227,605 Ontarians who experienced a TBI in 2010, the mean age of these individuals was 33.9 years old ± 21.3 (Ng et al., 2015).

TBI is also divided into three categories of the basis of resource utilization by the Canadian Institute of Health Information (CIHI) and the National Rehabilitation Reporting System (NRS), who collect information for hospital funding and statistics. These three categories are as follows: (1) the least resource-intensive, (2) moderately resource-intensive, and (3) most resource-intensive. For data collected across Canada from April 2011 to March 2016, for individuals with TBI admitted to inpatient rehabilitation, the least resource-intensive group mean ages were 53+/−22 (MacDonald, Martin, & Nath, 2017). For the moderately resource-intensive group, the mean ages were 55+/−22 (MacDonald et al., 2017). For the most resource-intensive group, the mean ages were 44 +/− 21 (MacDonald et al., 2017). For TBI, on the basis of the statistics provided by CIHI and NRS, the youngest patients consume the most resources.

By June 2000, the Ontario government had commenced the implementation of the Ontario Stroke System (OSS), committing $70 million over four years and then $30 million annually (Lewis, Trypuc, Lindsey, O’Callaghan, & Dishaw, 2006). This strategy included the designation of 11 Regional Stroke Systems and Telestroke program, to promote comprehensive, integrated, evidence-based, and province wide care (Lewis et al., 2006). This guideline promotes education related to stroke to ensure that the public is aware of the signs of stroke and how to access emergent care (Lewis et al., 2006). The Ontario Stroke Strategy dovetails with previous medical intervention guidelines regarding a life-saving medical injection (tissue plasminogen activator), as this medication needs to be administered within several hours of onset to prevent or reduce the effects of a clotting stroke (Lewis et al., 2006).

Nonetheless, the Ontario Stroke Strategy receives criticism on the basis of material relations, specifically age, influencing who has access to care. A 30-year-old patient and a 62-year-old patient confronted Ontario Health Minister Eric Hoskins in being denied rehabilitation treatment due to their age—they needed to be 65 years or older to qualify for post-stroke physiotherapy (Westoll & Nicholas, 2017, May 11). The OHIP bill removing access based on
age was later removed. The material issue remains that having a stroke in Ontario means that there is a strategy to address an individual’s deficits and to track their outcomes. No such strategy exists for TBI at a provincial or national level, suggesting that TBI is not a healthcare priority for provincial and federal governments. Distinct material differences exist between these groups, with stroke patients generally being older with an established place in the economy, versus TBI patients, who are younger and just entering the economy.

In a focus group during my ethnographic fieldwork addressing providing early rehabilitation to individuals with sTBI at a Level I Trauma Centre, health professionals identified key differences between stroke and TBI in terms of a provincial strategy and the MOHLTC’s strategic priorities. What is particularly interesting in the narrative below is the reference to the economic impact of not treating such young individuals with sTBI. With stroke, the material conditions of these older patients would generally be more secure at the time of injury; they have had or have jobs, homes, and savings. Summer, a rehabilitation professional, offered the perspective of the economic cost of young people, often in their early twenties, spending many years in institutions, as rehabilitation is not a priority for individuals with chronic sTBI:

Summer: In the ABI Network, at a strategic planning committee that we just had, there were big wigs from program planners and managers from all the different ABI facilities, and then there was me and [Thelma]. The Ministry doesn’t treat ABI as a funding priority. And that’s not just for us, that goes for rehabs, it goes for complex care, it goes for community housing, mental health, and issues with housing with these patients in the community, CHIRS, PEEL Support Services, everything. Their pipe dream is that we should be like treated the way stroke is. If you look at stroke, which is very similar to brain injury, you have regional stroke centres, best practice guidelines for complex patients, and mild, moderate, severe strokes. You have community outreach teams. And there’s like a gazillion resources out there from Heart and Stroke for stroke and it’s funded. There’s a big push from the Ministry. They inject money into stroke like nobody’s business. They have an e-stroke referral. Their wait times are low; their outcomes are high. They have seven-day-a-week therapy. All that kind of stuff. That’s because the Ministry sees it as a priority like cancer care and cardiac care, and they inject money into it. So, one day maybe ABI will be treated that way. But it’s not on the agenda. That’s why ABI is, they described, like the poor cousin of the stroke patients. And so, the same principles—neurological low-level stroke patients sitting in acute care, the same thing as in a low-level head injury patient. But we don't have the same access.

Lynn: Anybody else?

Zelda: We don't have the staffing.
Rita: Head injury patients are usually younger than stroke patients.

Summer: And they’re younger. And if you look at the economic burden of a young head injury patient who’s going to be living in the community for the next 50 years in a complex care facility with geriatric patients. If you look at the life expectancy of an 80-year-old stroke patient, not to diminish their right to have quality of life, but the economic burden is these people are out of the economy. They’re not contributing to society. We don’t allow them [patients with TBI] integration into society. Even mild head injury patients can't reintegrate into society and have a normal job. And that’s because they had a little concussion and now, they can't even work.

With stroke, there are extensive clinical practice guidelines, a stroke strategy, rehabilitation beds set aside in acute care, and a plan of care afterwards. These textually mediated government priorities are vastly different than the material circumstances for individuals with TBI. Initial TBI trauma care guidelines in critical care are in accordance with international critical care guidelines. However, the rest of the rehabilitation trajectory is inadequate, including strict admission criteria to access inpatient rehabilitation—not reflecting the myriad of possible functional outcomes for individuals with sTBI. Both TBI and stroke require urgent medical evaluation upon admission to hospital. Both are also in competition for the same critical care trauma resources:

Dr. Reed: Let’s say I’m with a very sick patient. A very sick patient in the trauma room. And I need to decide on taking the patient to neurosurg intervention to evacuate the hematoma. And when I go to CT and I try to get this patient to CT, there is another patient on the table. So, in the perfect world, you have CT beds available all the time.

Lynn: Free.

Dr. Reed: Free. But then there’s a stroke patient there, that they also…time is important.

Lynn: For many people.

Dr. Reed: And how I’m going to manage this. I’m going to just wait one minute, two minutes, three minutes, four minutes, and five minutes with time passing by. And I’m waiting with my patient there. But there's another patient in the CT scan. That’s more a system-related issue. So that’s one example that might happen. That’s the nature of the healthcare system and the resources they have available.

As Dr. Reed has indicated above, both individuals with stroke and those with sTBI are competing for the same healthcare resources, in this case a CT scanner. These individuals are also competing for the same funding resources—a piece of a 5.15-billion-dollar pie. In the scenario described above, the difference in access between the two patients, one with TBI and
one with stroke, is five minutes. Dr. Reed’s insistence that one patient—the patient with sTBI—needs to be seen immediately is a metaphor for the ultimate challenges regarding sTBI in the healthcare system. Timely access to resources is critical for sTBI patients. Prioritization for timely access and addressing the extensive and complex needs of individuals with sTBI is simply not a priority for the MOHLTC in Ontario.

### 7.7 Chapter Summary

In this chapter, I argue rehabilitation work in Level I Trauma for individuals with sTBI is coordinated translocally through textually mediated ruling relations, specifically CritiCall Ontario, ABI Network rehabilitation admission guidelines, and MOHLTC funding models. I argue language is a discursive organizer that both coordinates rehabilitation work and acts as a means of oppression, providing greater access to sTBI patients with faster recoveries and less access to individuals with slower recoveries who do not meet strict inpatient rehabilitation admission guidelines. The language of the ABI Resource Tool, specifically the term ‘rehab ready’, mediates ruling relations at translocal sites across numerous healthcare settings. The ABI Resource Tool coordinates the activities of the many individuals, including patients, families, and health professionals, as mediated through the ABI Network—the only gateway for admission to provincially designated inpatient rehabilitation beds.

Completing the ABI Resource Tool is the means of securing a bed in inpatient rehabilitation. ABI Network forms and admission guidelines are texts that are activated in many healthcare sites, including at non-tertiary care hospitals or by individuals in the community, in addition to trauma centres. I argue that the term ‘rehab ready’ acts as a discursive organizer in trauma care, determining which individuals receive the most intensive rehabilitation work. Individuals with sTBI expected to be ‘rehab ready’ are individuals with sTBI with faster recoveries who are more likely to re-enter the economy. Patients designated to become ‘rehab ready’ are the recipients of more intensive and timely rehabilitation work in trauma centres to mediate their transition to other healthcare spaces.

In this chapter I discuss how the Life or Limb Policy, enacted through the organization of CritiCall Ontario, casts a wide net for trauma patients, propelling them to Level I Trauma Centres. Patients with sTBI with faster recoveries are able to gain access to inpatient...
rehabilitation and receive access to the most intensive rehabilitation work by health professionals in the trauma centre; they may also access other healthcare spaces such as repatriation hospitals. The remaining individuals with sTBI who remain in Level I Trauma Centres, often with chronic medical conditions such as infections, pneumonia, and hydrocephalus, become suspended and unaccounted for in the liminal spaces of the trauma centre. They have limited access to rehabilitation work, curtailing their potential for recovery. I also argue that healthcare reform by the MOHLTC through the Ontario Case Costing Initiative has heralded the increasing medicalization of acute care hospital services; rehabilitation is not a priority in these funding formulas. Without a TBI strategy and designated healthcare priorities, funding, and beds in acute care, there is no strategic direction to account for individuals with sTBI in acute care liminal spaces to ensure that their needs are met.
Chapter 8

Discussion and Recommendations

8.1 Exploring the Three Gossamer Walls of the Researcher

In concluding this dissertation, I reflect upon choosing to examine the social organization of sTBI rehabilitation in a Level I Trauma Centre. What drew me to this topic and why did I examine this topic through institutional ethnography? In the preface, I highlighted several instances in my own personal experience in a trauma centre that led to my sense of disjuncture while assisting a friend with sTBI in the early days of her recovery. Her early rehabilitation was infrequent and appeared as an afterthought to her medical care. In this dissertation, I conclude that individuals with sTBI slated to attend inpatient rehabilitation receive less rehabilitation than expected by their families in a trauma centre. However, individuals with sTBI deemed unlikely to meet inpatient rehabilitation guidelines receive significantly curtailed rehabilitation in trauma centres in the absence of a clear discharge location. They are marginalized from publicly funded rehabilitation services through the enactment of textually mediated relations governing rehabilitation in Ontario in acute care healthcare spaces.

This marginalization takes a distinct form as individuals with sTBI, who are in the same diagnostic category, are cleaved into two separate groups very early in acute care rehabilitation: (1) individuals seen as likely to meet inpatient rehabilitation guidelines who may secure access to inpatient rehabilitation, where they will receive intensive daily multidisciplinary therapy; or (2) individuals seen as unlikely to meet restrictive inpatient rehabilitation guidelines, for whom access to rehabilitation in acute care becomes extremely limited due to scarce resources. As a result of their status in this second group, it is also likely that they will receive little to no rehabilitation once discharged from acute care. During my fieldwork, I glimpsed the other possible paths aside from inpatient rehabilitation for individuals with sTBI, splintering out from the trauma centre to repatriation hospitals, complex continuing care, long-term care, or returning home. On the other hand, gaining admission to inpatient rehabilitation is seen as a success for someone with acute sTBI, forecasting the potential for recovery.

Which path will be taken by an individual with sTBI who has not been deemed as ‘rehab ready’ depends on their medical status and is mediated by social relations organizing
rehabilitation, marginalizing many individuals with sTBI as they traverse the labyrinth of Ontario’s healthcare system. Individuals with sTBI and their families lack choice and control in terms of the rehabilitation received in Level I Trauma Centre, or access to rehabilitation afterwards. As the MOHLTC designates acute care, including trauma centres, as medicalized spaces, early acute rehabilitation is minimal. This rehabilitation is available only to the extent required to facilitate the patient’s discharge from acute care. Access to acute care rehabilitation services are curtailed due to limited funding. Textual relations for admission to inpatient rehabilitation are mediated through the ABI Network, granting access to rehabilitation for individuals with sTBI with the fastest recoveries. The remainder of individuals with sTBI will be excluded from publicly funded rehabilitation for the remainder of their recovery.

As I write the final chapter of this dissertation, I reflect upon these findings in light of Doucet’s (2008) metaphor of the three gossamer walls for researchers in constructing knowledge in qualitative research. I discussed these reflexive strategies in Chapter 4. These three gossamer walls exist between: (1) oneself and the ghosts that haunt us, (2) the researcher and the participants, and (3) the researcher and readers. For the first gossamer wall, Doucet asserted, “Ghosts also appear sparsely, but powerfully, in social science work… when we are haunted by a memory from our past, the sudden presence of these ghosts can have an impact on the stories we tell” (Doucet, 2008, p. 74).

This first gossamer wall led me in part to choose institutional ethnography as a method of inquiry due to my own ghosts in experience of being a caregiver for someone with sTBI. While I have provided glimpses of my own experiences as a caregiver to date, these were partial accounts occluding my later experiences. One ghost of my former selves included my own months of challenging experiences as a caregiver for someone with sTBI. In previous chapters, I eluded to the emotional experiences of caregivers as being the ‘collateral damage’ in caring for someone who sustains a sTBI. I attended a course with D. E. Smith after these troubling times; her method of inquiry, in being both empirical and emancipatory, resonated with me.

Institutional ethnography provided me with a powerful means of collecting empirical ethnographic evidence regarding the experiences of individuals with sTBI, their families, health professionals, and administrators in a trauma centre, and a means of political action to address these disjunctures in experience. Family members expressed that sTBI had a devastating effect on
the person with the injury and the family as a whole, with a broad sense of the meaning of the word ‘family’. Psychological distress of the family members for individuals with moderate to severe TBI and DOC has been well-documented in the literature (Moretta et al., 2017; O’Callaghan, McAllister, & Wilson, 2010). Health professionals in this study also discussed notable emotional distress in working with patients with sTBI and DOC. Significant rates of emotional burnout in healthcare workers working with individuals with DOC have been described previously (Gosseries et al., 2012).

One of the ghosts of my former selves also appeared between this first thin, luminous gossamer wall and my researcher self in Chapter 5, as I argued the brain is hidden from view after sTBI. This ambiguity and mystery during ethnographic fieldwork immediately captured my attention, as studies of the brain have been an interest of mine since young adulthood. The very complexity of initial sTBI, with unpredictable circumstances from the outset, complicates recovery afterwards. Liminal borders and uncertainty exist surrounding who will live and who will die after sTBI; for those who survive, even the physicians conveyed having only a veiled prediction of the future of their recovery. Narratives of surprise and uncertainty regarding the unpredictability of sTBI were recounted by physicians, health professionals, administrators, and families throughout my fieldwork. I also watched some of these unlikely narratives unfold in front of my eyes during participant observation.

Fins (2015), a neuroethicist and physician, extensively studied obscurity in outcomes after serious brain injury and the marginalization of these individuals due to the lack of access to rehabilitation. Fins interviewed 63 families after a member of the family sustained a severe brain injury through trauma, anoxia, or stroke. These individuals with severe brain injuries were in persistent vegetative states or minimally conscious at the commencement of interviews. Fins (2015) described the various paths these individuals followed thereafter in the American healthcare system. Fins (2015) asserted many American hospitals designate patients with severe brain injuries as being in a persistent vegetative state when they are actually minimally conscious. This misdiagnosis is purposely applied to facilitate placement in nursing homes, which are easily accessible but have very limited or no rehabilitation (Fins, 2015).

Fins (2015) explained one particular instance regarding a patient named Heather and her mother Cindy. Cindy described her interactions to Dr. Fins with physicians after her daughter’s
injury, including her attempts to secure proper diagnosis of her daughter Heather as being in MCS in order to access rehabilitation. Cindy’s descriptions of the ambiguity of neuroimaging and its inability to foretell some outcomes resemble the argument I proposed in Chapter 5 that the brain is hidden from view after sTBI. Fins recounted a conversation between Cindy and a neurologist at an academic medical centre illustrating this point:

In a confessional tone, he shared a secret most outsiders would not suspect: experts aren’t very good at prognosticating, even when they make use of neuroimaging techniques. In fact, sometimes the scans can be very misleading. The doctor told Cindy, “We can look at two patients’ scans and one can look very bad and bleak like Heather’s, and the other can look promising, and the two can have absolutely opposite outcomes. The one that looked good doesn’t do well and the one that looked terrible does very well” (Fins, 2015, p. 111).

Physicians during my ethnographic fieldwork disclosed similar stories regarding how diagnostic uncertainty arises from neuroimaging; individuals with sTBI can have surprising recoveries. Physicians and other health professionals also recounted right-to-die stories of families who opted to withdraw care early, rather than see individuals with DOC live in suffering and through numerous complications. The trauma centre where I completed fieldwork is also an academic hospital; senior physicians were teaching this wait-and-see approach to the physicians in training. This medical quandary leads me to question the connection between research and practice as sTBI prognostication continues to be ill-defined in some practical situations. Fins (2015) argued severe brain injury research itself is evolving, with new medical neuroimaging techniques being developed, in addition to changing classification guidelines in the field:

The problem, or cause for excitement, continues to be that much of what we see on neuroimaging is a surprise. That is why this still remains the province of research and not the domain of the practitioner. Medical practice is meant to be predictable. Research, by definition, is not. It is an exploration, guided by hypotheses to be true (or not), but reined in by conforming theories with empirical results. But if medical practice is meant to be predictable, how can the care of patients conform to established predictable norms when the very nosology by which we classify them is under an evolving critique? (Fins, 2015, p. 133)

Fins (2015) referred above to changing classification for DOC due to frequent misdiagnosis of individuals who are minimally conscious as being in a persistent vegetative state (PVS). Misdiagnosis rates of individuals who are in a minimally conscious state (MCS) as being in PVS vary between 18% and 43% (Gill-Thwaites, 2006). Misdiagnosis often occurs as hospital staff and resources are inadequate to recognize signs of consciousness (Gill-Thwaites,
These misdiagnosis rates provoke growing concerns regarding ethical care for individuals with MCS, who are conscious of the world around them, as cessation of life (withdrawing feeding, ventilation systems) is promoted (Gill-Thwaites, 2006; Nettleton, Kitzinger, & Kitzinger, 2014). A new classification system involves straightforward nomenclature included two terms: (1) unresponsive wakefulness syndrome (UWS) (no responses at all); and (2) MCS (any signs of consciousness, such as tracking objects visually, purposeful movements, or verbal responses) (Naro et al., 2018).

I argued in Chapter 6 that families develop arduous work routines to assist individuals with sTBI in a trauma centre. The second gossamer wall of reflexivity (Doucet, 2008) — the wall between the researcher and the participants — was most tangible in interviews with families of patients in PVS and MCS. My intense proximity to these individuals with chronic DOC was unfamiliar to me, in addition to families’ reasons for constructing intensive, at times 24-hour care schedules. Many of the stories that families described regarding activities they did to assist their family member with sTBI — for example, listening to music or giving massages — were remarkably similar to stories told by families whereby the individual with sTBI experienced faster recoveries. As many of the individuals with chronic sTBI were in the trauma centre for months, I interacted with these families on various occasions, either prior to the interview or afterwards, as they moved back and forth across the liminal spaces of the trauma centre.

I also argued in Chapter 6 and Chapter 7 that rehabilitation work with individuals with sTBI is shaped by textually mediated institutional relations reproduced by the ABI Network. Inpatient rehabilitation facilities and other discharge locations, such as complex continuing care (CCC) facilities set their admission criteria. These criteria are reproduced and enacted through the ABI Network textually through referral forms to these facilities; available through this network. Individuals with sTBI with slower recoveries and in DOC garnered significantly less rehabilitation as they could not meet admission guidelines for inpatient rehabilitation. These individuals had uncertain discharge locations and dates as admission to CCC is a very lengthy process.

Rehabilitation work observed during this study paralleled scientific research for early rehabilitation for individuals in intensive care, with mobilization in bed and dangling as core rehabilitation concepts (Doiron, Hoffman, & Beller, 2018; Olkowski & Shah, 2017; Winslow,
“Dangling is usually defined as raising an individual up from a supine position (flat or with the head elevated) in bed to a sitting position (flat or with the head elevated) with the legs hanging over the side of the bed” (Winslow et al., 1995, p. 82). Early mobilization, including dangling, is an intervention used by nursing and physiotherapy to sit patients up in intensive care and trauma care (Winslow et al., 1995). No single population studies for sTBI or DOC were located that identified the benefits of dangling with these individuals.

As I noted during this study, in chronic sTBI, mobilization in bed, dangling, and getting someone up to a wheelchair were part of rehabilitation work in the Level I Trauma Centre. However, the performance of these work duties was dependent on health professionals’ caseloads. One study included in the literature review employed physiotherapy intervention in the intensive care unit with individuals with DOC (n=4) through the use of a vertical tilt table with a stepping device (Frazzitta et al., 2015). The use of the vertical table was to avoid syncope or a temporary loss of consciousness due to lack of blood to the brain (Frazzitta et al., 2015). Blood pressure and pulse rate were monitored throughout the sessions and no adverse events were noted. Further high-quality studies in acute care would provide evidence of effective rehabilitation with sTBI and DOC in terms of these types of interventions, but are scant in the current extant literature.

Cognitive rehabilitation was normally provided by a number of health professionals on the trauma ward in this study, through repeated orientation to person, place, and time and participation in activities of daily living (ADLs). Family members were provided pamphlets which described the Rancho Los Amigos Scale and cognitive strategies to use at various levels of consciousness. Multi-modal sensory stimulation programs (Megha et al., 2013; Oh & Seo, 2003; Padilla & Domina, 2016), music therapy programs (Bower et al., 2014; Formisano et al., 2001; Schnakers et al., 2016), cognitive programs (Langhorn et al., 2015; Larson et al., 2011; Nott et al., 2008), intensive around-the-clock early rehabilitation (MacKay et al., 1992; Thompson et al., 2013), and continuous chain rehabilitation (Andelic et al. 2012; Andelic et al., 2014) are evidence-based interventions for sTBI described in the literature. These programs require extensive training, support, and participation by health professionals to develop and implement with patients and families. These types of evidence-based rehabilitation interventions remain elusive in the trauma centre with too many other competing demands and insufficient resources to provide targeted daily rehabilitation or these types of intervention programs.
New modern therapies, such as immersive virtual reality, have been provided to individuals with sTBI after discharge home to improve their daily functioning (Aida, Chau, & Dunn, 2018). Virtual reality (VR) was explored in a one study with individuals with sTBI in acute care at RLA Levels IV and V (Larson et al., 2011); however, the type of task—a cancellation task to eliminate items—was described as boring and irrelevant by participants. Applying VR at these stages of recovery, which does not require a therapist to be present, acknowledges two actualities of the acute care context: (1) time is limited for rehabilitation professionals to work with patients; (2) wandering patients with sTBI in Rancho Los Amigos (RLA) Levels IV and V are often bored and looking for something to do on the trauma ward. The absence of stimulation and time for intervention at times resulted in patients in these RLA stages attempting to elope the trauma ward, consuming considerable resources in terms of the time of health professionals, personal care workers, security, and the police. More appropriate VR interventions than the one described above, such as VR employing activities of daily living training, have demonstrated effectiveness in stroke populations (Faria, Andrade, Soares, & Badia, 2016). This training may be worthwhile with individuals with sTBI in acute care to provide necessary diversion and engagement in these stages and to promote rehabilitation.

An example of a technology with demonstrated effectiveness with DOC include evoked potentials, whereby a stimulus is presented to determine if there is a measurable cognitive response. Evoked potentials are usually included in the neurophysiological measures recorded in DOC multi-centre registries (Grill et al., 2013; Pascarella et al., 2018). Event-related potentials (ERPs) are evoked following a stimulus, often auditory or visual, which leads to a predictable cognitive response, usually referred to as P300 or N400 (Mah & Connolly, 2018), in reference to how many milliseconds they occur after the stimulus (300/400) and the direction of the amplitude of the brain wave (Positive/Negative). ERPs often use oddball paradigms, such as a repetitive stimulus followed by a deviant one, an unexpected word at the end of a sentence, or the subject’s own name (SON) (Wang et al., 2015). Occurrences of reliable cognitive ERP responses suggest a good prognosis for individuals with DOC (Mah & Connolly, 2018; Wang et al., 2015), when observable behavioural responses are not yet consistently produced. Functional MRI studies using similar paradigms have also produced tangible results with individuals in DOC (Owen, 2017). Somatosensory evoked potentials can predict recovery from DOC (Robinson, Micklesen, Tirschwell, & Lew, 2003).
Advocacy for improved access to a blended rehabilitation model is essential for sTBI to ensure all individuals with this disorder have access to rehabilitation. Doucet (2008) suggested a third gossamer wall exists between the researcher and audience as researchers construct knowledge. Doucet (2008) stated, “I have drawn attention to the theoretical and epistemological communities wherein our work is located and how other epistemological communities may take up our work and use it to promote differing knowledge claims and ultimately competing political goals” (p. 83). Traversing this gossamer wall involves autobiographical or identity work by the researcher to define what motivates our research; this work is integral to the research process (Doucet, 2008). The emancipatory goals provided by institutional ethnography shaped this research. Entering a dialogue with the readers lays the foundation for political action and change for individuals with sTBI in the early stages of recovery and those with chronic DOC who remain transfixed in acute care liminal spaces.

Limitations in access to rehabilitation care for individuals with sTBI who do not demonstrate sufficient recovery is textually mediated by inpatient rehabilitation admission guidelines. Fins (2015) referred to this concept in the United States as a ‘medical necessity’, meaning individuals with sTBI who do not improve quickly enough to meet insurance company guidelines do not gain access to rehabilitation. Considering Fins’ descriptions of limitations in access to rehabilitation for individuals with sTBI, American and Canadian healthcare systems share similar limitations in promoting recovery for individuals with sTBI and DOC, given the findings in this dissertation. Individuals with sTBI who do not improve quickly enough or sufficiently to meet inpatient rehabilitation guidelines become slated to attend CCC; rehabilitation in acute care becomes infrequent and medically driven by complications as these individuals wait for a bed. Fins (2015) recounted stories of patients placed in life-threatening situations after being forced out of hospitals by insurers who refused to pay for hospital care, even in light of ongoing serious medical needs. These individuals entered long-term care homes that could not manage the complexity of their needs, resulting in healthcare crises and readmission to the hospital (Fins, 2015).

In light of growing moral and ethical concerns regarding prolonged disorders of consciousness, Fins (2015) advocated for a mosaic of care for individuals experiencing DOC. “Tragically once lives are saved by brilliant intensive care, many patients are abandoned to what is euphemistically described as ‘custodial care’ where they are deprived of rehabilitation that
might help them recover” (Fins & Wright, 2018, p. 670). Fins (2015) pinpointed the need for increased research, intervention, and advocacy for individuals with chronic DOC. As the numbers of individuals with chronic DOC can be limited in any certain community and knowledge translation can be constrained, Fins (2015) advocated for national registries as I have described in the literature review, where information can be pooled and shared. Fins (2015) cited increasing numbers of individuals accessing critical care and surviving with DOC, while the number of hospital beds contracts, as being a major impetus for blending aspects of acute, rehabilitation, and chronic care:

Increases in critical care will result in more survival from brain injury and cardiac arrest thus requiring care in hospital beds that no longer exist. This shortage of services will compound the already significant discharge and placement challenges we have enumerated unless there is a proactive response to this need. Patients with disorders of consciousness, traumatic and anoxic etiologies will form part of this cohort. And they will need something that does not yet exist, a mosaic of care that blends the best of acute, rehabilitation, and chronic care to ensure that their disease trajectory does not strand them between current care structures (Fins, 2015, p. 108)

Such a blended model of care was described in the literature in one institution in a study in Denmark, whereby the institutionally and textually driven barriers do not exist in accessing rehabilitation after sTBI (Engberg et al., 2006). Patients were centralized in one location after being able to breathe independently without a ventilator after the initial injury (Engberg et al., 2006). Around-the-clock rehabilitation was provided as tolerated without the requirement for a transition across the liminal spaces of the healthcare institution. Rehabilitation was inclusively provided for all patients, including those with DOC. The results of this study were striking as 94% of the patients showed improvement as measured by the FIM and half of the patients were discharged home from the unit (Engberg et al., 2006).

This Danish study brings into question the very rehabilitation system we accept as necessary—the notion that access must be restricted to only those most likely to succeed and re-enter the economy. What if everyone with sTBI were provided with the opportunity to succeed? What would that healthcare system look like for individuals with sTBI and their families? With the current restrictions in our rehabilitation system, these are questions that cannot be answered. Individuals with sTBI and their families continue to be deeply marginalized by current healthcare system restrictions in rehabilitation for individuals with sTBI.
Thus, I propose a series of next steps to promote improved access to rehabilitation and awareness of useful rehabilitation strategies for individuals with sTBI.

8.2 Next Steps

1) Seeking more equitable access to rehabilitation for all individuals with sTBI:

The family members of individuals with sTBI remarked in many of the interviews that access to rehabilitation was important and even non-negotiable, regardless of the individual’s speed of progression and recovery at that time. Family members did not differentiate between which individuals with sTBI were an institutional priority—these institutional priorities were deployed by health professionals and administrators. Family members of individuals with sTBI recognized that they had rehabilitation goals, including those in lower levels of consciousness, such as decreasing dependence on technological interventions. Not being dependent on technology to breathe improves their ability to be out in the world and provides them with more options of accessing other healthcare liminal spaces, and even returning home with their families. I will repeat a quotation from one of the physicians, Dr. Sorensen, who envisioned a system of equitable access for individuals with sTBI at the trauma centre where I completed this study:

Dr. Sorensen: So, if this is a big trauma, stroke, and cancer centre, rehabilitation is a given, right? Almost everybody needs it. If they had a rehabilitation for this hospital, a rehabilitation institute, we’ll just send them there and they will do it. And it’s just across the street. If there’s an issue, you [the physicians] could go there. They could go faster because we’re close. It’s not like they’re going to a different institution. They could go sooner.

More comprehensive rehabilitation programs that do not require the transitions across healthcare liminal spaces are an essential consideration in sTBI rehabilitation. Fins (2015, 2018) invoked a bioethics perspective regarding lack of access to rehabilitation for individuals with sTBI and DOC, due to what is deemed as medical necessity in the United States. If there is uncertainty regarding their expected outcome, rehabilitation can be denied as it is not deemed medically necessary. Fins (2018) addressed how this lack of access contravenes the Americans with Disabilities Act. Similar concerns need to be expressed in Canada regarding how lack of access for individuals with sTBI, including those who are slow-to-recover and in DOC, is a human rights issue under the Canadian Human Rights Code. This human rights issue requires
immediate attention at provincial and national levels to redress inequities in care and rehabilitation for individuals with sTBI and DOC.

Canadian studies regarding rights and advocacy for individuals with sTBI who are slow-to-recover were notably missing in the extant literature, with one notable publication by Gray (2000) advocating for slow-to-recover programs. Studies examined in the literature review regarding sTBI were drawn from countries across numerous continents, from Western and Eastern Europe, Asia, the Middle East, and the US. However, the number of critical Canadian studies examining research directions and advocating for human rights for individuals with sTBI and DOC is a veritable paucity. This simply must change.

2) More high quality research:

Family members of individuals with sTBI described their own efforts to retrieve and access good quality research through the Internet and in locating applicable research studies. They would cite information that they had learned in their own research about TBI and how they applied this research knowledge into their work practices as caregivers. They also questioned how much research was available regarding individuals with early and even chronic sTBI, as did the health professionals in the study. Their research efforts and questions assisted to direct the state of the art review in this dissertation, as I sought more recent research publications regarding improving levels of consciousness. There were often limited research studies in this area and many of the studies were studies with few participants and/or of limited methodological rigor.

Significantly more qualitative and quantitative research is needed regarding the provision of rehabilitation for individuals with sTBI. Research regarding individuals with sTBI who transition through levels of consciousness would focus on interventions to evaluate and assist with their recovery. Research for individuals with chronic DOC would focus on useful interventions in increasing responsiveness and addressing their quality of life, and the needs of their families. Institutional ethnography work must be completed with individuals with sTBI as they transverse through other liminal healthcare spaces, including repatriation hospitals, CCC, inpatient rehabilitation, LTC, and into their homes and communities to explicate institutional relations shaping the provision of rehabilitation in these various locales.
3) National Registry for Chronic DOC:

Family members of individuals in DOC highlighted that they did not have a basis of comparison for the individual’s progress other than reflecting on incremental changes they had observed over time. Family members relied on information they heard from health professionals and other acquaintances. One family member estimated they would need to wait a year to see any substantial change for their loved one in DOC. Further meetings with various stakeholders, including government agencies and researchers who work with individuals in lower levels of consciousness could explore the development of a National DOC registry. In a national registry, individuals with chronic DOC are registered with details regarding their condition, and electrophysiological, diagnostic, and neurobehavioral information is collected and analyzed. Researchers in Italy (Pascarella et al., 2018) and Germany (Grill et al., 2013) track the outcomes and functioning of individuals with DOC at multiple centres in these countries through their registries. Individuals in PVS and MCS included in these registries contribute data on these states of consciousness and the possibility of recovery. Pascarella et al. (2018) suggest “Longitudinal systematic investigations conducted in large cohorts of patients with DOC could make it possible to identify reliable diagnostic and prognostic markers” (p. 19). Ideologies and beliefs in terms of withdrawal of care also vary between different countries (Fins, 2015; Grill et al., 2013, and Pascarella et al., 2018).

A national registry for DOC would permit a collection of information from across Canadian provinces and territories, setting the stage for improved care and rehabilitation for individuals with chronic DOC and their families, and further research regarding evidence-based rehabilitation with this condition. My study was completed a university-affiliated hospital and Level I Trauma Centre, whereby notable access to medical and rehabilitation expertise was available. Many individuals with sTBI and DOC would live in smaller and more geographically remote parts of Canada, whereby a national registry could provide important prognostic and diagnostic information not readily accessible to them otherwise.

4) Provincial and National TBI Strategies:

Many family members of individuals with sTBI discussed their concerns regarding the limitation rehabilitation available at the Level I Trauma Centre. They also reflected on their concerns regarding the future functioning of the individual with sTBI as time progressed.
Individuals with sTBI who were involved in a motor vehicle accident reflected that they knew they could access auto insurance for further rehabilitation and benefits for the family to replace lost income. For the individuals with sTBI who had sustained falls, been involved in recreational accidents, work-related accidents, or were assaulted or sustained gunshot wounds, no such additional benefits or private rehabilitation system exists. Family members of those individuals with sTBI not involved in motor vehicle accidents, did not seem to have an understanding of the very limited community resources for individuals with sTBI once they leave the walls of a healthcare institution.

As I have discussed in Chapter 7, material lines exist in resource provision for individuals with sTBI, as compared to individuals with stroke in Ontario. Class struggles between these two groups are illuminated as the rights of those with stroke are elevated over those with sTBI in terms of access to publicly funded rehabilitation. Millions of dollars in funding, established guidelines for intervention, designated stroke centres, rehabilitation beds in acute care, and increased access to treatment exist for stroke. These same models of care and access need to be designated for individuals with sTBI at provincial and national levels to account for the intense rehabilitation and care needs of these individuals. Strategies to address the needs of their families should also be created and established.

8.3 Limitations and Strengths of this Study

In concluding this dissertation, I consider the limitations and strengths of this study. One limitation I must consider, as this is an institutional ethnography dissertation, as evident in the literature review and in this chapter, is that I am equally enamored with institutional ethnography and the potential vast scientific exploration in sTBI. Of all of D. E. Smith’s books regarding institutional ethnography, *Writing the Social* (1999) is far and away my favourite; the writing is sublime. The clarity and complexity of D. E. Smith’s ideas are evident in the papers in this book, as she is preoccupied (as she described) with ruling relations, exploring her participation in these relations, and understanding “how they are at work in our consciousness” (D. E. Smith, 1999, p. 4). Making visible the ruling relations in acute care sTBI rehabilitation, using institutional ethnography, in addition to the emergent study design (Campbell, 2010), struck me as a powerful approach to study this particular phenomenon. This approach made visible what
was otherwise invisible in terms of the ruling relations guiding sTBI rehabilitation in a Level I Trauma Centre.

However, at the same time, I am equally fascinated by the possibility of designing and implementing similar scientific studies to those I read while completing the literature review. I can imagine myself going through various studies again, testing appropriate neurobehavioral measurement tools to be used on the trauma units, and initiating the steps required for a registry for DOC. I can imagine establishing neurophysiological measures including event-related potential studies (ERPs) and other diagnostic measures as part of this registry. I completed ERP studies in my undergraduate psychology degree and can see the utility of these measures with individuals with sTBI. I envision myself donning the equipment on individuals with sTBI required for virtual reality studies, including goggles and gloves that are part of these programs, in addition to finding new software programs appropriate for this population. I could easily slip into the capitalist modes of production inherent in these scientific endeavours, at risk of once again subjugating the voices of persons with sTBI (who are often unable to speak) and their families.

My equal fascination with the scientific and ethnographic methods of in this dissertation led me to the question: what is the ultimate aim in using the findings of this institutional ethnography? Generating increased access to what is missing—in this case, adequate rehabilitation—would also invariably involve an increased interface with science, such as surveillance through registries and the possible subjugation of patients’ and families’ perspectives through the proliferation of new scientific programs of study. I noted one such study during the literature review, whereby families in the control group were not able to visit their family members after sTBI while they were in the ICU (Abbasi et al., 2009). This study involved measuring the influence of hands-on early family involvement using a multi-modal sensory program in the experimental group in the very early stages of recovery (Abbasi et al., 2009). Tyler (1986) provided some insight into the ultimate purpose of a post-modern ethnography as I myself struggle with these competing ideologies:

For post-modern ethnography the implication is, if not clear, at least apparent that its text will be projected neither in the form of … inner paradox nor in the form of deceptive outer logic (of science), but as the tension between them, neither denying ambiguity nor endorsing it, neither subverting subjectivity nor denying objectivity, expressing instead
their interaction in the subjective creation of ambiguous objectivities that enable unambiguous subjectivity. The ethnographic text will thus achieve its purposes not by revealing them, but by making purposes possible. It will be the text of the physical, the spoken, and the performed, an evocation of quotidian experience, a palpable reality that uses everyday speech to suggest what is ineffable, not through abstraction, but by means of the concrete. It will be a text to read not with the eyes alone, but with the ears in order to hear “the voices of the pages” (Tyler, 1986, p. 136).

Whatever I or we fear in forging new pathways and directions created from our ethnographic research in healthcare studies, the purpose is clear: telling the stories of voices kept silent of individuals with sTBI and their families makes visible ruling relations guiding rehabilitation that are otherwise not apparent.

An additional limitation was related to the patients and families interviewed in the study. The families interviewed were readily accessible on the trauma ward and all were English-speaking. If the family or friends visited infrequently, were not known to the rehabilitation professionals or nurses on the ward, or were not English-speaking, I did not interview them. This served to further marginalize non-English-speaking families or those family members who needed to work long hours and did not visit the ward in daytime during the work week. Many of the families interviewed on the trauma ward were families who appeared to have the resources needed to develop extensive schedules of care; their lives enabled this participation. Family members often indicated that they had flexible jobs, flexible employers, or were self-employed in their own companies, allowing them to be present on the trauma ward for prolonged periods of time. These families were able to provide extensive stimulation, interaction, and advocacy for their family member with sTBI.

This type of sample is not necessarily representative of many families, whereby the main income earner in the family is the person with sTBI. Other family members need to work long hours to alleviate this new financial burden after this devastating injury, significantly affecting the quotidian activities of many family members. I did not communicate with family members through telephone interviews, employ translators, or attend the trauma ward on weekends or evenings to garner these more difficult-to-access interviews. I did not interview family members in the critical care and intensive care units, even though this option was available to me through the ethics protocol. I also did not interview families who chose to withdraw care early for the individuals with sTBI. In making these types of choices, I did not gain insight into why family
members chose to withdraw care early in sTBI or examine the very early phase of adjustment for families after sTBI.

One of the strengths of the study was the breadth and period of study, which included over one year and three months of prolonged observation and in-depth interviews. I interviewed individuals from numerous perspectives (patients, families, various types of nurses, numerous rehabilitation professionals, physicians, managers, and financial administrators). I attended weekly rounds and followed medical rounds in the critical and intensive care units. I also completed a focus group on the trauma ward to further explore issues I had observed and that we had discussed over the preceding year. I stopped data collection after garnering important documents and policies integral to the production and reproduction of ruling relations related to rehabilitation at the research site and other locales.

Interviewing individuals in different social positions granted me access to the same or remarkably similar stories from different perspectives. In one instance, a family recounted to me the story of their daughter, who had had significant injuries and had not initially been expected to live, due to the extent and severity of her initial sTBI. This family described the emotional intensity of the first days at the hospital as they waited to see if their daughter would survive. The family members described other events whereby their daughter was never expected to talk again, but did. She also went on to inpatient rehabilitation and eventually returned home. One physician recounted a strikingly similar story of a young woman not expected to live but she did during the same time period. There were other instances whereby the same or remarkably similarly stories were told to me by individuals from different perspectives. Stories from the families’ perspectives were still raw and poignant in the re-telling; physicians’ and health professionals’ narratives were remarkably candid in their surprise at various outcomes.

The study by Turgeon et al. (2011) critically examined the practice of Level I Trauma Centres withdrawing life support for individuals with sTBI within three days of injury. Turgeon et al. (2011) argued that three days was too soon to establish outcomes for individuals with sTBI. The parallel story by the family and the physician above illustrates the tangible results of waiting prior to the withdrawal of life support according to the critical care protocols, despite the bleak appearance of initial test results. Hearing about that unlikely individual who beats the odds is a story people want to know about regarding sTBI. But many other indelible stories exist,
including the individuals who do not return to their communities and have very limited or no access to rehabilitation to facilitate further recovery.

Another strength of the study is the openness that health professionals demonstrated to a critique of their services and the willingness of family members to participate in the study. Rehabilitation professionals and nurses approached patients and families regarding participating in the study, as required through the research ethics protocol in the trauma centre. These professionals did not necessarily seek patients and families with positive feedback about the trauma ward and the hospital. In some instances, professionals would preface identification of the patient and family with remarks that this family had issues with the hospital and various processes. Health professionals were noted at times to be under significant stress in completing their job duties due to the large numbers of severely injured patients. However, many professionals still found time to participate in periods of observation, interviews, a focus group, and ongoing casual discussion regarding issues related to the provision of rehabilitation for individuals with sTBI in the trauma centre.

Managers at times readily expressed their unease with various institutional provincial policies that left people with sTBI with limited access to rehabilitation services. Physicians whom I had never met, or only met briefly, offered without hesitation to participate in interviews and to be observed during medical rounds. Most notably, families of individuals with sTBI agreed to be interviewed at what was an incredibly stressful time in their lives. Invariably, the most notable strength of the study was the unified purpose and conviction of the numerous stakeholders in this study, who quickly identified the many problems for individuals with sTBI in acute care and actively sought solutions to these problems.

8.4 A Final Note of Reflection

In a final reflection on this study, I consider one comment by Dr. Pascale as he discussed managing sTBI in the critical phases of this injury: “When the patient has a brain injury, it’s a huge topic and we know 10% of it.” As a former caregiver for someone with sTBI, and in having completed the ethnographic fieldwork and literature review for this dissertation, I was struck by the profound meaning of this comment. I initially interpreted this comment as being scientific in nature, with so much to learn about sTBI, particularly in the early stages of consciousness; still relatively unchartered waters of discovery. From an ethnographic perspective, significantly
more study is essential to dismantle the complex assemblies of ruling relations entrenched in rehabilitation that promote marginalization of individuals with sTBI in healthcare liminal spaces. I hope this is a conviction you share with me.
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Appendices

Appendix A Information Hand-Out for Hospital Employees

**Full Study Title:** Institutional ethnography of rehabilitation in an acute neuro trauma unit. My name is Lynn Rutledge, and I am a PhD student in the Rehabilitation Science Institute. My supervisor is Dr. Susan Rappolt, Associate Professor and Chair of the Department of Occupational Science and Occupational Therapy at the University of Toronto. The Research Ethics Boards with [redacted] and the University of Toronto have approved this study. [redacted] is the Primary Investigator.

**Purpose of the Study:**

This study will look at work that is done for people with acute severe traumatic brain injury (TBI). This includes work, in the broad sense of the word, by hospital staff, family members, friends and other people who provide care. The purpose of the study is to understand why this work occurs as it does. This study will focus on this type of work in an acute care neuro trauma unit. Many books and research studies talk about what should be done for people with TBI. But no studies actually look at this work as it unfolds for people with TBI in an acute care neuro trauma unit.

**What is institutional ethnography?**

An institutional ethnography is a type of qualitative research study. Its focus is on how work is done in certain contexts. These studies also look at why this work unfolds as it does. This research study will provide an in-depth look at the work that is done with people with acute severe TBI in order to help them get better. This study does not look at the quality of care to see if it is effective. The study is simply to figure out and understand why help or treatment unfolds as it does.

**How can I help?**

People can assist with this study by performing the following tasks:
- Provide a 60- to 90-minute interview about the work that they do with a person with severe acute TBI.
- Describe any documents that they may use (e.g. forms, policies).
- Be observed doing their work for a period of two to four hours.
- Participation is voluntary.
- Participation or lack of participation will not affect your status at [redacted] or have any effect on job performance evaluations.

**Stipends:**

No stipends will be offered. Participants will be thanked for being a part of this study. If there are any questions about this study, please contact myself, Lynn Rutledge at [redacted].
to research ethics and participants’ rights can be directed to the Sunnybrook Research Ethics Board at 416-480-6100, ext. 88144.
Appendix B Information Hand-Out for Patients, Families, and Caregivers

**Full Study Title:** Institutional ethnography of rehabilitation in an acute neuro trauma unit. My name is Lynn Rutledge, and I am a PhD student in the Rehabilitation Science Institute. My supervisor is Dr. Susan Rappolt, Associate Professor and Chair of the Department of Occupational Science and Occupational Therapy at the University of Toronto. The Research Ethics Boards with Sunnybrook Health Sciences Centre and the University of Toronto have approved this study. **Wendy Chomski, C5 Patient Care Manager,** is the Primary Investigator.

**Purpose of the Study:**

This study will look at work that is done for people with acute severe traumatic brain injury (TBI). This includes work, in the broad sense of the word, by hospital staff, family members, friends and other people who provide care.

The purpose of the study is to understand why this work occurs as it does. This study will focus on this type of work in an acute care neuro trauma unit. Many books and research studies talk about what should be done for people with TBI. But no studies actually look at this work as it unfolds for people with TBI in an acute care neuro trauma unit.

**What is institutional ethnography?**

An institutional ethnography is a type of qualitative research study. Its focus is on how work is done in certain contexts. These studies also look at why this work unfolds as it does. This research study will provide an in-depth look at the work that is done with people with acute severe TBI in order to help them get better. This study does not look at the quality of care to see if it is effective. The study is simply to figure out and understand why help or treatment unfolds as it does.

**How can I help?**

People can assist with this study by performing the following tasks:

- Provide a 60- to 90-minute interview about what they do to assist a person (their family member/friend) with severe acute TBI.
- Describe any documents that they have noted that seem important.
- Be observed spending time with their family member/friend with an acute severe TBI.
- Participation is voluntary.

**Stipends:**

No stipends will be offered. Participants will be thanked for being a part of this study. If there are any questions about this study, please contact myself, Lynn Rutledge at [647-273-1740](tel:647-273-1740). Questions related to research ethics and participants’ rights can be directed to the [Sunnybrook Research Ethics Board](tel:416-480-6100 ext. 88144).
Appendix C Informed Consent to Participate in a Research Study for Observation for Hospital Staff

**Full Study Title:** Institutional ethnography of rehabilitation in an acute neuro trauma unit for individuals with severe traumatic brain injury.

**Principal Investigator:** Wendy Chomski, C5 Patient Care Manager, 416-480-4188

**INFORMED CONSENT**

You are being asked to take part in a research study. A research study is a way to find out more about a treatment or to answer a question about something that is not well known.

Participation or lack of participation will not affect your status at Sunnybrook Health Sciences Centres or have any effect on job performance evaluations.

Please read the information about the study in this form. The form includes details on the study’s risks and benefits. You should know these risks and benefits before you decide to take part in this study.

You should take as much time as you need to make your decision. You should ask the study staff to explain anything that you do not understand.

You should also make sure all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. This can include your colleagues.

It is best to have all your questions answered before you take part in this study.

Participation in this study is voluntary. You can withdraw from the study at any time.

**INTRODUCTION**

You are being asked to take part in this study because you work at the hospital with people with acute severe traumatic brain injuries (TBI) on the acute neuro trauma unit. You may also assist with this work in some way.

This study will look at work that is done for people with acute severe TBI. This includes work, in the broad sense of the word, by hospital staff, family members, friends and other people who provide care.

This is a qualitative study, which looks at the things people say and the things that they do.

This study will involve doing interviews and observing the work that is done with people with TBI. It will also look at documents (forms, policies) that relate to this work.
WHAT IS THE USUAL TREATMENT?

People with acute TBI will still get the usual standard of care. This care includes being assessed and treated by the hospital staff.

Taking part in this study will not affect any of the hospital services received by the person.

WHY IS THIS STUDY BEING DONE?

The purpose of the study is to understand why work with people with acute severe TBI occurs as it does. This study will focus on this type of work in an acute care neuro trauma unit.

Many books and research studies talk about what should be done for people with TBI. But no studies actually look at this work as it unfolds for people with TBI in an acute care neuro trauma unit.

WHAT WILL HAPPEN DURING THIS STUDY?

You are being asked to consider if you would like to participate in the study. If you choose to do so, you will be observed during your work shift for a duration of one to four hours. Up to four repeat observations could possibly be completed of one to four hours.

I will also take notes of my observations while on the neuro trauma unit. I will not be evaluating the effectiveness of your work. I am merely interested in the work that you do to assist patients with an acute severe TBI to recover.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

The study staff will invite 40 to 50 people to take part in this study. The study will only take place at this hospital. Collecting data at the hospital will take approximately one year.

It will take most likely another year to complete the study after the data has been collected. This will involve analysing the results and writing about the study.

WHAT ARE THE RESPONSIBILITIES OF STUDY PARTICIPANTS?

If you decide to join the study to do an interview, you will need to:

- Participate by being observed during a one to four hour period of your work shift.
- You may complete up to four repeat observations of one to four hours if you decide and consent to do so.
- Talk about your duties at work.
- Discuss any forms, documents or policies that you identify as being important to your work.
- Provide forms or documents that are relevant to the completion of your work duties if possible.
• Suggest other individuals who would also be helpful to talk to or to be observed in this study.

• Direct quotes while you are being observed or interviewed may be used in this research and in written materials. Data identifying certain people and places will be taken out prior to typing the field notes. I will ensure that you cannot be identified in any quotes that are used.

• After being observed as a part of the study, you may be asked to complete an interview. The length of this interview is 30 to 90 minutes. However, this is not mandatory. You can determine if you would like to participate in an interview at a later date.

• The patients observed will continue to receive the standard current level of care on the unit. This care will not be affected in any way by taking part in this study.

• You will not be contacted by telephone or mail after this study.

WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?

Taking part in this study has risks. Some of these risks we know about. There is also a possibility of risks that we do not know about and have not been seen to date.

Please call the student researcher Lynn Rutledge at 647-273-1740 if you have any side effects, even if you do not think they have anything to do with this study.

The risks we know of are:

• There are no medical risks to you in taking part in this study. But taking part in this study may make you feel uncomfortable. You may decline to answer questions or stop the interview at any time if you note discomfort. It is possible you may notice emotional risks like anxiety or sadness as we may talk about difficult issues.

• Also, you may not talk about information that identifies specific people or places. To reduce this risk, I will encourage you to avoid using specific names of people or places. All names will be removed when the transcripts are made.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

You will not benefit directly from taking part in this study. Your participation may or may not help other people with an acute severe TBI in the future. There are no medical benefits from taking part in this study.

CAN PARTICIPATION IN THIS STUDY END EARLY?

The study staff may decide to remove you from this study without your consent for the following reasons:

• The study staff decides that continuing in this study would be harmful to you.

• You are unable or unwilling to follow the study procedures.

If you are taken out of this study, the study staff will discuss the reasons with you.
You can also choose to end being a part of this study at any time. You do not need to provide a reason. If you choose to withdraw, your choice will not have any effect on the patients that you work with or your employment.

If you withdraw your consent, the information that you provided prior to leaving the study will still be used. No new information will be collected from you.

**WHAT ARE THE COSTS OF PARTICIPATING IN THIS STUDY?**

Taking part in this study will not involve any financial costs to you.

By signing this consent form, you do not give up any of your legal rights.

**ARE STUDY PARTICIPANTS PAID TO PARTICIPATE IN THIS STUDY?**

You will not be paid to take part in this study.

**HOW WILL MY INFORMATION BE KEPT CONFIDENTIAL?**

Any information you discuss in this study will be handled in a confidential manner.

No personal information about you, such as a personnel file, will be accessed during this study.

‘Study data’ is information about you that is collected for the study. This information will not directly identify you. This study data will include comments during the interviews, observing this work and looking at related documents (e.g. forms, policies). No documents that identify specific patients will be used (e.g. patient charts).

Any study data about you that is sent outside of the hospital will have a code. This data will not contain your name or address, or any information that directly identifies you.

Study data that is sent outside of the hospital will be used for the research purposes explained in this consent form.

The study staff will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

The student researcher will keep any personal information about you in a secure and confidential location for 10 years. This will include an encrypted hard drive and locked filing cabinets belonging to this researcher. It will then be destroyed according to Sunnybrook Policy.

When the results of this study are published, your identity will not be disclosed.

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please contact student researcher Lynn Rutledge, Rehabilitation Science Institute, University of Toronto.
DO THE INVESTIGATOR(S) HAVE ANY CONFLICTS OF INTEREST?

There are no conflicts of interest to declare related to this study. This means that the student researcher or the research committee do not have any other benefits from doing the study aside from doing this research. For example, we will not be paid money by any other groups for doing this study.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

You have the right to receive all information that could help you make a choice about taking part in this study. You also have the right to ask questions about this study.

You may also ask about your rights as a research participant, and have them answered to your satisfaction, before you make your decision. You also have the right to ask questions and to receive answers during this study.

If you have any questions about this study you may contact the person in charge of this study (Principal Investigator) or Student Researcher Lynn Rutledge, Rehabilitation Science Institute, University of Toronto, .

The Ethics Board has reviewed this study.

If you have questions about your rights as a research participant or any ethical issues related to this study, you may contact someone outside the study. If you wish to discuss with someone not directly involved with the study, you may call the .
DOCUMENTATION OF INFORMED CONSENT

You will be given a copy of this informed consent form after it has been signed and dated by you and the study staff.

Full Study Title: Institutional ethnography of rehabilitation in an acute neuro trauma unit for individuals with severe traumatic brain injury.

Name of Participant: ________________________________________

Participant/substitute decision-maker

By signing this form, I confirm that:

• This research study has been fully explained to me. All of my questions were answered to my satisfaction.

• I understand what is required to take part in this research study.

• I understand that direct quotes may be used from interviews or observations. All identifying information will be removed. This will include the names of specific people and places.

• I have been informed of the risks and benefits of taking part in this study.

• I have been informed of the rights of a person taking part in this study.

• I have read each page of this form.

• I have agreed, or agree to allow the person I am responsible for, to take part in this study.

____________________________________________________________
Name of participant/substitute decision maker (print)       Signature       Date

ASSISTANCE DECLARATION

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

☐ The consent form was read to the participant or substitute decision-maker. The person signing below agrees that the study was clearly explained to them.

☐ The person signing below acted as a translator for the participant or substitute decision-maker during the consent process. He/she agrees that they have clearly translated the information for the participant or substitute decision-maker. They believe that the participant or substitute decision-maker has understood what was translated.

____________________________________________________________
Name of Person Assisting (Print)                                               Signature       Date

Person obtaining consent
By signing this form, I confirm that:

- This study and its purpose have been explained to the participant named above.
- All questions asked by the participant have been answered.
- I will give a copy of this signed and dated document to the participant.

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Appendix D Informed Consent to Participate in a Research Study for Observation with Patients and Family Members/Caregivers

Full Study Title: Institutional ethnography of rehabilitation in an acute neuro trauma unit for individuals with severe traumatic brain injury.

Principal Investigator: [Redacted]

INFORMED CONSENT

You are being asked to take part in a research study. A research study is a way to find out more about a treatment or to answer a question about something that is not well known.

Please read the information about the study in this form. The form includes details on the study’s risks and benefits.

You should know these risks and benefits before you decide to take part in this study. You should take as much time as you need to make your decision.

You should ask the study staff to explain anything that you do not understand. You should also make sure all of your questions have been answered before signing this consent form.

Before you make your decision, feel free to talk about this study with anyone you wish. This can include your friends, family, and family doctor.

It is best to have all your questions answered before you take part in this study.

If you wish, a family member or friend may verbally translate this form into your preferred language.

Participation in this study is voluntary. You can withdraw from the study at any time.

INTRODUCTION

You are being asked to take part in this study because you have a family member or friend who is in the hospital with a severe traumatic brain injury (TBI) on the acute neuro trauma unit.

This study will look at work that is done for people with acute severe traumatic brain injury (TBI). This includes work, in the broad sense of the word, by hospital staff, family members, friends and other people who provide care.

This is a qualitative study, which looks at the things people say and the things that they do.

This study will involve doing interviews and observing the work that is done with people with TBI. It will also look at documents (forms, policies) that relate to this work.
WHAT IS THE USUAL TREATMENT?

People with acute TBI will still get the usual standard of care. This care includes being assessed and treated by the hospital staff.

Taking part in this study will not affect any of the hospital services received by the person.

WHY IS THIS STUDY BEING DONE?

The purpose of the study is to understand why work with people with acute severe TBI occurs as it does. This study will focus on this type of work in an acute care neuro trauma unit.

Many books and research studies talk about what should be done for people with TBI. But no studies actually look at this work as it unfolds for people with TBI in an acute care neuro trauma unit.

WHAT WILL HAPPEN DURING THIS STUDY?

You are being asked to consider if you and your family member/friend with an acute TBI would like to take part in this study. If you choose to do so, you and your family member/friend with a TBI will be observed on the acute neuro trauma unit.

You are being asked to consider if you would like to participate in the study. If you choose to do so, you will be observed for a duration of one to four hours. Up to four repeat observations could possibly be completed of one to four hours. I will also take notes while observing on the neuro trauma unit.

I am merely interested in the work that that is done to assist patients with a severe traumatic brain injury to recover. This work can include that being done by family members and friends.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

The study staff will invite 40 to 50 people to take part in this study. The study will only take place at this hospital. Collecting data at the hospital will take about one year.

It will take most likely another year to complete the study after the data has been collected. This will involve analysing the results and writing about the study.

WHAT ARE THE RESPONSIBILITIES OF STUDY PARTICIPANTS?

If you decide to join the study to do an interview, you will need to:

- Participate by being observed with your family member or friend for a one to four hour period while on the unit.

- You may complete up to four repeat observations of one to four hours if you decide and consent to do so.

- Talk about what you do to help your family member or friend. You may talk about your experiences on the unit.
• Suggest other individuals who would also be helpful to talk to or be observed in the course of the study.

• Describe any forms or documents that appear to be important.

• Direct quotes while you are being observed or interviewed may be used in this research and in written materials. Data identifying certain people and places will be taken out prior to typing the field notes. I will ensure that you cannot be identified in any quotes that are used.

• After being observed as a part of the study, you may be asked to complete an interview. The length of this interview is 30 to 90 minutes. However, this is not mandatory. You can determine if you would like to participate in an interview at a later date.

• The patients observed will continue to receive the standard current level of care on the unit. This care will not be affected in any way by taking part in this study.

• You will not be contacted by telephone or mail after this study.

WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?

Taking part in this study has risks. Some of these risks we know about. There is also a possibility of risks that we do not know about and have not been seen to date.

Please call the student researcher Lynn Rutledge at [redacted] if you have any side effects, even if you do not think they have anything to do with this study.

The risks we know of are:

• There are no medical risks to you in taking part in this study. But taking part in this study may make you feel uncomfortable. You may decline to answer questions or stop the interview at any time if you note discomfort. It is possible you may notice emotional risks like anxiety or sadness as we may talk about difficult issues.

• Also, you may not talk about information that identifies specific people or places. To reduce this risk, I will encourage you to avoid using specific names of people or places. All names will be removed when the transcripts are made.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

You will not benefit directly from taking part in this study. Your participation may or may not help other people with an acute severe TBI in the future. There are no medical benefits from taking part in this study.

CAN PARTICIPATION IN THIS STUDY END EARLY?

The study staff may decide to remove you from this study without your consent for the following reasons:

• The study staff decides that continuing in this study would be harmful to you.
• You are unable or unwilling to follow the study procedures.

If you are taken out of this study, the study staff will discuss the reasons with you.

You can also choose to end being a part of this study at any time. You do not need to provide a reason. If you choose to withdraw, your choice will not have any effect on the patients that you work with or your employment.

If you withdraw your consent, the information that you provided prior to leaving the study will still be used. No new information will be collected from you.

**WHAT ARE THE COSTS OF PARTICIPATING IN THIS STUDY?**

Taking part in this study will not involve any financial costs to you.

By signing this consent form, you do not give up any of your legal rights.

**ARE STUDY PARTICIPANTS PAID TO PARTICIPATE IN THIS STUDY?**

You will not be paid to participate in this study.

**HOW WILL MY INFORMATION BE KEPT CONFIDENTIAL?**

Any information you discuss in this study will be handled in a confidential manner.

No personal information about you, such as a personnel file, will be accessed during this study.

‘Study data’ is information about you that is collected for the study. This information will not directly identify you. This study data will include comments during the interviews, observing this work and looking at related documents (e.g. forms, policies). No documents that identify specific patients will be used (e.g. patient charts).

Any study data about you that is sent outside of the hospital will have a code. This data will not contain your name or address, or any information that directly identifies you.

Study data that is sent outside of the hospital will be used for the research purposes explained in this consent form.

The study staff will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

The student researcher will keep any personal information about you in a secure and confidential location for 10 years. This will include an encrypted hard drive and locked filing cabinets belonging to this researcher. It will then be destroyed according to [Sunnybrook Policy].

When the results of this study are published, your identity will not be disclosed.
You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please contact student researcher Lynn Rutledge, Rehabilitation Science Institute, University of Toronto, [聯絡方式]。

DO THE INVESTIGATOR(S) HAVE ANY CONFLICTS OF INTEREST?

There are no conflicts of interest to declare related to this study. This means that the student researcher or the research committee do not have any other benefits from doing the study aside from doing this research. For example, we will not be paid money by any other groups for doing this study.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

You have the right to receive all information that could help you make a choice about taking part in this study. You also have the right to ask questions about this study.

You may also ask about your rights as a research participant, and have your questions answered to your satisfaction, before you make your decision. You also have the right to ask questions and to receive answers during this study.

If you have any questions about this study you may contact the person in charge of this study (Principal Investigator) [聯絡方式] or Student Researcher Lynn Rutledge, Rehabilitation Science Institute, University of Toronto, [聯絡方式]。

The [聯絡方式] Ethics Board has reviewed this study.

If you have questions about your rights as a research participant or any ethical issues related to this study, you may contact someone outside the study. If you wish to discuss with someone not directly involved with the study, you may call the [聯絡方式]
DOCUMENTATION OF INFORMED CONSENT

You will be given a copy of this informed consent form after it has been signed and dated by you and the study staff.

Full Study Title: Institutional ethnography of rehabilitation in an acute neuro trauma unit for individuals with severe traumatic brain injury.

Name of Participant: ________________________________

Participant/substitute decision-maker

By signing this form, I confirm that:

- This research study has been fully explained to me. All of my questions were answered to my satisfaction.
- I understand what is required to take part in this research study.
- I understand that direct quotes may be used from interviews or observations. All identifying information will be removed. This will include the names of specific people and places.
- I have been informed of the risks and benefits of taking part in this study.
- I have been informed of the rights of a person taking part in this study.
- I have read each page of this form.
- I have agreed, or agree to allow the person I am responsible for, to take part in this study.

________________________      ________________________    ____________________
Name of participant/substitute decision maker (print)      Signature      Date

ASSISTANCE DECLARATION

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

☐ The consent form was read to the participant or substitute decision-maker. The person signing below agrees that the study was clearly explained to them.

☐ The person signing below acted as a translator for the participant or substitute decision-maker during the consent process. He/she agrees that they have clearly translated the information for the participant or substitute decision-maker. They believe that the participant or substitute decision-maker has understood what was translated.

_________________________    __________________
Name of Person Assisting (Print)      Signature      Date
Person obtaining consent
Person obtaining consent

By signing this form, I confirm that:
• This study and its purpose have been explained to the participant named above.
• All questions asked by the participant have been answered.
• I will give a copy of this signed and dated document to the participant.

Name of Person Assisting (Print)  Signature  Date
Person obtaining consent
Appendix E Informed Consent to Participate in a Research Study for Interviews with Hospital Employees

**Full Study Title:** Institutional ethnography of rehabilitation in an acute neuro trauma unit for individuals with severe traumatic brain injury.

**Principal Investigator:** [Redacted]

**INFORMED CONSENT**

You are being asked to take part in a research study. A research study is a way to find out more about a treatment or to answer a question about something that is not well known.

Participation or lack of participation will not affect your status at [Redacted] or have any effect on job performance evaluations.

Please read the information about the study in this form. The form includes details on the study’s risks and benefits. You should know these risks and benefits before you decide to take part in this study.

You should take as much time as you need to make your decision. You should ask the study staff to explain anything that you do not understand.

You should also make sure all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. This can include your colleagues.

It is best to have all your questions answered before you take part in this study.

Participation in this study is voluntary. You can withdraw from the study at any time.

**INTRODUCTION**

You are being asked to take part in this study because you work at the hospital with people with acute severe traumatic brain injuries (TBI) in the acute neuro trauma unit. You may also assist with this work in some way.

This study will look at work that is done for people with acute severe TBI. This includes work, in the broad sense of the word, by hospital staff, family members, friends and other people who provide care.

This is a qualitative study, which looks at the things people say and the things that they do.

This study will involve doing interviews and observing the work that is done with people with TBI. It will also look at documents (forms, policies) that relate to this work.
WHAT IS THE USUAL TREATMENT?

People with acute TBI will still get the usual standard of care. This care includes being assessed and treated by the hospital staff.

Taking part in this study will not affect any of the hospital services received by the person.

WHY IS THIS STUDY BEING DONE?

The purpose of the study is to understand why work with people with acute severe TBI occurs as it does. This study will focus on this type of work in an acute care neuro trauma unit.

Many books and research studies talk about what should be done for people with TBI. But no studies actually look at this work as it unfolds for people with TBI in an acute care neuro trauma unit.

WHAT WILL HAPPEN DURING THIS STUDY?

You are being asked to consider if you would like to participate in the study. If you decide to do an interview, we will meet in a private room or other area in the [redacted]. The interview may last 30 to 90 minutes. You will be asked questions about your work with a person with a severe acute TBI. Up to four interviews could be completed with your consent.

The interview will be recorded. The recording can be turned off if you wish. I will also take notes about what we talk about or what I observe on the unit.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

The study staff will invite 40 to 50 people to take part in this study. The study will only take place at this hospital. Collecting data at the hospital will take approximately one year.

It will take most likely another year to complete the study after the data has been collected. This will involve analysing the results and writing about the study.

WHAT ARE THE RESPONSIBILITIES OF STUDY PARTICIPANTS?

If you decide to join the study to do an interview, you will need to:

- Take part in an interview of 30 to 90 minutes. The interview will be recorded. You can ask to turn off the recorder. I will also take notes.
- You can provide further interviews (up to four) if you have more to add later. You can do so by getting in contact with me.
- If we decide to do additional interviews, they will usually last 30 minutes. They will be audio taped. You can ask to turn off the recorder. I will request to take notes.
• The interviews will take place at Sunnybrook Health Sciences Centre in the neuro trauma unit, or in a private room.

• In this interview, I will ask you questions about the work that you do with people that have an acute severe TBI.

• Direct quotes from these interviews may be used in this research and in written materials. Data identifying certain people and places will be taken out prior to typing the transcripts. I will ensure that you cannot be identified in any quotes that are used.

• The patients that take part in this study will receive the standard level of care on the unit. This care will not be affected in any way by taking part in this study.

• You will not be contacted by telephone or mail after this study.

WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?

Taking part in this study has risks. Some of these risks we know about. There is also a possibility of risks that we do not know about and have not been seen to date.

Please call the student researcher Lynn Rutledge at [647-273-1740] if you have any side effects even if you do not think it has anything to do with this study.

The risks we know of are:

• There are no medical risks to you in taking part in this study. But taking part in this study may make you feel uncomfortable. You may decline to answer questions or stop the interview at any time if you note discomfort. It is possible you may notice emotional risks like anxiety or sadness as we may talk about difficult issues.

• Also, you may not talk about information that identifies specific people or places. To reduce this risk, I will encourage you to avoid using specific names of people or places. All names will be removed when the transcripts are made.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

You will not benefit directly from taking part in this study. Your participation may or may not help other people with an acute severe TBI in the future. There are no medical benefits from taking part in this study.

CAN PARTICIPATION IN THIS STUDY END EARLY?

The study staff may decide to remove you from this study without your consent for the following reasons:

• The study staff decides that continuing in this study would be harmful to you.

• You are unable or unwilling to follow the study procedures.

If you are taken out of this study, the study staff will discuss the reasons with you.
You can also choose to end being a part of this study at any time. You do not need to provide a reason. If you choose to withdraw, your choice will not have any effect on the patients that you work with or your employment.

If you withdraw your consent, the information that you provided prior to leaving the study will still be used. No new information will be collected from you.

**WHAT ARE THE COSTS OF PARTICIPATING IN THIS STUDY?**

Taking part in this study will not involve any financial costs to you.

By signing this consent form, you do not give up any of your legal rights.

**ARE STUDY PARTICIPANTS PAID TO PARTICIPATE IN THIS STUDY?**

You will not be paid to take part in this study.

**HOW WILL MY INFORMATION BE KEPT CONFIDENTIAL?**

Any information you discuss in this study will be handled in a confidential manner.

No personal information about you, such as a personnel file, will be accessed during this study.

‘Study data’ is information about you that is collected for the study. This information will not directly identify you. This study data will include comments during the interviews, observing this work and looking at related documents (e.g. forms, policies).

No documents that identify specific patients will be used (e.g. patient charts).

Any study data about you that is sent outside of the hospital will have a code. This data will not contain your name or address, or any information that directly identifies you.

Study data that is sent outside of the hospital will be used for the research purposes explained in this consent form.

The study staff will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

The student researcher will keep any personal information about you in a secure and confidential location for 10 years. This will include an encrypted hard drive and locked filing cabinets belonging to this researcher. It will then be destroyed according to Sunnybrook Policy.

When the results of this study are published, your identity will not be disclosed.

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please contact student researcher Lynn Rutledge, Rehabilitation Science Institute, University of Toronto.
DO THE INVESTIGATOR(S) HAVE ANY CONFLICTS OF INTEREST?

There are no conflicts of interest to declare related to this study. This means that the student researcher or the research committee do not have any other benefits from doing the study aside from doing this research. For example, we will not be paid money by any other groups for doing this study.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

You have the right to receive all information that could help you make a choice about taking part in this study. You also have the right to ask questions about this study.

You may also ask about your rights as a research participant, and have your questions answered to your satisfaction, before you make your decision. You also have the right to ask questions and to receive answers during this study.

If you have any questions about this study you may contact the person in charge of this study (Principal Investigator or Student Researcher Lynn Rutledge, Rehabilitation Science Institute, University of Toronto, 647-273-1740.

The Ethics Board has reviewed this study.

If you have questions about your rights as a research participant or any ethical issues related to this study, you may contact someone outside the study. If you wish to discuss with someone not directly involved with the study, you may call the Ethics Board.
DOCUMENTATION OF INFORMED CONSENT

You will be given a copy of this informed consent form after it has been signed and dated by you and the study staff.

Full Study Title: Institutional ethnography of rehabilitation in an acute neuro trauma unit for individuals with severe traumatic brain injury.

Name of Participant: ________________________________________

Participant/substitute decision-maker

By signing this form, I confirm that:

- This research study has been fully explained to me. All of my questions were answered to my satisfaction.
- I understand what is required to take part in this research study.
- I understand that direct quotes may be used from interviews or observations. All identifying information will be removed. This will include the names of specific people and places.
- I have been informed of the risks and benefits of taking part in this study.
- I have been informed of the rights of a person taking part in this study.
- I have read each page of this form.
- I have agreed, or agree to allow the person I am responsible for, to take part in this study.

__________________________        _________________________    __________________
Name of Person Assisting (Print)           Signature         Date
Person obtaining consent

ASSISTANCE DECLARATION

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

☐ The consent form was read to the participant or substitute decision-maker. The person signing below agrees that the study was clearly explained to them.

☐ The person signing below acted as a translator for the participant or substitute decision-maker during the consent process. He/she agrees that they have clearly translated the information for the participant or substitute decision-maker. They believe that the participant or substitute decision-maker has understood what was translated.

____________________________
Name of Person Assisting (Print)
Person obtaining consent

__________________________    __________________
Signature         Date
Person obtaining consent

By signing this form, I confirm that:
• This study and its purpose have been explained to the participant named above.
• All questions asked by the participant have been answered.
• I will give a copy of this signed and dated document to the participant.

______________________________________________  ______________________  ____________
Name of Person (Print)  Signature  Date
obtaining consent
Appendix F Informed Consent to Participate in a Research Study for Interviews with Patients and Family Members and Caregivers

**Full Study Title:** Institutional ethnography of rehabilitation in an acute neuro trauma unit for individuals with severe traumatic brain injury.

**Principal Investigator:**

---

**INFORMED CONSENT**

You are being asked to take part in a research study. A research study is a way to find out more about a treatment or to answer a question about something that is not well known.

Please read the information about the study in this form. The form includes details on the study’s risks and benefits.

You should know these risks and benefits before you decide to take part in this study. You should take as much time as you need to make your decision.

You should ask the study staff to explain anything that you do not understand. You should also make sure all of your questions have been answered before signing this consent form.

Before you make your decision, feel free to talk about this study with anyone you wish. This can include your friends, family, and family doctor.

If you wish, a family member or friend may verbally translate this form into your preferred language.

It is best to have all your questions answered before you take part in this study.

Participation in this study is voluntary. You can withdraw from the study at any time.

**INTRODUCTION**

You are being asked to take part in this study because you have a family member or friend who is in the hospital with a severe traumatic brain injury (TBI) in the acute neuro trauma unit.

This study will look at work that is done for people with acute severe traumatic brain injury (TBI). This includes work, in the broad sense of the word, by hospital staff, family members, friends and other people who provide care.

This is a qualitative study, which looks at the things people say and the things that they do.
This study will involve doing interviews and observing the work that is done with people with TBI. It will also look at documents (forms, policies) that relate to this work.

**WHAT IS THE USUAL TREATMENT?**

People with acute TBI will still get the usual standard of care. This care includes being assessed and treated by the hospital staff.

Taking part in this study will not affect any of the hospital services received by the person.

**WHY IS THIS STUDY BEING DONE?**

The purpose of the study is to understand why work with people with acute severe TBI occurs as it does. This study will focus on this type of work in an acute care neuro trauma unit.

Many books and research studies talk about what should be done for people with TBI. But no studies actually look at this work as it unfolds for people with TBI in an acute care neuro trauma unit.

**WHAT WILL HAPPEN DURING THIS STUDY?**

If you decide to do an interview, we will meet in a private room or other area in the Sunnybrook Health Sciences Centre. The interview may last 30 to 90 minutes. Up to four interviews could be completed with your consent. You will be asked questions about how you personally help a person with a severe acute TBI.

The interview will be recorded. The recording can be turned off if you wish. I will also take notes about what we talk about or what I observe on the unit.

**HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?**

The study staff will invite 40 to 50 people to take part in this study. Collecting data at the hospital will take about six to nine months.

It will take most likely another year to complete the study after the data has been collected. This will involve analysing the results and writing about the study.

**WHAT ARE THE RESPONSIBILITIES OF STUDY PARTICIPANTS?**

If you decide to do an interview for the study, you will need to:

- Take part in an interview of 30 to 90 minutes. The interview will be recorded. You can ask to turn off the recorder. I will also take notes.

- You can provide further interviews (up to four) if you have more to add later. You can do so by getting in contact with me.

- If we decide to do additional interviews, they would usually last 30 to 60 minutes. They will be audio taped. You can ask to turn off the recorder. I will request to take notes.
The interviews will take place at Sunnybrook Health Sciences Centre in the neuro trauma unit, or in a private room.

In this interview, I will ask you questions about what you do to help the person you know with acute severe TBI.

Direct quotes from these interviews may be used in this research and in written materials. Data identifying certain people and places will be taken out prior to typing the transcripts. I will ensure that you cannot be identified in any quotes that are used.

The patients that take part in this study will receive the standard level of care on the unit. This care will not be affected in any way by taking part in this study.

You will not be contacted by telephone or mail after this study.

WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?

Taking part in this study has risks. Some of these risks we know about. There is also a possibility of risks that we do not know about and have not been seen to date.

Please call the student researcher Lynn Rutledge at 647-273-1740 if you have any side effects, even if you do not think they have anything to do with this study.

The risks we know of are:

- There are no medical risks to you in taking part in this study. But taking part in this study may make you feel uncomfortable. You may decline to answer questions or stop the interview at any time if you note discomfort. It is possible you may notice emotional risks like anxiety or sadness as we may talk about difficult issues.

- Also, you may not talk about information that identifies specific people or places. To reduce this risk, I will encourage you to avoid using specific names of people or places. All names will be removed when the transcripts are made.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

You will not benefit directly from taking part in this study. Your participation may or may not help other people with an acute severe TBI in the future. There are no medical benefits from participating in this study.

CAN PARTICIPATION IN THIS STUDY END EARLY?

The study staff may decide to remove you from this study without your consent for the following reasons:

- The study staff decides that continuing in this study would be harmful to you.

- You are unable or unwilling to follow the study procedures.

If you are taken out of this study, the study staff will discuss the reasons with you.
You can also choose to end being a part of this study at any time. You do not need to provide a reason. If you choose to withdraw, your choice will not have any effect on the current or future medical treatment or healthcare for your loved one.

If you withdraw your consent, the information that you provided prior to leaving the study will still be used. No new information will be collected from you.

**WHAT ARE THE COSTS OF PARTICIPATING IN THIS STUDY?**

Participation in this study will not involve any financial costs to you.

By signing this consent form, you do not give up any of your legal rights.

**ARE STUDY PARTICIPANTS PAID TO PARTICIPATE IN THIS STUDY?**

You will not be paid to participate in this study.

**HOW WILL MY INFORMATION BE KEPT CONFIDENTIAL?**

Any information you discuss in this study will be handled in a confidential manner.

No personal information about you, such as a personnel file, will be accessed during this study.

‘Study data’ is information about you that is collected for the study. This information will not directly identify you. This study data will include comments during the interviews, observing this work and looking at related documents (e.g. forms, policies).

No documents that identify specific patients will be used (e.g. patient charts).

Any study data about you that is sent outside of the hospital will have a code. This data will not contain your name or address, or any information that directly identifies you.

Study data that is sent outside of the hospital will be used for the research purposes explained in this consent form.

The study staff will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

The student researcher will keep any personal information about you in a secure and confidential location for 10 years. This will include an encrypted hard drive and locked filing cabinets belonging to this researcher. It will then be destroyed according to [Sunnybrook Policy].

When the results of this study are published, your identity will not be disclosed.

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please contact Student Researcher Lynn Rutledge, Rehabilitation Science Institute, University of Toronto. [Contact Information]
DO THE INVESTIGATOR(S) HAVE ANY CONFLICTS OF INTEREST?

There are no conflicts of interest to declare related to this study. This means that the student researcher or the research committee do not have any other benefits from doing the study aside from doing this research. For example, we will not be paid money by any other groups for doing this study.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

You have the right to receive all information that could help you make a decision about taking part in this study.

You may also ask about your rights as a research participant, and have them answered to your satisfaction, before you make your decision. You also have the right to ask questions and to receive answers during this study.

If you have any questions about this study you may contact the person in charge of this study (Principal Investigator) or Student Researcher Lynn Rutledge, Rehabilitation Science Institute, University of Toronto, [Contact Information].

The Ethics Board has reviewed this study.

If you have questions about your rights as a research participant or any ethical issues related to this study, you may contact someone outside the study. If you wish to discuss with someone not directly involved with the study, you may call the [Contact Information].
DOCUMENTATION OF INFORMED CONSENT

You will be given a copy of this informed consent form after it has been signed and dated by you and the study staff.

Full Study Title: Institutional ethnography of rehabilitation in an acute neuro trauma unit for individuals with severe traumatic brain injury.

Name of Participant: ____________________________
Name of Participant: ____________________________
Name of Participant: ____________________________
Name of Participant: ____________________________
Name of Participant: ____________________________

Participant/substitute decision-maker

By signing this form, I confirm that:
• This research study has been fully explained to me. All of my questions were answered to my satisfaction.
• I understand what is required to take part in this research study.
• I understand that direct quotes may be used from interviews or observations. All identifying information will be removed. This will include the names of specific people and places.
• I have been informed of the risks and benefits of taking part in this study.
• I have been informed of the rights of a person taking part in this study.
• I have read each page of this form.
• I have agreed, or agree to allow the person I am responsible for, to take part in this study.

Name of participant/substitute decision maker (print)  Signature  Date

Name of participant/substitute decision maker (print)  Signature  Date

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Name of participant/substitute decision maker (print) | Signature | Date |

**ASSISTANCE DECLARATION**

Was the participant assisted during the consent process?  [ ] Yes  [ ] No

[ ] The consent form was read to the participant or substitute decision-maker. The person signing below agrees that the study was accurately explained to them.

[ ] The person signing below acted as a translator for the participant or substitute decision-maker during the consent process. He/she agrees that they have clearly translated the information for the participant or substitute decision-maker. They believe that the participant or substitute decision-maker has understood what was translated.

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<th>Name of Person Assisting (Print)</th>
<th>Signature</th>
<th>Date</th>
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**Person obtaining consent**

By signing this form, I confirm that:

- This study and its purpose have been explained to the participant named above.

- All questions asked by the participant have been answered.

- I will give a copy of this signed and dated document to the participant.

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<th>Name of Person (Print)</th>
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Appendix G Interview Guide

The interview guide consists of anticipated questions to be asked in the course of interviews with clients’ family members and friends and hospital employees in the acute neuro trauma unit, as well as hospital coordinators or administrators eligible for the study. These questions have been adapted from Kval and Brinkmann (2009) and Aronson Fonte (2008).

Example Questions for Hospital Staff and Coordinators:

*Grand tour/introductory questions:*

Can you tell me about your work?

Can you tell me about what you do?

*Probing questions:*

Could you tell me more about that?

Can you tell me specifically about the work that you do with individuals with acute severe TBI?

You just said that (repeat example). How did that work?

Can you tell me about the situation? What happened?

What did you do?

How do you remember it?

*Follow-up questions:*

You had just mentioned that (repeat example from informant). Could you please expand on that?

What happened in the situation that you mentioned?
Interpreting questions:

You mean that…?

Is it correct that this is what happens?

Specifying/direct questions:

Can you tell me about work on this unit that promotes recovery?

Can you tell me about what you do to help clients become more independent/functional?

Illustrative example questions:

Give a time when (e.g. you assisted someone’s rehabilitation process)?

Could you give me an example of that?

Illustrative extreme questions:

Could you describe an example of when (your work went well, when your work was difficult)?

What is the easiest/hardest thing about your work?

Hypothetical questions:

Imagine that your work could be done differently. What would that look like?

If you had a magic wand, how would you change your work process/flow or the work that you do?
Structuring questions:

I would like to introduce another topic…

I would like to talk about this…

Controversial questions:

I would like to ask you a difficult question…

Some people say that this is difficult work…

Example Questions for Family Members/Friends of Individuals with Acute Severe TBI:

Grand tour/introductory questions:

Can you tell me what you do when you visit/come here?

Tell me about being on this unit, visiting your family member/friend?

Probing questions:

Could you tell me more about that?

You just said that (repeat example). How did that work?

Can you tell it to me? What happened?

What did you do?

How do you remember it?
**Follow-up questions:**

You had just mentioned that (repeat example from informant). Could you please expand on that?

What happened in the situation that you mentioned?

**Interpreting questions:**

You mean that…?

Is it correct that this is what happens?

**Specifying/direct questions:**

Tell me about what you do to help your family member/friend improve?

Are there things that you do to help your family member/friend get better?

**Illustrative example questions:**

Give a time when you did something to help your family member getter better, improve, or be more independent.

Could you give me an example of that?

**Illustrative extreme questions:**

Could you describe an example of when helping your family member/friend went well or was difficult?

What is the easiest/hardest thing about helping your family member/friend?
Structuring questions:

I would like to introduce another topic…

I would like to talk about this…

Example Probes for Individuals with Severe Acute TBI if Conscious/Communicative:

The purpose of these probes are to understand what individuals with severe acute TBI are trying to do or are seeking to do, in the type of ‘work’ that they seek or want to accomplish. These probes have been adapted from Kvale & Brinkman (2009), Aronson Fontes (2008) and Paterson and Scott-Findlay (2002).

Grand tour/introductory questions:

What are you doing?

What are you trying to do?

Where do you want to go?

What do you want to do?
Appendix H Informed Consent to Participate in a Research Study for Focus Groups with Hospital Employees

**Full Study Title:** Institutional ethnography of rehabilitation in an acute neuro trauma unit.

**Principal Investigator:** Wendy Chomski, C5 Patient Care Manager, 416-480-4188

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**INFORMED CONSENT**

You are being asked to take part in a research study. A research study is a way to find out more about a treatment or to answer a question about something that is not well known.

Participation or lack of participation will not affect your status at Sunnybrook Health Sciences Centres or have any effect on job performance evaluations.

Please read the information about the study in this form. The form includes details on the study’s risks and benefits. You should know these risks and benefits before you decide to take part in this study.

You should take as much time as you need to make your decision. You should ask the study staff to explain anything that you do not understand.

You should also make sure all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. This can include your colleagues.

It is best to have all your questions answered before you take part in this study.

Participation in this study is voluntary. You can withdraw from the study at any time.

---

**INTRODUCTION**

You are being asked to take part in this study because you work at the hospital with people with acute severe traumatic brain injuries (TBI) in the acute neuro trauma unit. You may also assist with this work in some way.

This study will look at work that is done for people with acute severe TBI. This includes work, in the broad sense of the word, by hospital staff, family members, friends and other people who provide care.

This is a qualitative study, which looks at the things people say and the things that they do.
This study will involve doing Focus Groups and observing the work that is done with people with TBI. It will also look at documents (forms, policies) that relate to this work.

**WHAT IS THE USUAL TREATMENT?**

People with acute TBI will still get the usual standard of care. This care includes being assessed and treated by the hospital staff.

Taking part in this study will not affect any of the hospital services received by the person.

**WHY IS THIS STUDY BEING DONE?**

The purpose of the study is to understand why work with people with acute severe TBI occurs as it does. This study will focus on this type of work in an acute care neuro trauma unit.

Many books and research studies talk about what should be done for people with TBI. But no studies actually look at this work as it unfolds for people with TBI in an acute care neuro trauma unit.

**WHAT WILL HAPPEN DURING THIS STUDY?**

You are being asked to consider if you would like to participate in the study. If you decide to do a Focus Group, we will meet after rounds on in the Sunnybrook Health Sciences Centre.

The Focus Group may last 10 to 30 minutes. You will be asked questions about your work with individuals with severe acute TBI.

The Focus Group will be recorded. The recording can be turned off if you wish. I will also take notes about what we talk about or what I observe on the unit.

**HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?**

The study staff will invite 60 to 70 people to take part in this study. The study will only take place at this hospital. Collecting data at the hospital will take about 12 to 15 months.

It will take most likely another year to complete the study after the data has been collected. This will involve analysing the results and writing about the study.

**WHAT ARE THE RESPONSIBILITIES OF STUDY PARTICIPANTS?**

If you decide to join the study to do a Focus Group, you will need to:

- Take part in a Focus Group of 10 to 30 minutes. The Focus Group will be recorded. You can ask to turn the recorder off. I will also take notes. Up to three focus groups will be completed.

- If we decide to do additional Focus Groups, they will usually last 10 to 30 minutes. They will be audio taped. You can ask to turn the recorder off. I will request to take notes.
• The Focus Groups will take place at [Redacted] in the neuro trauma unit, in the room where rounds are completed.

• In this Focus Group, I will ask you questions about the work that you do with people that have an acute severe TBI.

• Direct quotes from these Focus Groups may be used in this research and in written materials. Data identifying certain people and places will be taken out prior to typing the transcripts. I will ensure that you cannot be identified in any quotes that are used.

• The patients that take part in this study will receive the standard level of care on the unit. This care will not be affected in any way by taking part in this study.

• You will not be contacted by telephone or mail after this study.

WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?

Taking part in this study has risks. Some of these risks we know about. There is also a possibility of risks that we do not know about and have not been seen to date.

Please call the student researcher Lynn Rutledge at [Redacted] if you have any side effects, even if you do not think they have anything to do with this study.

The risks we know of are:

• There are no medical risks to you in taking part in this study. But taking part in this study may make you feel uncomfortable. You may decline to answer questions or stop the Focus Group at any time if you note discomfort. It is possible you may notice emotional risks like anxiety or sadness as we may talk about difficult issues.

• Also, you may not talk about information that identifies specific people or places. To reduce this risk, I will encourage you to avoid using specific names of people or places. All names will be removed when the transcripts are made.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

You will not benefit directly from taking part in this study. Your participation may or may not help other people with an acute severe TBI in the future. There are no medical benefits from taking part in this study.

CAN PARTICIPATION IN THIS STUDY END EARLY?

The study staff may decide to remove you from this study without your consent for the following reasons:

• The study staff decides that continuing in this study would be harmful to you.

• You are unable or unwilling to follow the study procedures.

If you are taken out of this study, the study staff will discuss the reasons with you.
You can also choose to end being a part of this study at any time. You do not need to provide a reason. If you choose to withdraw, your choice will not have any effect on the patients that you work with or your employment.

If you withdraw your consent, the information that you provided prior to leaving the study will still be used. No new information will be collected from you.

**WHAT ARE THE COSTS OF PARTICIPATING IN THIS STUDY?**

Taking part in this study will not involve any financial costs to you.

By signing this consent form, you do not give up any of your legal rights.

**ARE STUDY PARTICIPANTS PAID TO PARTICIPATE IN THIS STUDY?**

You will not be paid to take part in this study.

**HOW WILL MY INFORMATION BE KEPT CONFIDENTIAL?**

Any information you discuss in this study will be handled in a confidential manner.

No personal information about you, such as a personnel file, will be accessed during this study.

‘Study data’ is information about you that is collected for the study. This information will not directly identify you. This study data will include comments during the Focus Groups, observing this work and looking at related documents (e.g. forms, policies).

No documents that identify specific patients will be used (e.g. patient charts).

Any study data about you that is sent outside of the hospital will have a code. This data will not contain your name or address, or any information that directly identifies you.

Study data that is sent outside of the hospital will be used for the research purposes explained in this consent form.

The study staff will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

The student researcher will keep any personal information about you in a secure and confidential location for 10 years. This will include an encrypted hard drive and locked filing cabinets belonging to this researcher. It will then be destroyed according to [Sunnybrook Policy].

When the results of this study are published, your identity will not be disclosed.

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please contact student researcher Lynn Rutledge, Rehabilitation Science Institute, University of Toronto. [Contact Information].
DO THE INVESTIGATOR(S) HAVE ANY CONFLICTS OF INTEREST?

There are no conflicts of interest to declare related to this study. This means that the student researcher or the research committee do not have any other benefits from doing the study aside from doing this research. For example, we will not be paid money by any other groups for doing this study.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

You have the right to receive all information that could help you make a choice about taking part in this study. You also have the right to ask questions about this study.

You may also ask about your rights as a research participant, and have your questions answered to your satisfaction, before you make your decision. You also have the right to ask questions and to receive answers during this study.

If you have any questions about this study you may contact the person in charge of this study (Principal Investigator) or Student Researcher Lynn Rutledge, Rehabilitation Science Institute, University of Toronto.

The Ethics Board has reviewed this study.

If you have questions about your rights as a research participant or any ethical issues related to this study, you may contact someone outside the study. If you wish to discuss with someone not directly involved with the study, you may call the...
DOCUMENTATION OF INFORMED CONSENT

You will be given a copy of this informed consent form after it has been signed and dated by you and the study staff.

Full Study Title: Institutional ethnography of rehabilitation in an acute neuro trauma unit.

Name of Participant: ____________________________________________

Participant/substitute decision-maker

By signing this form, I confirm that:
• This research study has been fully explained to me. All of my questions were answered to my satisfaction.
• I understand what is required to take part in this research study.
• I understand that direct quotes may be used from Focus Groups or observations. All identifying information will be removed. This will include the names of specific people and places.
• I have been informed of the risks and benefits of taking part in this study.
• I have been informed of the rights of a person taking part in this study.
• I have read each page of this form.
• I have agreed, or agree to allow the person I am responsible for, to take part in this study.

________________________  _____________________________  _____________
Name of participant/substitute Decision maker (print)  Signature  Date

ASSISTANCE DECLARATION

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

□ The consent form was read to the participant or substitute decision-maker. The person signing below agrees that the study was clearly explained to them.

□ The person signing below acted as a translator for the participant or substitute decision-maker during the consent process. He/she agrees that they have clearly translated the information for the participant or substitute decision-maker. They believe that the participant or substitute decision-maker has understood what was translated.
By signing this form, I confirm that:

• This study and its purpose have been explained to the participant named above.
• All questions asked by the participant have been answered.
• I will give a copy of this signed and dated document to the participant.
Appendix I Focus Group Guide

The interview guide consists of anticipated questions to be asked in the course of focus groups conducted on the C5 Trauma Unit.

**Example Questions:**

*Probing questions:*

Generally, in the course of interviews and observations on the unit in the past year, I have noted that there are individuals with severe traumatic brain injury who tend to improve quickly (‘rehab ready’) and individuals with significant care needs who will go to Complex Continuing Care

What are the challenges of working with individuals with severe TBI who go to rehab quickly?

What are the challenges of working with individuals with severe TBI who remain on the unit for a long time (e.g. several months)? What are the difficulties in their care?

*Specifying/direct questions:*

Are there specific documents or materials that would be helpful to provide to individuals with severe TBI and their families?

Can you tell me about what an ideal rehabilitation unit would look like for individuals with severe TBI on an acute care rehab unit like this one?

- How would the rooms be placed?
- What would the rooms look like (e.g. one person per room, two or three people)? Opaque walls, a glass-viewing wall?

*Hypothetical questions:*

If the work with people with severe TBI could be done differently, what would it look like? How would it be different? Would there be different spaces needed? Would different resources be needed?
Appendix J Confidentiality Agreement with the Transcriptionist

**Title:** An institutional ethnography of rehabilitation in an acute neuro trauma unit.

This worker agrees to keep all of personal data obtained while keeping this work private. This worker or their company will not, through direct or indirect means, use, publish, discuss or otherwise disclose private data of any kind obtained during this research study.

The tasks of this worker include transcribing all data obtained in the audio records word for word into all transcribed records. All transcribed records will be kept as guided by provincial privacy legislation. This data will accessed on a secure website or through the use of password-protected documents.

This worker agrees that all electronic and written materials shared with this researcher will remain in a secure place. Only the transcriptionist and/or their company can access these records in this secure area. This worker agrees to destroy all electronic and written data associated with this study after the records have been given to this researcher.

**Signature:**

I have read my assigned tasks as a transcriptionist to this research and I understand and agree to my assigned tasks.

________________________  ________________________
Transcriptionist’s Name  Researcher’s Name

________________________  ________________________
Transcriptionist’s Signature  Researcher’s Signature

________________________  ________________________
Date  Date
Appendix K Analytic Techniques

Techniques from Bisaillon

I have included this appendix to add transparency to my analysis, in explicating the specific data analysis techniques employed in this dissertation in greater detail. I have analyzed various points in the pilot interviews in this appendix, using specific transcript excerpts to substantiate my arguments. In the first section, I have considered the analytic categories employed by Bisaillon (2012, 2013), which include the following: work, people, institutions, talk, and text. In the second section of this appendix, I have provided examples regarding analysis using the four readings from the Listening Guide (Doucet & Mauthner, 2008; Gilligan et al., 2003). This type of early analysis of pilot interviews assists to shape the unfolding analysis by sensitizing the researcher to pivotal aspects of social relations in the fieldwork setting as the analysis proceeds.

Work

Rehabilitation work is completed by many different people and professionals in a Level I Trauma Centre. The significance of this rehabilitation work was identified by many informants, including physicians and administrators who do not perform this work, but highlighted the need for this work in a Level I Trauma Centre. Rehabilitation professionals described the intricacies in rehabilitation work during periods of observation and interviews in working with individuals with sTBI. Nursing work addresses assisting to progress the functioning of individuals with sTBI in tandem with the goals of the team. Some families become intensely involved in rehabilitation work for their family member with sTBI, pulled into this work soon after admission. Leslie, an intensive care nurse, oriented us to the initial uncertainty following sTBI:

Leslie: In the ICU, traumatic brain injury patients are so ill that they typically can’t speak; they can’t really interact beyond a very basic level. And sometimes their consciousness is so low that one can never really be sure what they’re taking in.

This understanding of the initial dramatic presentation after sTBI sets the stage for rehabilitation work I will discuss in the three analysis chapters of this dissertation. The impact of the sTBI on the person’s functioning can be difficult to discern in the early stages after injury. These initial stages of recovery can illuminate a precipice for those with sTBI and others.
involved in their care and rehabilitation. Levels of consciousness of individuals with early sTBI exist in a liminal territory bounded by uncertainty. I recall this uncertainty in being a caregiver for an individual with sTBI, as each new day can announce miraculous new recoveries—saying a word or a sentence, taking a step, or sitting upright unassisted for the first time. Each new day may also announce no recovery at all, only further uncertainty regarding outcomes after sTBI. I will discuss this rehabilitation work in greater detail in Chapter 7.

People

Analyzing the topic of people allowed me to consider the many professionals in a Level I Trauma Centre, including physicians, nurses, physiotherapists, occupational therapists, speech language pathologists, dieticians, advanced practical nurses, unit managers, and administrators, who each had a different role in the trauma centre. Families and caregivers found themselves in foreign territory in being unfamiliar with the environment of a Level I Trauma Centre and the new realities of a family member with such a serious injury. Caregivers had extensive contact with nurses, physicians, and rehabilitation professionals in the critical care and intensive care units due to the high nurse-to-patient ratios and open visual spaces in these units. Patients with sTBI move to the trauma ward if they show improvement or if they are medically stable enough to remain in the trauma ward, even with limited recovery.

Different types of interactions were described between the health professionals and the family members of individuals with sTBI during interviews and periods of observations with both groups of informants. Many family members described positive and supportive interactions with health professionals in the trauma centre. Emotional intensity also often characterized the interactions between health professionals and families of individuals with sTBI. Leslie, the ICU nurse, discussed the tense exchanges between health professionals and family members when the patient with sTBI does not improve. These volatile interactions are described by Leslie below:

Leslie: I wasn’t prepared for the emotional intensity of it. There are several parts to that as it can become quite volatile. And, not only are family members distraught, they can become very angry, and so the emotions are mixed and the experiences that they are having can become quite convoluted. The antagonism can make it almost frightening as a nurse, and so one can be in between the family members and the physician.
I have used this particular transcript excerpt above as it provides a salient example of the raw intensity of emotions in these circumstances. In many instances, individuals with sTBI are saved by urgent medical procedures and kept alive through medical technology. But they may recover minimally or not at all. Physicians deliver this news to families and discuss the withdrawal of life support if there is no chance of recovery, given the results of various medical tests. The emotional work for the health professionals can become quite intense when poor outcomes are likely for the individual with sTBI and the family tries to adjust to this distressing new information.

A patient in one bed with sTBI in critical care may recover and move on to other units, while the patient in the next bed may be kept alive by artificial means of ventilation and respiration but has experienced brain death as a result of the severity of trauma. These two patients can superficially appear very similar with the same lines and tubes, but the extent of damage and potential for recovery from the trauma to the brain and body are vastly different. I will discuss these issues in greater detail in the analysis in Chapter 5.

Institutions

Family members and friends soon find themselves taking on caregiving roles for individuals with sTBI due to the intensity and consistency required for this work. While nurses staff trauma wards on a 24/7 basis, the work required with individuals with sTBI quickly outpaces nurse-staffing ratios. Place and space can contravene recovery in a Level I Trauma Centre after sTBI, as the liminal space of the trauma room, located near the Emergency Department to save a person’s life after sTBI, can stand at odds with other liminal trauma spaces in the institution, with bustling all day and all night with schedules and routines. I will discuss place and space in greater detail in Chapter 7. In the following transcript excerpt, I described staying overnight to assist my friend with a sTBI after she had pulled out her feeding tube on numerous occasions that day. Even though there was an observer, who is a personal care worker, in the room with the several other patients, I stayed to ensure she would not pull out this feeding tube again as she was losing weight so quickly:

Lynn: You have this circus of activity going in this room and people are supposed to be sleeping. It’s the middle of the night and the lights are on, the nurses are walking in, people are talking, the other patients are all talking. It’s a circus! And they’re supposed
to be recovering from a brain injury? I stayed over that night to make sure that she didn’t haul it out [the feeding tube]. I tried to do basic teaching around that. “That’s a tube; it goes to your nose; it is meant to feed you.” I would loosen the restraints and let her explore to understand: “You’re a person, you have a face, and you have a body”.

This transcript excerpt assists to bring the institution into view as families and friends become an informal workforce assisting in the care of an individual with sTBI when demands for care exceed what the institution provides. While visiting and overnight policies exist in the trauma centre, they are often not invoked with families who provide additional care. It requires many people to assist and monitor someone with sTBI soon after the injury or in the event of medical complications and chronic sTBI. Families soon found themselves entering roles as informal caregivers, assisting and learning from the health professionals and doing the ‘work’ of the institution, providing care and rehabilitation.

Talk

Talk includes the language people use in various situations; close analysis of how language is deployed can assist in making social relations visible. Language can signify priorities advanced by the institution, taking precedence over the wishes of families and even health professionals. The social organization of rehabilitation work becomes apparent in how various professionals talk about recovery after sTBI and priorities in rehabilitation for the health professionals. Talk brings the institution into view, as discursive contingencies shape how rehabilitation work is accomplished. The following is an excerpt from the pilot interview with Gloria, a physiotherapist who had previously worked on a neuro trauma unit. She discussed how talk shaped rehabilitation work, encouraging her to work very long hours to promote recovery with people with sTBI:

Gloria: Every morning, there would be rounds with the charge nurse. Usually one of the doctors would fly in and their main concern was, once the patient was stabilized “When can we get this person out? What is the quickest you can get this done?” There were those discussions about who were priority cases, but for the most part, you knew as a therapist that what you needed to do to get them going. And I think that was probably one of the struggles I had. You knew these patients needed rehab every day and I worked my darnest to do that. Your day wasn’t just 9 to 5 or 9 to 4:30. I was there later, until 7 at night, just to see everybody. Thinking about the whole neuroplasticity of the nervous system and capitalizing on that as quickly as you can to try to activate the nervous system.
Talk is mediated institutionally through text; text is ultimately often the discursive organizer of institutional activity in institutional ethnography.

Text

Informants pinpointed various texts, forms, and scales deployed in trauma rehabilitation work, including the Glasgow Coma Scale (GCS) and Ranchos Los Amigos Scale (RLA). These are international guidelines for charting severity and recovery in TBI. The GCS is one of the two methods through which the initial severity of the traumatic brain injury is usually determined and communicated. For the purposes of this study, a severe traumatic brain injury is described as having sustained a GCS of 8 or lower. The severity of traumatic brain injury is also rated by looking at the period of time to recover consciousness, specifically the initial period of amnesia (de Guise et al., 2017). The GCS was a more readily available documentary indicator, frequently addressed during multidisciplinary rounds.

Textually mediated contingencies define options for next destinations for individuals with sTBI. The following is an excerpt from the pilot interview with Gloria, a physiotherapist, regarding how one scale in particular, the RLA, defines textually mediated institutional discourse:

Gloria: Because it’s acute care, with discharge, you have to try to determine where should this person go? Are they needing to go to rehab or what’s the potential here as well? You’re trying to figure all that out because things happen quickly. Beds are limited and you’re trying to get people out as soon as you can and with proper services. The Rancho Los Amigos Scale is important to us because, often unless they were a V and are ‘rehab ready’, they wouldn’t accept them there [at inpatient rehabilitation]. I think a lot of our work was really to push the patient to get them to a level of being ‘rehab ready’.

The term ‘rehab ready’ is drawn from the inpatient rehabilitation forms for admission to these facilities. I expand upon the use of this term and its implications in the analysis in Chapter 6 and Chapter 7. I will consider how using the Listening Guide assisted to formulate the analysis in the following section.

Using the Listening Guide

I also used the Listening Guide (Doucet & Mauthner, 2008; Gilligan et al., 2003) as a data analysis strategy in this study. I will refer to excerpts from one particular pilot interview
with ICU nurse Leslie to describe examples of analytic points I noted in employing the Listening Guide (Doucet & Mauthner, 2008; Gilligan et al., 2003). The Listening Guide includes four readings, including: (1) reading for plot and your reaction to it; (2) looking at ‘I poems’; (3) looking for contrapuntal or opposing voices; (4) overall analysis. This method is particularly helpful in pinpointing how individuals experience tensions and contradictions in their work. These issues become apparent as informants talk about themselves, when describing competing priorities through contrapuntal voices about what they do, and what they think is important in their work.

Doucet and Mauthner (2008) suggested the Listening Guide can be applied to specific transcripts as opposed to all of them as a method to assist in analysis. I found employing the techniques described in the Listening Guide to be very instrumental in my analysis. I used this analytic technique to a varying degree with all of the transcripts. Some transcripts were interparadigmatic, layered with meaning spanning microsociological to macrosociological levels of interpretation (Chriss, 1996) and required more detailed readings and analysis. Other transcripts appeared to circle more centrally around one or two issues at a similar level of interpretation, such as interventions that health professionals or family members employed to assist individuals with sTBI with recovery. The four readings of the transcript with Leslie, the ICU nurse, are described in the sections below.

**Reading One – Reading for Plot**

Using the example of the pilot interview of an ICU nurse, the overall plot of the transcript describes being a nurse in the ICU, including the learning involved in this role in working with individuals with sTBI and their families, and addresses the substantial textual requirements in this position. In the transcript, the nurse talked extensively about her own learning while training as an ICU nurse, and the learning involved for families to become acquainted with the consequences of sTBI and adjust to the environment of the ICU. Leslie has significant experience working in the ICU; she compared her academic training as a nurse with the actual experience of working in the ICU with individuals who have sustained a sTBI. Leslie reflected on how the stimulation and activity of the ICU, with many health professionals and technological devices with noisy alarms, may not be the best place for people with TBI to recover.
The ICU has restricted access, which Leslie described as “hived off from the rest of the hospital.” Individuals need to be permitted access to the ICU due to the severity of the illnesses and the injuries of the patients, in order to reduce the risk of infection and further complications. In addition, patients and staff may need to be protected from the public, in case someone unlawfully attempts to enter, particularly when a patient is present in the trauma centre after a violent assault or gunshot wounds. The restricted access of the space is contrasted with the legal battles that can erupt periodically regarding end-of-life decisions, displayed very publicly in the media. These legal issues contribute to the emotional intensity in the ICU described by Leslie.

The bustling activity of the environment itself includes many technological machines and noisy monitors presenting overwhelming sensory stimuli, in addition to the number of individuals, including physicians, residents, medical students, nurses, and other health professionals present in the ICU. Leslie indicated that nurses have many responsibilities for patients, including closely monitoring their functioning through numerous machines and observation, performing detailed documentation accessed by the remainder of the staff, and contacting physicians to clarify orders. These responsibilities can overshadow talking to, educating, and supporting families. Nursing work in the ICU is performed in reference to managerial and medical influences using international evidence-based guidelines to sustain life. Patient care and maintaining life are set against the economics of these choices. Leslie described how lack of recovery can be seen as a problem created by the patient:

Leslie: Can you imagine being a 40-year-old that has suddenly been termed ‘chronic’? So, it’s these paradoxical terms that are floated around, that are driven around people not progressing, and occupying acute care space in hospitals, even though we’ve intervened with high technology; the view is the patient is the problem.

Leslie addressed the social positioning of the physicians, with the senior physicians at the top of the hierarchy, residents, and then nurses. Families of the patients seek discussion with senior physicians over residents and nurses. However, these doctors are not always present or unavailable as families seek to address their concerns. The work of the physicians is described as a thinking job, in addition to communicating with families regarding very serious or delicate issues. Nurses and the more junior physicians-in-training engage in more manual and physical work, providing procedures to individuals with sTBI. Nurses are pulled into the physicians’ schedules and routines, sometimes unwillingly due to other responsibilities; physicians’ rounds
require the nurses’ time to interact or listen during rounds, regardless of other pressing responsibilities.

Leslie addressed how nurses make individuals with sTBI look better than they are for the sake of families and other health professionals, covering the effects of the consequences of sTBI with the illusionary disguise of good body hygiene. Nurses are responsible for dealing with infections, ensuring they do not occur or are closely monitored. Nurses adhere to a number of hospital policies for required procedures. These policies are accessible through computer technology and nurses are trained in these policies during in-class training. Nursing policies related to people with TBI involve lines and tubes, and physical restraints. Nurses work with TBI patients to both reduce excessive over stimulation and agitation, and to wake up somnolent patients and those in coma-like states.

Nurses and other health professionals use technological monitors, devices, charts, and graphs to predict the patient’s level of arousal and the next step in intervention; physicians define the ranges for intervention. Many of the policies nurses and physicians follow in the ICU for neurological patients are derived from international, evidence-based practice guidelines. Nurses monitor TBI patients rigorously to prevent permanent or fatal events (such as changes in intracranial pressure leading to coning, when the brain is pushed out through the bottom of the skull), act on physicians’ orders, and provide a steady stream of information to physicians. Forms and charts help predict neurological events and need to be regularly updated. While the ICU is a challenging environment, this ICU nurse found it to be a satisfying place to work. She preferred the higher levels of communication and very direct discussion regarding the possibility of death, as compared to other units where she had worked, where the topic of impeding death was avoided.

I reflexively considered my reactions to the plot, which is part of reading one in the Listening Guide (Doucet & Mauthner, 2008; Gilligan et al., 2003). Families appeared to need to adjust to extensive changes in functioning for the person after sTBI while in the ICU. I recalled a similar experience in having been a caregiver for someone with TBI as I read this nurse’s descriptions of the reactions of families in seeing their family member with sTBI. The unfamiliar technology, including many lines and tubes, and the stillness and even agitation of someone with sTBI are quite disconcerting to observe. The nurse’s description of the
technological management of this work, in addressing numerous devices and machines that nurses constantly monitor and interact with, highlighted the numerous responsibilities assigned to nurses in the ICU.

The extensive information nurses need to access, including various policies and procedures, appeared overwhelming in the management of all of these sources of information. Nurses and other health professionals must deploy specific and detailed knowledge in order to operate and understand numerous technological devices and machines, and to inscribe the technocratic outputs of these machines. As the ICU nurse described various responsibilities, I was surprised by how many tasks she needed to complete, from talking to physicians, other health professionals, and families; closely monitoring the patient; reading and following orders; completing documentation required for various graphs and charts; and being aware of numerous policies and procedures for the ICU. Nursing work in the ICU appears laborious, entailing extensive responsibility in terms of providing nursing care for patients with sTBI. I also only asked about nursing work with individuals with sTBI, but ICU nurses can see numerous types of patients with different complex conditions in their work.

Reading Two - Looking at ‘I Poems’

The intention of this reading is to look for the ‘I poems’ in how the informant talks about herself and how these reflections of the narrated self can change within the transcript. Initially, her ‘I poems’ centered around not being familiar with what ICU patients looked like and how they behaved. She indicated she learned more about ICU patients through post-professional training as opposed to on-the-job training or the daily care of patients. She was aware that she needed to learn many technical skills as an ICU nurse. However, the emotional exchanges with the family members had a significant impact on her training as well. She reflected on how the training and experience in the ICU precluded understanding the long-term implications of brain injury, particularly in terms of the invisibility of this injury after leaving the ICU:

Leslie: I just think the recovery part is so interesting that’s beyond the ICU. Something I think is important is the invisibility of the disability for most people; people who recover. Because we talked about some sad cases where people do get out and look okay but they’re not okay.
In analyzing her ‘I poems,’ the ICU nurse reflected on how she found the invisibility of TBI to be the most interesting, as recovery is often partial. Leslie questioned how much she knows or can answer questions about TBI for patients’ families as the patients are in the ICU soon after injury. She addressed her own beliefs in effective early rehabilitation with sTBI, in introducing herself to patients with sTBI and talking very calmly to the patients, assuming that someone is ‘there’, even though the person can appear very impaired and incapacitated. She felt being conscious of bodies is important and that making the bodies of people with TBI look good to families and other health professionals was an important part of her role as an ICU nurse.

Leslie considered how her career as a nurse differed in other wards in the hospital; she described her preferences for certain practices in the ICU. She preferred that death is a topic directly addressed by physicians in the ICU, as opposed to other units, such as the cancer unit, where death was often not discussed. While she described the environment of the ICU as quite stressful with a number of responsibilities and the intensity of the exchanges with physicians and families; she gravitated towards the enclosed and exciting environment of the ICU over that of other units. Due to the openness of the unit, she could see everything going on in the ICU, even if she had a lot to attend to. In other units, she felt she needed to run from room to room to accomplish her duties. In her ‘I poems’, the nurse was quite focused on what she had learned from the scientific and grey literature and how this knowledge had shaped her understanding of the work practices in the ICU. She understood that patients who were the most ill were cloistered in the ICU together so that they could be better assisted.

Her ‘I poems’ reflect the seriousness with which she interpreted her nursing responsibilities. In her role as a nurse, she was trained to complete certain assessments, which she addressed carefully. She asserted that documentation in the ICU must be judiciously completed as others will be looking for it; she attends to this task in tandem with the other demands in the ICU. She described experiencing feelings of competence in having the proper forms completed and producing graphics of the patients’ vital statistics to closely monitor their health status. These vitals are reported to others, including physicians, other nurses, and health professionals. Leslie described engaging with physicians as one of her major responsibilities as an ICU nurse; nurses physically carry out physicians’ orders and need to ensure these orders are correct.
This informant described rehabilitation responsibilities she considered to be important, including stimulating the patient, such as provoking a pain response, as a part of one of the nursing assessments. She considered the documentation and the communication with other nurses as significant in monitoring the patient’s status and in making decisions. She considered what various tests, charts and graphs indicate regarding a patient’s status and prepared herself for possible issues and potential disasters by conscientiously integrating this information. The informant preferred the ICU over other environments as death was talked about openly. She found the environment exciting, challenging, and efficacious as she could see patients readily within the ‘panopticon’ (Foucault, 1963) of the ICU.

**Reading Three - Contrapuntal Voices**

Throughout the transcript of the ICU nurse Leslie, at least two contrapuntal voices are evident, as the informant talked in opposing voices regarding how she viewed her roles and responsibilities as social convention. The first voice is one that valued science, medicine, and technology, speaking about the importance of research and evidence-based medicine. She described the scientific presence in the ICU as follows: “That was hidden and hived off from the world of the ICU, which has its own research, which is powerful and very research-focused. Evidence-based medicine is alive and well in the ICU.” Leslie recognized the significance and influence of science and technology in the ICU. She also spoke in a second contrapuntal voice that recognized and sought to alleviate the distress experienced by patients’ families. She highlighted the suffering of the person with sTBI, as well as that of the family:

Leslie: We render them incapable of speaking, usually through breathing tubes and other devices and medications. The family’s suffering is really quite apparent. But there is this great divide between one’s energies of looking after the body, so that the patient can survive at least the acute part and then seeing what happens. The suffering of the full body, and the suffering of the person who is wandering in and out of the ICU.

This ICU nurse attempted to balance the needs of the family, including their need for support, guidance, and education, with the other scientific and technology needs associated with the care of the sTBI patient. She voiced this shift in priorities between the emotional work she performs with families and the scientific and technological work she presented to physicians and other health professionals.
Throughout this transcript, she acknowledges medical procedures that she viewed as important, while recognizing the shock experienced by families as they observe these procedures and the devastating changes in the person with sTBI: “So, traumatic brain injury patients have lots of infections, because they have so many exposures to lines and tubes and a ton of people probing at them. It’s a frightening, roller coaster experience and I think probably a terrible initiation to healthcare for people who haven’t been there.” She discussed her experiences with the presence of two ‘patients’, the actual patient in need of acute intervention, often requiring lifesaving and sustaining measures, and the family, needing support.

In highlighting the emotional work with families, this ICU nurse noted the following: “So, they might not get a good preparation for that and you know, they might be in quite a debilitated state themselves, after hanging out in the hospital, day and night for days and weeks. So that is hard work, just being present.” She addressed the close supervision of the patients and the near proximity to an ICU nurse in the experience of families as the patient is moved to less heavily staffed units with either signs of improvement or lack of signs of recovery. Paradoxically, the close quarters and supervision intended to cloister very sick patients together in a panoptical view (see panopticon; Foucault, 1963) become a comforting place for families. However, the ICU unit still has its perils, with many patients dying, as Leslie describes below:

Leslie: I would say it is the ability to tolerate the environment and to tolerate the uncertainty of the drama that is unfolding in front of you. Because people do die with great frequency in the ICU, even though people might think the opposite, or that we pull them back.

This ICU nurse discussed how scientific rationality becomes out of step families’ understanding and concerns. These families do not have the time to adjust and accept significant changes in their loved ones’ functioning. When patients do not respond to technological and medical interventions, physicians may wish to discontinue these interventions. The ICU nurse acknowledges the technocratic rationality of medicine in the ICU, as patients need to be weaned off technological implements, such as ventilators, early in their rehabilitation if they are likely to recover. She discussed how these moral and ethical responsibilities to families, in acknowledging their suffering and loss, are in stark contrast to discussions about withdrawing life support when the patient will not recover. The nurse recognized that through education,
time, or being present in the unit, some families align with professionals’ views and give up hope that any significant recovery will occur, prompting the decision to withdraw life support.

Reading Four - Overall Analysis

This is an interview with an ICU nurse who explained her role in the ICU with patients with TBI. Her discourse demonstrated a particular focus on the importance of the completion of various texts, namely a large nursing flowsheet, chart notes, and a cardex in order to compile, organize and record information about patients. This interview highlighted her work with sTBI patients, their families, and other health professionals. The ICU nurse highlighted that texts are completed to communicate with others, mainly physicians and other health professionals. In a number of instances, this nurse recounted how the responsibility for the completion of these forms, particularly the large flow sheet that generates a graphic representation of the vital statistics of the patient, becomes the privileged focus for the ICU nurse. These textually mediated forms of representation can, in a sense, replace the patients themselves, as physicians and other health professionals interact with the text, rather than with the patient themselves—including their many bodily substances, secretions, and odors.

Current evidence-medicine embraces the technologies of the ICU and its innovations—blipping, barking, warning, and forestalling death or predicting its eventuality. Outcomes purported by these technologies are recorded and monitored with vigilance—the institutional surveillance of an individual with sTBI. Nurses and physicians try to induce pain as a means to evaluate an individual’s level of consciousness, reproducing interventions described in evidence-based guidelines for individuals with sTBI. Patients become represented as a series of numbers, graphs, charts, and sounds, to be interpreted second-by-second, minute-by-minute, and hour-by-hour by the many health professionals inhabiting the ICU. What is not communicated and appears unknown is knowledge of the final outcome after an individual sustains a sTBI. This knowledge is hidden from view—leaving the boundaries of the ICU may signal a changed outcome with less reliance on technology.

These technologies described above represent advances in medical and nursing work and are enacted through educational and institutional regimes. Increasing technological advances in the panoptical surveillance, and monitoring of numeral and statistical human existence means
maintaining life, perhaps in many cases, beyond what anyone envisioned life would be. This new existence of the most severely brain injured, very often young and sometimes older bodies, heavily encumbered with lines and tubes, and an inability to communicate or even move to new liminal spaces that can support this technology. As more senior physicians progress through their training and are elevated in their medical status, they become removed in many instances from the direct hands-on care of these patients. This care is left for physicians-in-training; the immediate care of the body, and knowledge about it, is largely in the domain of nurses.

Very ill persons with sTBI have been revived and maintained in the land of the living by technological advances. Institutional discourse embraces improving bed flow; bodies must move, whether it is to another unit or into another ontological existence through death. Societal discourses of evidence-based practice, seemingly welded by economic ideologies, work contrary to the discourses of the emotional work of caregiving for the patients and their families. The stories of quiet silent rooms where lines and tubes are unhooked for lives to end remain largely remain hidden from view, with the exception of the occasional litigious backlash by families against this perceived paternalistic medicine. The discourses of evidence-based practice and moral responsibility are hooked into the ‘need’ to end a life of poor quality and with an unlikely prognosis of recovery. Leslie illustrated how ruling regimes can separate and insulate knowledge and communication within the isolated context of the ICU.

**Reflections Regarding Analytic Strategies**

In this appendix, I have used two different analytic methods suggested for IE to analyze my pilot transcripts. Using the techniques suggested by Bisaillon (2012, 2013), I was able to consider how the happenings regarding text, people, talk, institutions, and work illustrated key analytic points and set up processing exchanges of significance. Using this technique, I highlighted key statements from the informants and organized them into concepts specific to IE. The Listening Guide allows for a deeper and more intensive readings of the transcripts. I analyzed the transcript of the ICU nurse using this intensive method to prepare for the analysis of the later research transcripts obtained during ethnographic fieldwork.

Using progressive readings of the Listening Guide, I was able to start at a basic microsociological level of exchanges between the various individuals in the ICU: doctors,
nurses, rehabilitation professionals, patients, and families/caregivers. The ICU is hived off from the trauma centre spatially and ideologically; entry and information exchange are restricted within its liminal boundaries. Nurses in the ICU receive little input about the eventual outcomes of their patients, and once a patient has been transferred out of the ICU due to an improvement or change in their condition, re-entry to the unit is resisted to promote increased bed flow. This nurse talked in the contrapuntal voice of supporting evidence-based practice with its textual and technological innovations, while simultaneously resisting these same innovations, which displace the emotional work needed with patients and families. This transcript hints at larger social relations at play on a macrosociological level, suggesting there is an invisibility to individuals with sTBI. Ultimately, individuals with sTBI who do not recover, or recover slowly, can remain hidden from view in Level I Trauma Centres.
It's been a long time running
It's been a long time coming
It's well worth the wait

*Long Time Running, The Tragically Hip*