

Self-Narrative Following Acquired Brain Injury:
An Exploration of Subjective, Linguistic, and Other Associated Factors

by

Barbara Jenni
Bachelor of Arts, University of Victoria, 2011

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of the Requirements for the Degree of

MASTER OF ARTS

in the Department of Linguistics

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Abstract

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The re-creation of a holistic narrative that integrates the pre- and post-injury self is integral to recovery following acquired brain injury (ABI). However, individuals may struggle with deficits in linguistic skills required for narrative, along with reduced functioning, feelings of grief, difficulties with cognition, and other communicative challenges. This mixed-methods study analyzed data gathered from six non-aphasic adult participants with ABI during semi-structured interviews and through assessments. Thematic analyses showed that individuals experience a change in their sense of self pre- vs. post-injury, reflected in their self-narratives, and that even clinically undiagnosed changes in speech, language, and communication are impactful. Results from linguistic analysis and assessments suggest a relationship among a person's cognitive capacity, his/her sense of loss, and pre- vs. post-injury narrative of self speech rates. Participants spoke comparatively slower about their post-injury self, with those participants with higher feelings of loss showing a reduction in their speech rates comparatively more.

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Abbreviations

Abbreviation

CLCD
% Complete Sentences
% Lexical Informativeness
% Phonological Selection
BIGI
CLQT
LCQ
LIU
LOE
MLU
QOLIBRI

Meaning

Cognitive-Linguistic Communication Disorders
Percent Complete Sentences
Percent Lexical Informativeness
Percent Phonological Selection
Brain Injury Grief Index
Cognitive Linguistic Quick Test
La Trobe Communication Questionnaire
Lexical information unit
Level of Education
Mean length of utterance
Quality of Life in Brain Injury Questionnaire

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Six participants contributed the data for this study: Walter, Tobias, Page, Doris, Andrea, and Joan. These are only pseudonyms, but know that your stories alone have allowed me to shine a little light on the topic of self-narrative following acquired brain injury. I am indebted to your willingness to share so openly and generously.

The inspiration for this study came from my work with adults with acquired brain injuries. I continue to hold each one of you close to my heart.

Finally, I thank my family, and most of all, my husband; because you are in my life, all of this has become possible.

Dedication

To those searching for words.

And to TVL, with love always.

Chapter 1 – Introduction

Through narratives we create meaning and share our self with others. Page¹ used the metaphor of making a new little house when she spoke about her identity following her acquired brain injury: “So I got little bits of pieces of me from the past, pulled into the present. And then the present you know, new stuff, pull it together, and that’s my new house, you know. It’s a solid house.” Yet, narrative, or the arrangement of connected events into a story, evolves through our capacity to engage with and use language. This capacity to build our narrative can be affected following acquired brain injury. During our interview, Doris commented that for the first few months following her acquired brain injury, she “couldn’t get the words out, it’s like [...] you want to say something, but you just can’t lift that page up to get to the next page to read what’s on that page.”

During the time of recovery from and rehabilitation after an acquired brain injury, the rebuilding of a sense of self is a theme that is well known to be pronounced for individuals (Lorenz, 2010), and one that I have witnessed repeatedly in the people I met through my own professional work. An acquired brain injury can have marked – and complex – consequences on the individual’s abilities and perceptions (Tsao, 2012), including any and all aspects of his or her cognition, social network, vocational trajectory, physical and mental health (Chen & Novakovic-Agopian, 2012), as well as language and communication skills (Elbaum & Benson, 2007).

The experience of acquired brain injury is also known to be accompanied by feelings of grief and loss (Nochi, 1998). Walter told me about a visit with his neurologist, “[who] did all the tests and you know, he said ‘oh yeah, you're totally fine. You have

¹ All names of participants are pseudonyms to protect their anonymity.

nothing to worry about.’ And I think that struck a cord with me, because I said ‘why, you know, actually I do have something to worry about, something really traumatic happened and I haven't even dealt with it and I don't know even how to deal with it’.” Survivors of acquired brain injuries thus are faced with integrating various aspects about their identity and experiences in a new narrative of self that includes most prominently the PRE- and POST-injury self (Lorenz, 2010; Nochi, 1998, 2000). This process can be described as creating a self-narrative (Sarbin, 1986).

Highly personal and subjective in content, creating a story about one’s self with words is also a complex task that requires specific language skills to construct and convey the intended content in a logical and cohesive manner. However, communication skills after acquired brain injury have been shown to be impaired at the micro-linguistic level in the form of e.g., lexical errors or difficulties with syntactic organization, as well as at the macro-linguistic level, e.g., in cohesion and coherence, including topic management and accuracy (Galetto, Andreetta, Zettin, & Marini, 2013). Such changes are often subtle, difficult to assess, and can affect individuals differently. For Andrea, it meant that after her injury “if [she was reading] a story, [she] would get confused, quite confused and lost and [would] have to go back and reread some [of it],” while Joan commented during our interview, “conversation is a back and forth, you tell a story, they tell a story. I don’t have that anymore, I don’t have that skill anymore.” If acquired brain injury can alter a person’s ability to comprehend someone else’s story or to exchange stories with others in conversation, the question presents itself, how does acquired brain injury affect a person’s ability to create his or her own story of self?

To date, no other study has investigated how acquired brain injury may affect an

individual's ability to (re-)create and share a narrative of self or how individuals with acquired brain injury perceive their ability or experience potential challenges in creating such a narrative. To address this gap, this study triangulated data from a quantitative analysis of linguistic narrative performance with a qualitative exploration of personal narratives about the self and language after acquired brain injury, as well as associated psychological and cognitive factors. In recognition of the deep personal impact acquired brain injury can have on an individual, one purpose was to learn from adults with acquired brain injury how they experience their PRE- and POST-injury self, as well as how they perceive their speech, language, and communication following their injury. Adding to that, a second purpose of the study was to find out whether and how adults with acquired brain injury differed in their linguistic performance of self-narrative when speaking about their PRE-injury vs. their POST-injury self. Finally, given the complexity of potential outcomes following acquired brain injury, a third purpose was to look at whether the subjective experiences and the narrative performances linked with one or more aspects commonly associated with acquired brain injury, including functioning, grief, cognitive performance, and self-reported communicative abilities.

This study contributes to the understanding of the complexities of how acquired brain injury can impact language skills, specifically narrative skills. It also validates and expands on previous findings about how individuals with acquired brain injury perceive their PRE- and POST-injury sense of self. Last but not least, this study documents the subjective experience of living with non-aphasic speech, language, and communication changes following acquired brain injury, a topic previously not addressed in the literature.

This thesis is organized into several chapters. Following this introduction, I first

provide a review of the literature, concluding by stating the research questions addressed in this study. Next, I describe the methods and procedures, before presenting the results of the study. Finally, I discuss the results, as well as limitations of the study, before concluding with suggestions about the implications of my findings.

Chapter 2 – Literature Review

2.1 Brain Injury and Narrative of Self

The event of a brain injury in a person's life “tears violently at the whole of individual mind, body, and spirit” (Tasker, 2003, p. 337). And while the majority of symptoms in most cases of (traumatic) brain injury are said to resolve within days or weeks (Williams et al., 2012), the experience of brain injury can impact a person's understanding of her or his self at an existential level and shatter how their pre-injury understanding and story of self fits their post-injury self (Gelech & Desjardins, 2011; Mogerman, 2006; Morse & O'Brien, 1995; Muenchberger, Kendall, & Neal, 2008).

2.1.1 Definition of brain injury. Injuries to the brain, along with the spinal cord and peripheral nerves, are a form of injury to the nervous system (Dimancescu, 2007) and are differentiated into congenital brain injuries, i.e. those present at birth, and subsequently acquired brain injuries. The diagnostic category of acquired brain injury includes traumatic brain injuries, as well as anoxia, stroke, infection, toxic-metabolic injury, and brain tumours (Elbaum & Benson, 2007, p. 21). The literature generally accepts the three classifications mild, moderate, and severe brain injury, based on the Glasgow Coma Scale score (Maas et al., 2013). The majority of injuries sustained are categorized as mild (Jantz, Comerchero, Canto, & Pierson, 2015). However, there remains confusion around the exact association of diagnostic criteria for brain injury with consistent terminology, specifically with regards to mild brain injuries (Moore, Jaffee, & Ling, 2012).

2.1.2 Prevalence and impact. The occurrence of acquired brain injury is a major global health issue (Chen & Novakovic-Agopian, 2012; Collins, Pastorek, Tharp, &

Kent, 2012; Williams et al., 2012). Acquired brain injury can affect any and all aspects of an individual's cognition, physical and mental health, social network, and vocational path (Chen & Novakovic-Agopian, 2012), as well as his or her language and communication skills (Elbaum & Benson, 2007). On a different level, it is also in many instances an existential and life-altering event for the affected individual (Butera-Prinzi, Charles, & Story, 2014; Chamberlain, 2006).

2.1.3 Rehabilitation. Much of brain injury research has focused on the recovery of neurocognitive functioning (Williams et al., 2012). Depending on circumstances, type of injury, and outcome, rehabilitation after acquired brain injury may include neuropsychiatric and neuropsychological treatments, occupational therapy, speech and language therapy, physiotherapy, community-based rehabilitation, and counselling (Elbaum & Benson, 2007), as well as other forms of treatments addressing, e.g., sleep/wake disruptions, vestibular issues, or endocrine disturbances (Collins et al., 2012). Behavioural, neurobiological, and genetic approaches are driving advances in rehabilitation practice, alongside an increased use and implementation of assistive devices and adaptive technologies (Mateer, 2013).

2.1.4 Insight. An important step in recovery from an acquired brain injury is that the individual develops a sufficient level of insight into their deficits in order to become effective in using adaptive and compensatory strategies (Elbaum & Benson, 2007) during or after rehabilitation. Expanding the focus from cognitive functioning following brain injury, researchers more recently have begun conceptualize the emotional impact associated with brain injury (Carroll & Coetzer, 2011). Therapeutic counselling, education, and feedback are ways in which individuals with acquired brain injuries can be

supported in gaining more insight (Elbaum & Benson, 2007) and dealing with feelings of loss and grief. The use of self-narrative has been shown to strengthen the process of increasing awareness and insights following brain injury (Chamberlain, 2006; Mogerman, 2006; Nochi, 1998).

2.1.5 Definition of narrative of self and relevance. Through the process of creating a narrative of self, an individual can organize what may otherwise be disconnected aspects of his or her self into a cohesive self (Sarbin, 1986). Narrative of self is a means to actively construct and re-construct meaning of and within one's life story (Hermans, 1999). Telling one's story also enables an individual to cooperate through language with others and make his or her life interpersonal (Taylor & Francis, 2013). For those living with an acquired brain injury, the process of re-creating a holistic self-narrative is an important aspect not only during the initial recovery from brain injury, but life-long (Chamberlain, 2006; Lorenz, 2010; Mogerman, 2006; Nochi, 1998). Furthermore, the inclusion of the subjective experience of the individual with brain injury is importantly emphasized in psychotherapeutic work (Prigatano, 1999), and interventions focusing on the change of self-concept have been effective in the process of recovery (Elbaum & Benson, 2007).

2.2 Brain Injury and Speech, Language, and Communication

2.2.1 The role of language during recovery. By naming – or externalizing through language – the physiological and psychological effects resulting from brain injury, the trauma of the disruption of one's life narrative can be processed and feelings of grief, incompetence, or inadequacy can be validated and recovered from (Butera-Prinzi

et al., 2014). This acknowledgment of the central role that language plays in the recovery process from brain injury not only justifies, but also calls for the investigation of how language – a skill deeply embedded in our cognitive facilities – may be affected by brain injury. It is well established that communication difficulties and subsequent unsatisfactory experiences of interpersonal communication can persist long-term in individuals with brain injuries, including those with mild brain injuries (O’Flaherty & Douglas, 1997).

2.2.2 Aphasia. Deficits in the area of linguistic production and comprehension following acquired brain injury are foremost assessed in regards to specific phenomena as they relate to types of aphasia. Aphasia is an acquired communication disorder occurring in one or more modalities and is characterized by language impairments associated with brain lesions in focused regions (Kirshner, 2012), for example Broca’s aphasia following a stroke. However, most other types of acquired brain injury are less localized and different types of insults to the brain can cause diffuse injuries (Barwood & Murdoch, 2013), affecting various regions and resulting in more complex sequelae (Williams et al., 2012). In these cases, individuals may still suffer from non-aphasic communicative deficits.

2.2.3 Cognitive-Linguistic Communication Disorders. In recent years, efforts have been made to develop appropriate tools to identify, discuss, and assess the underlying causes of non-aphasic communication disorders (Blyth, Scott, Bond, & Paul, 2012; Elbaum & Benson, 2007; Lê, Coelho, Mozeiko, & Grafman, 2011). One widely adopted umbrella term to describe the phenomena in the literature is that of cognitive–linguistic communication disorder (CLCD) (Body & Perkins, 2012). This approach

assumes that using language involves the use of attention, memory, and planning, skills that are not only drawn on in relation to language. The aim is to develop a framework to further investigate the integrated skills occurring at the intersection of performance of isolated functions and complex demands of everyday environments (Body & Perkins, 2012).

A second term that is frequently used, specifically in the field of speech pathology, is cognitive-communication disorders (CCD), defined by the College of Audiologists and Speech-Language Pathologists of Ontario as “communication impairments resulting from underlying cognitive deficits due to neurological impairment” (*Preferred practice guideline for Cognitive-Communication Disorders*, 2002, p. 3). Since these umbrella terms largely describe the same or similar phenomena (Body & Perkins, 2012), I will use CLCD for the purpose of this study.

2.2.4 Lack of insight vs. readiness. Speech pathologists have suggested a lack of readiness in patients with acquired brain injuries to receive information about and support to deal with communication challenges as a barrier to provide extensive education during the course of rehabilitation (Short, McCormack, & Copley, 2014). Other studies have identified that there is a shortage of specific supports offered during speech and language rehabilitation with regards to feedback on speech, language, and communication impairments following brain injury and subsequent potential associated challenges when relying on spontaneous speech in daily life (Duff, Proctor, & Haley, 2002).

2.2.5 Speech, language, and communication needs. It is my opinion that research on CLCD belongs to a specific field within research on human communication in that it investigates speakers with speech, language, and communication needs (SLCN).

Aside from CLCD following acquired brain injury, SLCN may result from such diverse conditions as stuttering, aphasia, dementia, developmental disorders and disabilities, voice problems due to aging, and others. SLCN all have in common that “they have a wider impact on people’s lives than their linguistic system and use of it alone” (p. 749); living with a communication difficulty has personal and social consequences (Markham, van Laar, Gibbard, & Dean, 2009).

SLCN naturally are a main focus of research in speech and language pathology (Ball, Mueller, & Nelson, 2014), but researchers from other fields, including neuropsychology, linguistics, nursing, and occupational therapy, have also conducted studies with people with SLCN (e.g., Kvigne, Gjengedal, & Kirkevold, 2002; Marini et al., 2011; Sjöqvist Nätterlund, 2010).

2.3 Approaches to Research on SLCN and CLCD

2.3.1 Complexities of speech, language, and communication needs. SLCN researchers are recognizing that each *clinical* diagnosis is experienced differently across individuals, as well as across time (Grohn, Worrall, & Simmons-Mackie, 2014; McCormack, McAllister, McLeod, & Harrison, 2012). Adding to the intricacies of studying SLCN is that communication itself is a complex process occurring simultaneously at the micro-level of the individual or local interaction, as well as within the larger society, i.e. at the macro-level (Simmons-Mackie, 2014). Researchers looking at topics of human communication can deal with these complexities by applying a range of theoretical frameworks and methodologies (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007), yet the majority of studies involving SLCN to date are

conceived within a positivist framework and conducted using quantitative methods (Ball et al., 2014).

2.3.2 Quantitative approaches to SLCN research. As Armstrong (2005) explained, commonly quantitative SLCN studies, including those about cognitive-linguistic communication disorders rely on an “intra-psychological” (p. 137) model of language in which traditional levels of the grammar, including phonology, syntax, and semantics, exist as a set of rules within the mind of the speaker; language impairments or disorders are understood in terms of errors or breakdowns of this formal grammar. This research has led to valuable insights and further to the development of therapeutic supports for individuals with SLNC (Simmons-Mackie, 2014). However, the singular quantitative approach is limited in that it “typically do[es] not reach beyond the surface features of a client’s problem” (DiLollo & Woltern, 2004, p. 5) and controls rather than accounts for the actual contextual variables that contribute to the heterogeneity of clinical diagnoses and how people experience the impact of their SLCN (Tetnowski & Damico, 2001).

2.3.3 Qualitative approaches to SLCN research. In addition to quantitative approaches, researchers can also choose to conduct studies on SLCN using a qualitative approach. Speech and language pathologists for example have been urged over the last three decades to expand on experimental research and use more qualitative paradigms (Skeat & Perry, 2008) to “obtain more authentic, functional and naturalistic data” (Damico, Simmons-Mackie, Oelschlaeger, Elman, & Armstrong, 1999, p. 652) on SLCN. Qualitative research distinguishes itself from a quantitative approach by its focus on understanding the process of what is going on in any particular situation, compared to

measuring outcomes (Heigham & Crocker, 2009). Based on insights from these subjective experiences, including the biographical variables of each individual participant, service provisions, interventions, and care can be improved for affected people (Ball et al., 2014; Philpin, Jordan, & Warring, 2005). Additionally, Lloyd et al. (2006) stress that disability research can strengthen the position of those with speech, language, and communication needs by including their voices and providing opportunities to express their own perspectives; through this, processes of disempowerment are challenged.

2.3.4 A call for novel methodological approaches to SLCN research. As more researchers apply qualitative methods to different types of SLCN diagnoses, aim to understand specific phenomena, and in the process learn more about the subjective experience of speech, language, and communication needs, the specific challenges of doing research involving SLCN become better understood. Recently, scholars including Lloyd, Gatherer, and Kalsy (2006) have begun to argue for a need to adapt methods and modify expectations in order to achieve the goal of qualitative research to “hear the voice” (p. 1386) of participants with SLCN. However, there remains a general tendency in the professional and academic literature on specifically cognitive-linguistic communication disorders to value objective information over subjective experience, and most studies “fail to ask participants/clients to tell us their ‘story’” (DiLollo & Woltern, 2004). The practice of speech and language pathology to be more task focused than concerned with person-centered care (DiLollo & Favreau, 2010) is consistent with the focus put on neurocognitive functioning in brain injury rehabilitation (Williams et al., 2012). One of this study’s purposes, to assess linguistic performance of self-narrative, is

also rooted in a quantitative approach to SLCN.

Contrasting this, in person-centered care, the focus of the therapist, clinician, or health care provider is on the *person* as opposed to the *task*, and the personal knowledge and experiences of the patient are recognized and valued (DiLollo & Favreau, 2010). Short et al. (2014) suggested “investigating [the] client perspectives [...] following brain injury, particularly in relation to [CLCD]” and that “knowing what clients want and perceive as useful may help [...] meet their needs” (p. 229). To that effect, this study not only aims to learn from the self-narratives of non-aphasic adults about how they experience their PRE- vs. POST-injury self, but also how they perceive the effects of acquired brain injury on their SLCN. Thus, taken together, the purposes of this study demand a methodological approach that combines both quantitative and qualitative techniques.

2.3.5 Mixed-methods approach and assumptions. Mixed-methods strategies in research refer to an approach that integrates both qualitative and quantitative methods. A number of mixed-methods strategies have been formalized, the three most basic designs being Convergent Parallel Mixed-Methods, Explanatory Sequential Mixed-Methods, and Exploratory Sequential Mixed-Methods (Creswell, 2014).

Which design is chosen depends on how the two forms of data are to be integrated or support each other, but the underlying assumption of any mixed-methods approach is that by combining qualitative and quantitative inquiries a more complete understanding of the problem or research question can be achieved (Glogowska, 2011). The assumption that a situation can be approached through a variety of methods, techniques, and procedures echoes the worldview of pragmatism, which rejects the notion that there is

only one particular view of what ‘reality’ or ‘knowledge’ is (Heigham & Crocker, 2009). Operating from a pragmatic paradigm, the design of this study is based on using both available qualitative and quantitative methods and techniques to gain an understanding of how acquired brain injury affects the self-narrative of the individual. This study investigates both quantifiable and subjectively experienced outcomes following acquired brain injury, and therefore the mixed-methods approach is most appropriate.

In the following two sections, I discuss the qualitative and quantitative methodological approaches reviewed and selected for use in this study. I begin with an overview of qualitative approaches and considerations that informed the study purpose and design.

2.4 Qualitative Approaches to Investigate Self-Narrative

2.4.1 Qualitative methodological approaches. *Qualitative research* is an umbrella term that includes various data collection methods (Brédart, Marrel, Abetz-Webb, Lasch, & Acquadro, 2014; Lichtman, 2013; Polkinghorne, 2005) and has been used in studies on brain injury and speech, language, and communication needs alike. Thematic analysis, a tool for identifying meaningful themes within data, is used widely within qualitative research and applied in somewhat different manners depending on the broader theoretical framework or epistemological position of the researcher (Braun & Clarke, 2006). Other methods of analysis include those operating at the level of the linguistic structure, such as conversation analysis (Damico et al., 1999) or Systemic Functional Linguistics (Armstrong, 2005). Even behavioural aspects have been analyzed, such as the strategic use of gaze shifting during conversations by people who stutter

(Tetnowski & Damico, 2001).

2.4.2 Who do we talk to? Few studies on cognitive-linguistic communication disorders (CLCD) exist that have used a qualitative paradigm, and if so, they generally look at dyadic settings, i.e. communicative interactions between two persons. Dyadic conversations are commonly used to investigate how communication difficulties following brain injury affect the quality of relationships, specifically with significant or close others and family members (Lehan, Arango-Lasprilla, Aragon, Quijano, & Godwin, 2012; O’Flaherty & Douglas, 1997). Dyads are also used to explore how both participants in a pair evaluate self and other’s performance (Hoepner & Turkstra, 2013). I have found no published qualitative study directly inquiring with affected individuals alone how they experience their speech, language, and communication following an acquired brain injury (with the exception of those diagnosed with aphasia, whose experiences are well documented).

2.4.3 Relevance of qualitative exploration. One purpose of this study was to interview adults with acquired brain injury to learn how they perceive their PRE- vs. POST-injury self, as well as how they perceive their SLC following their injury. Polkinghorne (2005) recognized that the topic of inquiry in qualitative research is at its core the “human experience as it appears in people’s lives” (p. 137). Thus, qualitative methodologies provide suitable approaches to investigate the subjective experiences of those living with acquired brain injury or SLCN, while recognizing their individual differences and the complex situational variables.

2.4.4 Challenges to the “standards” of the qualitative interview. Kirkevold and Bergland (2007) note that the “qualitative research interview is a quintessential data

collection method in qualitative studies [and] by far the preferred method by qualitative researchers” (p. 68), and that the ideal interview is in-depth, unstructured, long, and free of interference and preconceived expectations from the researcher. Inadvertently, this ideal poses requirements to the participants, including most crucially for individuals that “they are ‘open’ to their experiences, [...] have the ability to maintain focus on the phenomenon [...] and that they have the necessary narrative competence to provide detailed, coherent, and logically structured account of their experiences” (Kirkevold & Bergland, 2007, p. 70). These “hidden” expectations can cause unforeseen challenges during the implementation of a study involving individuals with brain injuries or with speech, language, and communication needs.

Depending on their condition, participants with brain injuries or SLCN may tire easily during an interview, struggle with concentration problems, provide conflicting accounts when recalling events, become confused by abruptly changing interview topics or questions or by other stimuli, struggle with image management preventing them from openly sharing their thoughts and feelings, need significantly more time to respond to questions, become physically exhausted from the act of articulating speech, fear not being understood by the researcher, or become upset by the process of recounting their experiences (e.g. Arnesven Bronken & Kirkevold, 2013; Carlsson et al., 2007; Kirkevold & Bergland, 2007; Lloyd et al., 2006; Paterson & Scott-Findlay, 2002; Philpin et al., 2005). Most obviously though, individuals with acquired brain injuries or SLCN are in some way and to some extent impacted in their linguistic and communicative ability to “provide” what is assumed to be good data in traditional qualitative research. It is the

researcher's responsibility to adapt methods in a manner such that the study is suitable for the questions to be addressed and for the participants.

2.4.5 Narratives about the self. Narratives – or stories – also provide a rich source of data for qualitative analysis and specifically the exploration and understanding of the creation of meaning in an individual's life (Taylor & Francis, 2013). The focus may be on the story, the storyteller, or the listener (Taylor & Francis, 2013) or on the relationship between how people tell their life-histories, i.e. experiences, and their life-stories, i.e. how the experiences are presented in the present (Green & Thorogood, 2009). Diverse approaches are available and used in (qualitative) narrative inquiries to 'elicit' stories, typically semi-structured or unstructured interviews. By choosing an appropriate approach in accordance with the particular focus and purpose of the study, researchers can provide a space for people to tell their stories (Taylor & Francis, 2013). Qualitative interviews have been used in a number of previous studies looking to understand how acquired brain injuries affect an individual (Gelech & Desjardins, 2011; Lennon et al., 2014; Nochi, 1998, 2000; Thomas, Levack, & Taylor, 2014). This study continues in this tradition. However, rather than engaging participants in an ongoing question-response pattern, the interview format was designed to invite participants to spontaneously tell their story about their PRE-injury and POST-injury self. As a result, the elicited narrative about participants' subjective experiences would also provide the data for the analysis of the participants' linguistic performance. I now review and comment on linguistic assessment methods to further explain this decision from a quantitative perspective.

2.5 Assessing Linguistic Performance in Spontaneous Narrative

2.5.1 Evaluating language deficits following acquired brain injury. This study assesses narrative skills following acquired brain injury in non-aphasic adults. Measures and instruments designed for aphasia are considered (to be) inadequate to identify and assess the non-aphasic communicative deficits found in many individuals with acquired brain injury (Biddle, McCabe, & Bliss, 1996; Body & Perkins, 2012). This is because, first, acquired brain injury often involves damage to the frontal lobes, affecting planning, execution, and control of behaviours (Chen & Novakovic-Agopian, 2012). Aphasia tests are highly structured and provide cueing, which in return can result in inflated scores. Secondly, aphasia tests are designed to identify very specific linguistic deficits and focus on decontextualized skills. By ignoring demands on more complex cognitive processes, these tests are not designed to reveal impairments required for successful real-life communication tasks, an area often affected in non-aphasic individuals with acquired brain injury (Biddle et al., 1996).

2.5.2 Standardized CLCD assessment methods and evaluation tests. A range of tests are used in the field of speech and language pathology to evaluate communicative abilities (Elbaum & Benson, 2007). A shortcoming in the context of CLCD, and this study, is that these test batteries often do not assess spontaneous speech or narrative (Blyth et al., 2012), do not provide explanatory models pertaining to the underlying cognitive causes of the communicative deficits (Body & Perkins, 2012), or are simply not sensitive enough to identify symptoms of CLCD (but do identify aphasia) (Duff et al., 2002). In their screening of CLCD in patients, speech pathologists may be recommended to use “a checklist, questionnaire, or organized recording system specific to cognitive-

communication functions” (College of Audiologists and Speech-Language Pathologists of Ontario, 2002), although it is not clear what criteria are used in these tools. A recent survey showed that higher-level discourse and pragmatic skills are not routinely assessed by speech pathologists. And when assessed, frequently aphasia tests are used that are not recommended for use with adults with acquired brain injury (Frith, Togher, Ferguson, Levick, & Docking, 2014).

2.5.3 Spontaneous narrative skills and acquired brain injury. A promising research avenue for the investigation and assessment of CLCD though is the use of narrative skills and discourse. The pattern of impairment in linguistic narrative performance is found to be more varied across individual participants in groups of adults with acquired brain injuries than adults without, indicating that different types of injuries have different outcomes (Lê, Coelho, Mozeiko, & Grafman, 2011; Lê, Coelho, Mozeiko, Krueger, & Grafman, 2011). Performing spontaneous narrative taxes the cognitive, linguistic, and communicative abilities of speakers (Biddle et al., 1996; Galetto et al., 2013; Turkstra, Coelho, & Ylvisaker, 2005), and is therefore a preferred approach in studies investigating how acquired brain injury affects (non-aphasic) individuals. Spontaneous narrative also most closely emulates the communicative practices of spontaneous and personal discourse (Biddle et al., 1996; Lê, Coelho, Mozeiko, Krueger, et al., 2011; Marini, Galetto, et al., 2011). Biddle et al.’s study (1996) was one of the first ones moving away from structured story retelling tasks in investigations of communication deficits following acquired brain injury.

Narrative, or story telling, expresses content that requires more organization, coherence, and cohesion (Coelho, 2002) than for example, simple word finding tasks, and

it therefore provides an opportunity to see how speakers with (or without) acquired brain injury use language when faced with more complex situations. In most studies investigating CLCD following acquired brain injury, the quantitative analysis tends to rely on tokens of narrative, i.e. a choice of linguistic variables extracted from short samples elicited under controlled conditions (Byom & Turkstra, 2012; Coelho, 2002; Galetto et al., 2013; Marini, Galetto, et al., 2011; O’Flaherty & Douglas, 1997; Tucker & Hanlon, 1998; Turkstra, 2008).

2.5.4 Elicitation methods of spontaneous narrative using stimuli. A large part of research dedicated to CLCD has been successful at identifying specific aspects within linguistic and communicative performance that appear to be affected in individuals following (traumatic) brain injury (compared with healthy control groups) through the elicitation and analysis of spontaneous speech or narrative. *Narrative* in these studies refers primarily one type of narrative inquiry, that is, data collected from elicited spoken language for the purpose of quantitative analysis. Previous CLCD studies relied on various elicitation methods, including the conversational map technique during which individual participants relate personal experiences of a generic nature (e.g., “getting lost”) following a cueing recount of an experience shared by the interviewer (Biddle et al., 1996), pre-recorded cues such as a 16-frame video viewed at self-pace without audio (Lê et al., 2011), or a sheet with images of a scene (e.g., a picnic) and sequence of images of two events, respectively (Marini et al., 2011).

Not all tasks elicit speech that is equally spontaneously produced (and instead is recounted), nor do these tasks all recreate a naturalistic discourse setting; in fact, most studies tend to intentionally avoid an interactional communicative exchange between

participant and interviewer. For the purpose of a quantitative analysis of more complex communication skills, these methods do achieve reliability through highly consistent elicitation sessions, which are often documented in video or audio recordings.

2.5.5 Isolating linguistic measures for quantitative analysis. Elicited data of narrative discourse demands some sort of linguistic analysis. No conclusive evidence has been brought forward yet as to which linguistic measure correlates most clearly with which cognitive measure, and most studies on CLCD do not collect extensive neuropsychological assessment data in addition to linguistic data in their design. However, narrative speech of individuals with acquired brain injury has been shown to be more repetitive, contain greater instances of lacking content information, be of higher dysfluency and lower speech rate, and violate both cohesion and coherence more frequently than the speech of healthy control group participants (Biddle et al., 1996; Coelho, 2002; Marini, Galetto, et al., 2011). It has also been shown for example that content measures of *story completeness*, i.e. the distribution of critical story components, reflect a separate skill from *story goodness*, i.e. the expression of logical relationships through temporal and causal organization (Lê et al., 2011).

A number of key measures widely used in the literature in the analysis of narrative data elicited from individuals with CLCD include propositions (Biddle et al., 1996), T-units, that is, a dominant clause and all its dependent clauses (Coelho, 2002), and critical story components (Lê, Coelho, Mozeiko, Krueger, et al., 2011). Specifically, propositions have been used as a variable in the evaluation of the information domain, such as core information, inferences, and so on of narrative (Hay & Moran, 2005).

2.5.6 Linguistic measures and processing. The research team around Marini (Galetto et al., 2013; Marini, Andreetta, et al., 2011; Marini, Galetto, et al., 2011) has achieved informative results based on a model that associates specific linguistic measures to micro- and macro-levels of language processing, including *productivity*, *lexical* and *grammatical processing*, *informativeness*, and *narrative organization*. The measures also cover a range of linguistic performances that, if impaired following acquired brain injury, may impact a person's ability to be effective during spontaneous speech, language, and communication, including narrative. The researchers' detailed explanation and documentation of these measures enabled me to use the measures in this study.

Productivity measures include units of produced output during speech, phonologically well-formed words (whether appropriate and relevant or not), counts of utterances based on breaks in the speech, and complete sentences. Ratios are calculated for speech rate and mean length of utterance.

Lexical processing is associated with the ability to retrieve well-formed words during speech; the used measure Percent phonological selection is the percentage of words vs. units, i.e. how many of the units produced were actually well-formed words rather than non-words or false-starts.

Morpho-syntactic processing is analyzed by calculating the percentage of complete sentences vs. all utterances. This ratio of Percent complete sentences is understood to provide a measure of effectiveness in grammatical organization.

Informativeness measures first include a count of lexical information units, that is, all phonologically well-formed and grammatically appropriate words that provide pragmatically relevant (additional) information. A ratio of lexical information units vs.

words is then calculated; the Percent lexical informativeness measures the speaker's effectiveness to encode appropriate information during speech. Finally, the informative speech rate is calculated based on lexical information units per minute, providing a measure distinct from the normal speech rate (informativeness measures also include a measure for thematic selection, where the elicited output is analyzed to determine whether pre-set thematic topics were covered during the produced narrative; this measure is only appropriate in settings where an elicitation technique includes a picture or storyline and was therefore not included in this study).

Narrative organization measures include ratios of cohesive, local coherence, as well as global coherence errors divided by the total number of utterances multiplied by 100. Percent cohesive errors measures whether contiguous utterances are structurally connected. Percent local coherence errors measures whether utterances of a story are conceptually related to the preceding one, while Percent global coherence errors measures whether utterances of a story are conceptually related to remote utterances.

These measures have been used only to investigate how the speech of non-aphasic adults with traumatic brain injury compares to a healthy sample (Galetto et al., 2013; Marini, Galetto, et al., 2011). This study is the first to explore whether speech, and more specifically narrative skills following acquired brain injury, may show within-sample variability depending on the topic of narrative.

2.6 Other Potential Factors Associated with Acquired Brain Injuries

Given the complexity of potential outcomes following acquired brain injury, this study also aims to consider four commonly associated factors: functioning, grief and

adjustment, cognition vs. language, and self-perceived communicative abilities. I now briefly discuss each of these factors.

2.6.1 Functioning. Brain injury is associated with impacting functional abilities (Nichol et al., 2011). An immediate goal of rehabilitation is thus to help individuals regain or strengthen their overall abilities or teach adaptive and compensatory strategies to function successfully in daily life and act as autonomous and independent individuals (WHO World Health Organization, n.d.). The level of functioning is frequently assessed through the use of patient-recorded outcome measures; this is an established approach in the broader field of health-related Quality of Life research (Dijkers, 2004; Land, Michalo, & Sirgy, 2012; Phillips, 2006), but has only recently been introduced as a criterion following acquired brain injury (Truelle et al., 2010). Of relevance to this study is the observation that personal sense of self is an integral aspect of a person's subjective view of functioning (Koskinen et al., 2011).

2.6.2 Grief and adjustment. Following acquired brain injury, it can be difficult for a person to comprehend the changes in their personality, identity, and ability from their pre-morbid functioning, as these changes originate from a cognitive injury that remains in a sense invisible to outside observation (Coetzer, Ruddle, & Mulla, 2006). Coming to terms with these changes has been associated with feelings of shame, suffering, and grief (Thomas et al., 2014), and requires that the individual is able and willing to tolerate despair, anger, and vulnerability while learning to face and make meaning of their experience (Tasker, 2003). The disruption to an individual's sense of self pre- and post-injury is accompanied by a sense of grief over the loss of self, which interact during the process of reconstructing the self (Lennon et al., 2014).

2.6.3 Cognition vs. language. In the context of cognitive-linguistic communication disorders (CLDC), the assumption is that a direct correlation between linguistic performance and cognitive functioning exists and the goal is to add to the understanding of this correlation (Tucker & Hanlon, 1998). No significant results have been achieved yet that can directly link *specific cognitive* measures to *specific linguistic* measures (Body & Perkins, 2012; Marini, Galetto, et al., 2011). However, some studies that included administering cognitive communication/high level language tests in their design have been able to identify diverse communicative impairments in participants with acquired brain injury versus healthy control groups, strengthening the view that cognitive impairments following brain injury affect linguistic skills (Angeleri et al., 2008; Angeleri, Bosco, Gabbatore, Bara, & Sacco, 2012; Barwood & Murdoch, 2013; Blyth et al., 2012; Body & Perkins, 2012; Lê, Coelho, Mozeiko, Krueger, et al., 2011).

2.6.4 Self-perceived communicative abilities. Poignantly, individuals with brain injury do not always spontaneously identify communication difficulties as a specific area of ongoing challenge, even when reporting experiencing breakdowns in conversations or negative outcomes of communicative interactions (O’Flaherty & Douglas, 1997). In order to capture and evaluate perceived communication abilities, specifically in the context of acquired brain injury, approaches have targeted an individual’s self-awareness about specific outcome constructs or parameters of communicative skills, such as “When talking to others do you leave out important details?” (Douglas et al., 2000, p. 257).

2.7 Summary

The literature reviewed in this chapter reflects how extensive – and important – the research conducted on the occurrence and outcomes of acquired brain injury to date has been, while also considering both qualitative and quantitative methodological approaches suitable to investigate the topic of narrative of self following acquired brain injury. Acquired brain injury can affect the individual on multiple levels, including their speech, language, and communication abilities. Language is central during recovery and for the process of gaining insight and re-creating a holistic narrative of self following acquired brain injury. It is widely assumed that language involves processes not only drawn on during linguistic performance, but also during general cognitive tasks. Additionally, because language use occurs in context, each individual's personal experience of acquired brain injury contributes in some way to the circumstances under which he or she uses language.

2.8 Research Questions

The overall goal of this study is to *understand how acquired brain injury affects an individual's narrative of self*, grounded by the assumption that linguistic, cognitive, as well as individual psycho-social factors are at play. Ensuating from the presented literature review, this study addresses the following research questions:

- 1) How do non-aphasic adults with acquired brain injury *personally narrate* (as thematically explored) their
 - a. PRE-injury self?
 - b. POST-injury self?

- c. experience of their (post-injury) speech, language, and communication (SLC)?
- 2) How do non-aphasic adults with acquired brain injury *perform linguistically* in a spontaneous narrative task (as assessed through micro- and macro-linguistic measures), as elicited
 - a. in a baseline spontaneous story task?
 - b. in narrative about the PRE- and POST-injury self?
 - 3) In non-aphasic adults with acquired brain injury, how do linguistic performance of narrative skills and personal narrative about the self and SLC associate with
 - a. self-reported *functioning*, as measured by the Quality of Life in Brain Injury Questionnaire?
 - b. self-rated current experience of *grief and adjustment*, as measured by Brain Injury Grief Index?
 - c. assessed *cognitive performance*, as measured by the Cognitive Linguistic Quick Test?
 - d. self-reported *communicative abilities*, as measured by the La Trobe Communication Questionnaire?

Chapter 3 – Methods

This study uses a Convergent Parallel Mixed Methods (CPMM) design.

Qualitative and quantitative data of parallel variables and concepts, that is, different types of information about the *narrative of self* and potential associated factors were collected, with a roughly equal weighting of qualitative and quantitative data during the analysis and interpretation (Creswell, 2014).

3.1 Participants

3.1.1 Participant selection. Potential participants were required to meet four inclusive and three exclusive, self-reported, selection criteria in order to be invited to partake in the study. Potential participants had to (a) have been diagnosed to have experienced a brain injury at a minimum of 12 months previous; (b) be clear of any aphasia diagnosis; (c) live independently in the community with limited ongoing rehabilitative and/or community supports; and (d) have no history of substance abuse, psychiatric conditions pre- and post-injury, or developmental delay. Potential participants also must (e) not have sustained a stroke; (f) not have a concurrent mental health diagnosis; and (g) not currently receive services through or have been served in the past by my employer.

3.1.2 Justification. It is known that *time since injury* can affect neurogenic performance after brain injury (Tsao, 2012), and it is therefore an important fact to consider when selecting participants with brain injuries. While some studies only include participants who are in a phase of neurological stability (Marini et al. 2011), to-date, what the most appropriate specific amount of time since injury results in stability is either not

consistently defined or addressed (Biddle et al., 1996; Douglas, Bracy, & Snow, 2007; Lê, Coelho, Mozeiko, & Grafman, 2011; Lê, Coelho, Mozeiko, Krueger et al., 2011). For the purpose of my study, the acquired brain injury must have occurred a minimum of 12 months prior to participating in the study. This decision was based on my own professional experience working with adults with brain injury, where I have found, that during the first year of the rehabilitative process, the forces of integrating new insights and adjusting to challenges and losses are most profound. The risk of experiencing stress by participating in the study would have been too high. I also did not set a maximum time since injury, as recovery following acquired brain injury unfolds varyingly depending on individual pre- and post-injury circumstances (Maas et al., 2013).

The requirements that potential participants lived independently in the community (with possible limited supports) and had no concurrent diagnoses were included a) as a minimal control to limit *severity of injury* (Ponsford, Draper, & Schönberger, 2008), and b) to further control the degree of heterogeneity of the pool of participants.

Research participants are primarily selected based on their capability to produce quality data. Paterson and Scott-Findlay (2002) found that qualitative researchers of impacts of cognitive change tend to select participants who can provide articulate and meaningful descriptions of their experiences of speech, language, and communication needs, resulting in a “biased, or more precisely an ‘elite’ sample” (Kirkevold & Bergland, 2007, p. 71). For this study, the main selection criteria were that the individual has acquired a *brain injury more than 12 months ago, but not sustained a stroke and not been diagnosed as aphasic*, as the focus of the study was to investigate non-aphasic cognitive-linguistic communication deficits. No other selection criteria regarding the potential

participants' speech, language, and communication skills were set, so as to allow for participants with diverse experiences to contribute to the study.

3.1.3 Participant characteristics. Six English-speaking adults participated in the study, two males and four females (see Table 1). The mean age of the participants was 38 years ($SD = 18$, Range = 18-59). Mean time since injury was 83 months ($SD = 63$, Range = 15-169). Etiology of injury included motor vehicle accident ($n = 2$), illness ($n = 1$), fall ($n = 2$), and being hit by an object ($n = 1$).

Table 1. Participant characteristics

Participant ID	Type of injury	Gender	Age (years)	Age at injury (years)	Time since injury (months)	LOE
S001	Illness	M	33	31	21	University
S002	Fall	F	35	21	169	Some high school
S003	MVA	M	28	18	123	High school
S004	Hit by object	F	60	59	15	College
S005	MVA	F	69	59	120	University
S006	Fall	F	44	40	48	University

Note. MVA = motor vehicle accident; LOE = level of education

3.2 Data Collection Instruments

The data collection was conducted using two questionnaires (Background and Level of fatigue), a baseline spontaneous story task, a semi-structured interview, and four non-linguistic assessment instruments (Quality of Life in Brain Injury; Brain Injury Grief Index; Cognitive-Linguistic Quick Test; and La Trobe Communication Questionnaire).

3.2.1 Questionnaires

(a) Background questionnaire. The background questionnaire (Appendix A) was used to obtain participants' background information, including full name, age, age at time

of injury, and date of the injury or time since injury. Additionally, they were asked to briefly elaborate on the type of injury they had sustained, the types of rehabilitation and support services they had received in the past (e.g. occupational therapy, physio therapy, speech and language therapy, cognitive behavioural therapy) and were receiving, and on their current living situation. Because it has been suggested that level of education pre-injury may affect skills in narrative cohesiveness (Coelho, 2002), participants were asked about their level of education (LOE) completed at the time of injury and level (or types) of education completed since the injury, and their current occupation. Finally, by administering this questionnaire in the format of an informal and friendly conversation, it also offered an opportunity to begin developing rapport with the participants (Hunt, Chan, & Mehta, 2011; Mitchell & Irvine, 2008).

(b) *Level of fatigue questionnaire.* Fatigue is a common symptom following acquired brain injury (Elbaum & Benson, 2007), but gathering from published literature remains unaddressed in the design of many studies (e.g. Biddle et al., 1996; Galetto et al., 2013; Lê, Coelho, Mozeiko, Krueger, et al., 2011). Naturally, individuals with acquired brain injury cannot always be well rested before accomplishing a task in their day-to-day lives, and may have to communicate with others while feeling fatigued. Although the degree of fatigue is a subjective experience, fatigue does cause poorer functioning in any context or on any task and results in worse cognitive performance (Chen & Novakovic-Agopian, 2012). For the purpose of my study, in order to correlate subjective experience of fatigue with performance measures, participants were asked to indicate their level of fatigue on a scale of 1 to 4, with 1 = *well rested and fully alert*, 2 = *rested and alert*, 3 = *getting tired*, and 4 = *very fatigued, I should be resting* (Appendix B).

3.2.2 Baseline linguistic measure spontaneous story narrative. A baseline of spontaneous narrative performance was established through the conversational map technique originally developed by Peterson and McCabe (1983) and later used by Biddle et al. (1996). Since the original prompts for adults included “Having a car accident” and “A broken bone”, the prompts used in this study were modified to reduce any potential for triggering of trauma when recounting past experiences (Appendix C).

3.2.3 Semi-structured interview. Through a semi-structured interview, open-ended questions were used to elicit spontaneous narrative about the pre- and post-injury self and about the participants’ perceptions about their speech, language, and communication (Appendix D).

3.2.4 Non-linguistic assessment instruments

(a) Quality of Life in Brain Injury (QOLIBRI). The QOLIBRI questionnaire was used to measure subjectively experienced levels of functioning in the domains of thinking abilities, emotions and view of self, functional independence, social relationships, feelings, and physical problems (Truelle et al., 2010) (Appendix E).

(b) Brain Injury Grief Index (BIGI). The BIGI was used to measure the participants’ current subjective experience of grief, i.e. their perceived loss vs. adjustment following brain injury (Coetzer et al., 2006; Coetzer, Vaughan, & Ruddle, 2003; Ruddle, Coetzer, & Vaughan, 2005) (Appendix F).

(c) Cognitive Linguistic Quick Test (CLQT). The CLQT is a normed performance screening tool for people with acquired neurological dysfunction, including brain injury. The CLQT was used to assess the areas of attention, memory, executive functions, language, and visuospatial skills; the linguistic sub-set includes tests for

confrontation naming, generative naming, personal facts, and comprehension. The CLQT can only measure differences in performances compared to the normal limits of a diverse population sample and is not able to detect deficits relative to a participant's premorbid performance (Helm-Estabrooks, 2001) (Appendix G).

(d) La Trobe Communication Questionnaire (LCQ). The LCQ was administered to collect data on the self-perceived communicative abilities (Douglas, Bracy, & Snow, 2000; Douglas, O'Flaherty, et al., 2000) (Appendix H).

3.3 Data Collection Procedures

3.3.1 Recruitment and informed consent. Frequently, potential participants for studies on speech, language, and communication needs or acquired brain injuries are recruited from active caseloads (e.g. Markham et al., 2009) or via hospitals or agencies where individuals are seeking services (e.g. Etter et al., 2013). This poses ethical risks in that those individuals are in a vulnerable position and may feel obliged to participate in order to (continue) to receive services. In some instances, the researcher assumes a double-role when having acted as a service provider for the individual in the past, or even continuing to do so during the study (e.g. Niemi & Johansson, 2013). This can increase the vulnerability experienced by the participant, or can be of advantage to the research process overall, including the participant. For this study, potential participants who have received in the past or are currently receiving services through my employer were excluded to prevent situations of perceived coercion, power-over, or vulnerability. Additionally, potential participants were not directly recruited, but received information

about the study through a trusted third-party to emphasize that they were not required to participate.

Facilitators of two local community resource agencies providing services to people with acquired brain injury and four professionals known to be working with people with acquired brain injuries were contacted about assisting with recruitment. They were provided with a script and a flyer to distribute to potential participants who they felt would be interested in participating in the study and who would likely meet the selection criteria.

After facilitators and professionals distributed the information flyer, nine potential participants contacted me by phone or email. In a subsequent phone conversation, the potential participants received more detailed information about the study and were given the opportunity to ask questions. Three potential participants did not meet the selection criteria (one had suffered a stroke, one was in active recovery from drug addiction, and one was a previous client of mine). The other six participants were invited to meet in person to complete the consent process and participate in the study. To address potential concerns around the consent process, a summary of the procedures was provided during the first phone call. Participants were also told that, at their discretion, they could bring along a person for support (none did). The study received ethics approval from the Human Research Ethics Board of the University of Victoria (Protocol #15-001).

3.3.2 Protocol. A primary concern in any investigation of narrative skills following acquired brain injury is how the participants' cognitive performance will be affected by the research design itself (Coelho, 2002). Each condition of participants who fall on the outer ends of the neurotypical spectrum (Cannizzaro & Coelho, 2013) poses its

own set of challenges. Qualitative inquiry acknowledges the effect of the researcher on all aspects of the process (Cheek, Onslow, & Cream, 2004), and when interacting with individuals with brain injuries or speech, language, and communication needs the ability of the researcher to facilitate a safe and supportive context for the participant is even more accentuated. For this study, I consciously relied on my ten-year experience of engaging with adults with brain injury in my role as a Community Rehabilitation Worker.

By potentially needing to help participants remember and keep track of their thoughts, I prepared myself to act as a resource for the participants, as well as a researcher (Arnesven Bronken & Kirkevold, 2013). Conducting interviews with individuals with cognitive or communicative challenges can result in great fatigue not only for the participant but also for the researcher. Depending on the effect of their condition, participants may misinterpret or forget questions, offer incomplete answers, loose focus, or use speech that is difficult to follow and comprehend (Carlsson et al. 2007). Accordingly, I prepared for the need to be more attentive during the interviews and become fatigued more quickly myself, reminding myself throughout to remain responsive and reflective. I also prepared for the need to be able to tolerate “long stretches of silence, false starts and the fact that information may not seem obviously intelligible or relevant to the interests of the researchers” (Kirkevold & Bergland, 2007, p. 74). Therefore, data collection was spread across two separate days; I also cleared my schedule of other tasks on these days and repeatedly offered taking breaks.

Two meetings took place in a small and quiet research office on campus at the University of Victoria. The office was furnished with three desks, four chairs, a filing cabinet and bookshelves. The participants were asked to sit at one pre-determined desk,

backing the window to minimize exposure to bright lights, as light sensitivity is a frequent outcome following acquired brain injury (Collins et al., 2012). The researcher sat by the corner of the desk, facing the participant. On the desk were pens and markers, as well as a clipboard for the use by participants.

During the first meeting, informed consent was obtained. Simple language was used in the written consent form for this study, as well as a larger font and much white space (Appendix I). The consent form was reviewed in person with the potential participants (Egan, Chenoweth, & McAuliffe, 2006). Participants were also provided with a list of available community resources for debriefing following the data collection process (Egan et al., 2006; Paterson & Scott-Findlay, 2002) (Appendix J). All participants provided written consent to participate in the study after the procedures were fully explained. Each participant received a cash gift of \$30 in recognition that people with brain injury are at risk of financial marginalization (Brown & Emery, 2010), as well as to honour their expertise in their lived experience.

The second meeting was scheduled within one week of the first meeting, except with one participant who had to reschedule the second appointment for the following month due to a conflicting medical appointment.

3.3.3 Data collection session one. During the first session, participants provided informed consent and completed the background questionnaire and four non-linguistic assessment instruments. One participant requested a beverage break at the beginning of the session, and one other participant used the washroom half-way through the assessment portion.

(a) *Background questionnaire*. The background questionnaire was administered in the format of a relaxed conversation at the beginning of the first meeting; participants were asked the questions and I wrote down their answers.

(b) *Non-linguistic assessment instruments*. Participants were provided with a paper-copy of the *QOLIBRI* questionnaire and asked to read each question and mark the response score that was closest to how they felt (today or in the last week). One participant asked that the questionnaire be read out loud instead of reading it. The questionnaire was completed in 15-20 minutes. Next, the participants were provided with a paper-copy of the *BIGI* questionnaire and asked to underline the response that came closest to how they had been feeling in the past week. Two participants asked that I read out the questionnaire. Participants completed the questionnaire in 10-15 minutes. Third, the full *CLQT* was administered according to the Examiner's Manual instructions; completing the test took about 30 minutes with each participant. Finally, participants were provided with a paper copy of the *LCQ* and circled the choice that best answered the questions asked. Two participants asked that I read out the questionnaire.

3.3.4 Data collection session two. On the second day, the participants completed the *semi-structured interview*. In this study, participants were informed in advance about the questions of the interview, so as to provide them with time to consider their thoughts without feeling pressure to provide "good" answers on the spot (see also Marini et al., 2011, p. 2906, for keeping cues visible during story telling).

The participants were reminded that I was interested in their personal experiences. I then stated that "I have some questions that we can use to guide our conversation but there are no right or wrong answers", before proceeding with the first interview question.

Participants did not have any questions before the interview commenced. Throughout the interview, I intermittently summarized the content of the participants' narratives back to them as a means to check that my understanding and interpretation of what they shared was accurate. Each interview was digitally recorded with a Zoom Handy Recorder H4.

3.3.5 Additional data collection during both sessions. To obtain a baseline of spontaneous story narrative performance, participants were presented with four brief scenarios of personal events and asked to share a related story if they had experienced a similar event. Participants were randomly assigned to complete this *baseline linguistic measure spontaneous story narrative* task either at the end of the first session (rotation A), at the beginning of the second (rotation B), or at the end of the second session (rotation C). All four stories were also digitally recorded (Zoom Handy Recorder H4). Finally, at the beginning and end of both sessions, participants were asked to complete the *level of fatigue questionnaire*. I wrote down their responses.

The concurrent data collection strategy (Creswell, 2014) was chosen so as to minimize changes in outcomes following acquired brain injury due to ongoing recovery time since injury (see Figure 1). The total time for Session 1 was between 1.5 and two hours, and about two hours for Session 2.

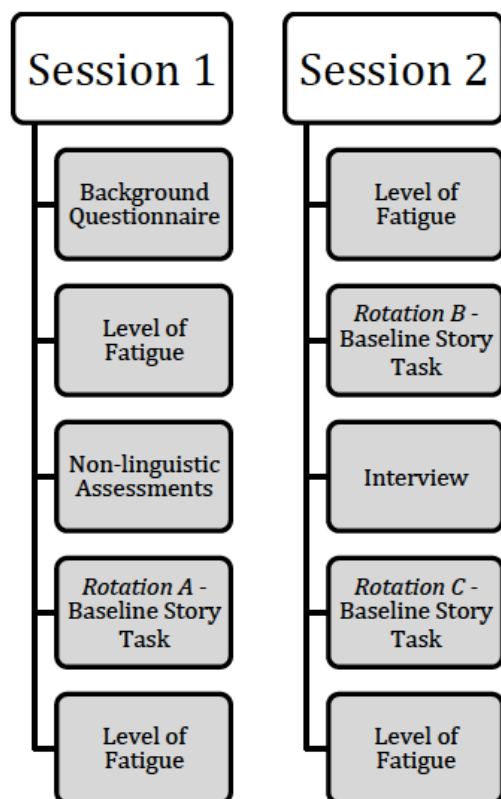


Figure 1. Data collection procedures.

3.4 Data Preparation and Coding

3.4.1 Data preparation. The recordings of the spontaneous story narratives and the semi-structured interviews were imported into qualitative data analysis software (NVivo 11, for PC) and transcribed verbatim using NVivo; all phonological and discourse fillers, pauses, and false starts were included (see Table 2).

Table 2. Symbols used in transcribing oral data

Symbol	Meaning
.	Completion (with falling intonation)
,	A brief, natural pause
-	Discontinued utterances, including false starts
...	Short hesitation; pauses less than three seconds
... ..	Long hesitation; pauses longer than three seconds
[characters in square brackets]	Description of non-verbal behaviour or information, or marking personally identifying information
?	A question (with rising intonation)

The length of each baseline spontaneous story was timed digitally using NVivo. Because length is an index of narrative complexity (Biddle et al., 1996), only the longest of the four spontaneous story narratives was used in the analysis. All transcripts, of both the spontaneous story narratives and the semi-structured interviews, were checked against the recordings for accuracy (Rohleder & Lyons, 2015).

3.4.2 Researcher location. Identifying one's own preconceived notions and beliefs about a topic prior to commencing qualitative analysis is known as bracketing (Creswell, 2014); this step of qualitative analysis is particularly important where the researcher has also engaged with the participants or individuals similar to the participants in a professional capacity (Hunt et al., 2011). Addressing and suspending one's own personal and/or professional bias is done to increase the credibility of qualitative analysis (Plexico, Manning, & DiLollo, 2005). I have worked with adults with acquired brain injuries for over ten years in the role as a Community Rehabilitation Worker, and the impetus for this study originated directly from my contemplations about my work experiences. Before commencing data analysis (and also prior to each interview), I reflected on my preconceived assumptions, which included that participants would speak more about who they were before their injury than since the injury, and also share primarily positive aspects about their PRE-injury self while speaking about negative outcomes since their injury. Further, I expected that POST-injury self-narratives would be notably less cohesive and less detailed than PRE-injury self-narratives. After making myself aware of my potential biases, I read each transcript several times to develop an empathetic understanding of the content, that is, the participants' subjective experiences (Niemi & Johansson, 2013).

3.4.3 Data coding semi-structured interview. A generic thematic analysis method was used to conduct the qualitative analysis of narrative (Braun & Clarke, 2006, 2014; Creswell, 2014). Generic thematic analysis is appropriate in those instances where the researcher aims to understand the participants' subjective opinions, reflections, or beliefs (Percy, Kostere, & Kostere, 2015). The analysis including each round of coding was conducted in NVivo 11 for PC.

After having read each interview transcript several times in full, I proceeded to code each interview according to whether the participants were speaking about themselves, their lives, or circumstances before the brain injury (PRE) or after the brain injury. In the next reading, the narrative sections referring to time after the brain injury were further divided into a phase of active recovery (right after the injury to before now) and now (POST). Finally, I read the entire interview again to code for references related to speech, language, and communication following brain injury (SLC). This provided three specific sections of interview narrative content: PRE, POST, and SLC; each section was further coded and analysed separately, following the same steps outlined below.

First, I re-read the interview segments included in the PRE, POST and SLC sections against the complete interviews to strengthen the dependability of my initial decision-making process (Morrow, 2005); this was completed three months after the initial coding. No changes were deemed necessary.

Following Percy et al.'s (2015) inductive analysis approach, each participant's segments were coded individually without setting any pre-existing categories. Sections that stood out were highlighted and collected in a separate folder in NVivo.

Within the PRE section, I highlighted any reference to how participants felt, what they hoped for, how they were doing, what their struggles or successes were in relation to their experience of their identity, and sense of self or experience of self in relation to others. Within the POST section, I highlighted any references where participants talked about who they were now, what their experience of their self was, how they relate to themselves now, how they relate to others, how they talk about their acquired brain injury, how they feel now, how they describe their identity, and how they experience their sense of self. Finally, for the SLC section, I focused on any reference that stood out in response to speech, language, and communication needs, hopes, and experiences.

3.5 Data Analysis

The data analysis steps below are organized by research question. An abbreviated version of the corresponding research question (hereafter RQ) is repeated ahead of each section.

*RQ1: How do non-aphasic adults with acquired brain injury **personally narrate** their PRE-injury or POST-injury self, or their experience of their (post-injury) speech, language and communication (SLC)?*

3.5.1 Thematic analysis of personal narratives. The references (i.e. selections of text) yielded from the semi-structured interviews during the data coding process were read again. During this process, initial categories were formed based on similarities; the categories were given descriptive names to summarize the content. As patterns started to cluster across categories, initial themes were developed. At this point, the full-length sections were read again to test whether the initial themes remained meaningful within

the context of the entire sections of PRE, POST, or speech, language, and communication (SLC) narrative. Initial themes were then further organized and reduced; each final main theme was titled with a phrase directly derived from a corresponding participant statement and described in more detail in my own words. Each final theme contains a number of sub-themes with supporting layers of narrative references. The entire decision process was documented in a journal; I also maintained a separate section in my journal to document my personal reflections about the research process. Although participants varied somewhat in their answers, consistently, the majority of or all participants contributed to each of the final themes.

3.5.2 Analysis of personal narratives about the PRE- and POST injury self.

The primary purpose of the generic thematic analysis of PRE and POST sections was to identify whether and how participants' narrative about the *pre*-injury self differed from narrative about their *post*-injury self. The statements from the PRE section were difficult to analyze. First, the reference texts were comparatively short and less detailed or descriptive in content. Secondly there were only 180 initial coded references (i.e. selected sections of narrative data), which were further reduced to 116 references; these were then organized into six subcategories, which informed one main theme. For the analysis of the POST section, 281 initial references were reduced to 145 references; these were organized into 16 subcategories, which informed four themes. A sample of the coding schemes of PRE and POST-injury self-narratives is shown in Tables 3 and 4, respectively.

Table 3. Sample coding scheme PRE-injury self-narrative

PRE-injury self narrative		
<u>Theme</u>	<u>Subcategories</u>	<u>Sample statement</u>
Cohesive lives: I felt the way I felt. (<i>Walter</i>)	Everybody had experienced some successes before the BI	I had been successful in [that country]. (<i>Walter</i>)
	Everybody was at a different stage in life before the BI	I was going to go to [province] and was going [...] be a web designer. (<i>Page</i>)
	In retrospect, people missed or lacked different opportunities before the BI	I had experiences where you know I was very much wasting my time. (<i>Walter</i>)
	In retrospect, people reflect differently on their personality before the BI	I was chitty-chatty and used humour. (<i>Joan</i>)
	Relationships to others were diverse before BI	I was always the one that jumped up and helped everybody [...]. (<i>Doris</i>)
	The imagined or hoped for future was different for everybody before the BI	I had a goal. (<i>Tobias</i>)

Table 4. Sample coding scheme POST-injury self-narrative

POST-injury self narrative		
<u>Theme</u>	<u>Subcategories</u>	<u>Sample statement</u>
Pivotal differences: It's just not the same. (<i>Joan</i>)	BI - an opportunity	It'll push me harder to achieve things [...]. (<i>Tobias</i>)
	Defined by BI	People treat me differently. (<i>Walter</i>)
	Everything (else) changed	My whole life has kind of changed. (<i>Joan</i>)
	Limitations	I can only work with what I have. (<i>Page</i>)
	Loss	I don't view myself as [participant's name] anymore. (<i>Doris</i>)
Experience of time: I've gone through different stages. (<i>Page</i>)	Risks and fragility	It's just weaker, like more frail. (<i>Walter</i>)
	Age	I feel so lucky that I'm older [...]. (<i>Joan</i>)
	Before, after and since injury	Cause I had it for so long [...] I accept that I have a head injury. (<i>Tobias</i>)
Perspective as a choice: Carrying on with what's left. (<i>Page</i>)	Future and time ahead	I want to have a life. (<i>Doris</i>)
	Acceptance	I think I've figured it out. (<i>Page</i>)
	Luck	I'm very fortunate one who has gotten to this point. (<i>Doris</i>)
	Mindful thinking	You just have to continuously [...] change almost every thought. (<i>Andrea</i>)
	Not give up	I didn't really give up. (<i>Tobias</i>)
Reclaiming self cohesion: Everything that's left, that's you. (<i>Page</i>)	Focus on self	And it's commitment, that I have to put me first. (<i>Joan</i>)
	I'm the same person	Everything around me changed, but I still feel the same. (<i>Walter</i>)
	Me in relation to others Strategies	I don't really have any good friends anymore. (<i>Doris</i>) I'm still acting. (<i>Tobias</i>)

3.5.3 Analysis of personal narratives about SLC. The primary purpose of the generic thematic analysis of the SLC section was to identify how participants experienced their speech, language, and communication following acquired brain injury. A total of 335 initial references were collected from the SLC sections; these were reduced to 213 final references; these were organized into 12 subcategories, from which the final three themes were identified. A sample coding scheme is shown in Table 5.

Table 5. Sample coding scheme Speech, Language, and Communication

Speech, Language, and Communication		
<u>Theme</u>	<u>Subcategories</u>	<u>Sample statement</u>
Recovery and SLC: To function like a human being again. (<i>Page</i>)	Motivation to (re-)gain SLC skills	That was my motivation, for people to understand who I am. (<i>Page</i>)
	The interaction of cognition and SLC	I don't remember what they've said, two hours later. (<i>Joan</i>)
	Use of SLC is integral during recovery & to moving on	I have my words [...]. These words have taken on special meanings for me. (<i>Walter</i>)
SLC changes after BI are real: I maybe sounded like I wasn't drowning, but I was. (<i>Doris</i>)	Writing has a place during recovery too	I write down what happens to me and how it feels. (<i>Page</i>)
	Experiences of speech changes	My husband said I slurred, a lot. (<i>Doris</i>)
	Experiences of language changes	I had lots to say but I had so much trouble saying out loud. (<i>Page</i>)
	Experiences of communication changes	Conversation is back and forth, you tell a story, they tell a story, that I don't have that anymore, I don't have that skill to do that anymore. (<i>Joan</i>)
	Experiences of losses related to SLC changes	I was part of the storytelling guild, so I, storytelling was really part of my life. (<i>Joan</i>)
	Experiences of isolation as a result of SLC changes	It is very disconnected, it's very lonely, and it almost disconnects you from your self. (<i>Doris</i>)
SLC Strategies: I have key stories now, I practice. (<i>Joan</i>)	Experiences of living with SLC changes	It's just like blurting stuff out, because you just can't hold back. (<i>Andrea</i>)
	Adaptive planning & strategies to succeed in SLC	I have a bit of a plan, what I'm gonna talk about. (<i>Joan</i>)
	Practice, practice, practice	What is that word, I know it starts with a C and so I'd flip through the dictionary. (<i>Andrea</i>)

*RQ2) How do non-aphasic adults with acquired brain injury **perform linguistically** in a spontaneous narrative task as elicited in a baseline spontaneous story task or during a semi-structured interview about the PRE- or POST-injury self?*

3.5.4 Data analysis of linguistic performance during spontaneous narrative.

An in-depth linguistic analysis was completed of the PRE and POST transcript sections of the semi-structured interviews, focusing on four main aspects of micro- and macro-linguistic processing: *productivity*, *lexical and grammatical processing*, *informativeness*, and *narrative organization* (Galetto et al., 2013; Marini, Andreetta, et al., 2011; Marini, Galetto, et al., 2011). The same aspects were analyzed for the spontaneous story narrative, with the exception of *narrative organization*; despite using the longest of the four spontaneous stories, the segments were too short to justify an analysis of their organizational structure.

(a) Productivity measures. Following Marini, Galetto, et al. (2011), productivity measures included units, words, utterances, and complete sentences, as well as speech rates and mean length of utterances (MLU). Unit counts included each word, non-word, and syllabic false start uttered. Word counts included each phonologically well-formed word, including false starts longer than one second, discourse fillers, and repeats. Counts of utterances were calculated based on four criteria of breaks occurring in the speech of participants: acoustic (empty pauses, i.e. silence, full pauses, i.e. fillers, “I think...,” “let me guess...”); semantic (a conceptually homogenous piece of information, consisting of a predicate and all arguments or whenever a new proposition is introduced); grammatical (a grammatically complete sentence including its subordinate clauses); and phonological (a false start or interrupted word). A sentence was deemed complete and counted if all

arguments required by a word were correctly inserted into the body of the sentence and no omissions of morpho-syntactic information were found (Marini, Andreetta, et al., 2011).

(b) Lexical and grammatical processing measures. Lexical processing was measured calculating the percentage of words vs. units; this measure, named Percent phonological selection, refers to the ability to retrieve phonologically well-formed words (Galetto et al., 2013). For morpho-syntactic processing, the percentage of complete sentences vs. utterances was calculated; this ratio is understood to provide a measure of grammatical organization (Marini, Galetto, et al., 2011).

(c) Informativeness measures. Informativeness measures included lexical information units (LIU) and Percent of lexical informativeness, that is, the percentage of LIU vs. words. Counts of LIU included content and function words that are phonologically well-formed and grammatically and pragmatically appropriate (excluded were lexical fillers, “you know...”; fillers, “uhm”; lexical repetitions; words without clear referents; tangential utterances; and conceptually incongruent utterances) (Marini, Andreetta, et al., 2011). The Percent of lexical informativeness is deemed an adequate measure of effectiveness in encoding information in speech (Marini, Galetto, et al., 2011). An Informative speech rate was calculated based on the number of LIU per minute (Galetto et al., 2013).

(d) Narrative organization. Three measures of narrative organization were calculated by dividing the number of cohesive, local and global coherence errors by the total number of utterances and multiplying by 100: Cohesiveness shows how contiguous utterances are structurally connected, while coherence reflects how utterances of a story

are conceptually related to the preceding one (local coherence) or to remote utterances (global coherence) (Marini, Andreetta, et al., 2011).

(e) Statistical analysis. The statistical analysis conducted in this study aimed to identify clinically interesting differences or associations between variables and whether differences between PRE and POST variables were meaningful (Linebach et al., 2014).

First, simple values for units, words, utterances, complete sentences, LIU, cohesion errors and local and global coherence errors were counted manually. The length of each segment in the PRE and POST section was timed digitally using NVivo and a total length of time of PRE and POST section was tabulated in Excel. Ratios for speech rate, MLU, Percent phonological selection, Percent complete sentences, Percent lexical informativeness, informative speech rate, and Percent cohesive, local and global coherence errors were also calculated in Excel. The PRE and POST raw scores of each linguistic measure were transferred into statistical software (PAWS Statistic 18 – SPSS, for PC). Medians (*Md*), means (*M*; arithmetic averages), standard deviations (*SD*; variability describing the spread of data from the mean) and ranges (minimum and maximum scores) were calculated for all variables, as well as Difference Scores for the linguistic PRE vs. POST variables (Linebach, Tesch, & Kovacsiss, 2014; Pett, 2016).

The number of participants in this study was $N = 6$; this number is considered too small to use with parametric tests (Pett, 2016). With non-parametric tests, however, the sample size can be as small as 2 (Linebach et al., 2014), making them appropriate for use in this study. The Wilcoxon Signed Rank test was used to determine whether differences between PRE vs. POST linguistic variables were significant. This difference test also

provides the magnitude of differences, i.e. how large the significance of difference is (Linebach et al., 2014) and is used widely in health care research (Pett, 2016).

The probability that a claim is made that differences exist between groups when in fact there are none is known as the level of significance, or alpha (α). Traditionally set at $\alpha = 0.05$ (or 0.01), in small-sample studies, $\alpha = 0.10$ is still appropriate, especially in health care settings where the results can be of clinical relevance (Pett, 2016). The research questions in this study are not making any claims about directionality, and as such, alpha is two-tailed (Pett, 2016).

*RQ3) In non-aphasic adults with acquired brain injury, how do linguistic performance of narrative skills and personal narrative about the self and SLC associate with self-reported **functioning**, experience of **grief and adjustment**, assessed **cognitive performance**, and self-reported **communicative abilities**?*

3.5.5 Analysis of non-linguistic assessment instruments. A point score between 1 and 5 was possible for each question in the **QOLIBRI**, with 1 = *not at all*, 2 = *slightly*, 3 = *moderately*, 4 = *quite*, and 5 = *very*. The scores were added for each dimension and then divided by the number of possible responses to calculate the mean score (all participants answered all questions). Scale means have a maximum possible range of 1 to 5. By subtracting 1 from the mean and multiplying by 25 the scale means were converted to a 0-100 scale, with a lowest possible value of 0 (worst possible quality of life) and a maximum value of 100 (best possible quality of life) (“Qolibri Questionnaire Scoring,” n.d.).

Each question in the **BIGI** had a possible score of 0, 1, or 2, with 0 = *never*, 1 = *sometimes*, and 2 = *mostly*; the score factor Loss and score factor Adjustment were calculated by adding the point score for each factor as per the BIGI response matrix. The lower the Loss score, the better the assessed individual had dealt with loss; the higher the Adjustment score, the better adjusted the person was (Coetzer et al., 2003).

Raw scores of the **CLQ** were converted into a severity score as per the manual; a severity score was calculated for each domain, as well as composite severity score. The range of severity was from 1 to 4, with 4 = *within normal limits*, 3 = *mild*, 2 = *moderate*, and 1 = *severe* (Helm-Estabrooks, 2001).

Point scores for all five different domains (quantity, quality, relation, manner, and cognitive) of the **LCQ** were totalled; the score range for each question was 1 to 4, with 1 = *never or rarely*, 2 = *sometimes*, 3 = *often*, and 4 = *usually or always*, and the total score range was 30 to 120. Higher scores reflect a perception of perceived difficulties (Douglas, Bracy, et al., 2000).

3.5.6 Association of linguistic performance and non-linguistic assessment scores, demographic and level of fatigue data. Demographic data scores from the background questionnaire (gender, age, age at injury, time since injury, LOE), scores from the Level of fatigue questionnaire (fatigue at beginning of session and end of session, for both days) and the scores from QOLIBRI, BIGI, CLQT, and LCQ assessments were added to the same file of PRE and POST variables in the statistical software (PAWS Statistic 18 – SPSS, for PC). Descriptive stats were calculated for all variables (Linebach et al., 2014; Pett, 2016). An association test for two dependent variables was used to find relationships between linguistic variables and non-linguistic

assessment scores, demographic and level of fatigue questionnaire scores, as well as to determine the degree to which one variable may be related to another variable (Linebach et al., 2014). The correlations were calculated across all PRE and POST linguistic vs. the non-linguistic variables (age, age at injury, time since injury, LOE, level of fatigue, and scores from QOLIBRI, BIGI, CLQT, and LCQ), using the two-tailed Spearman's *rho* test. The Spearman's *rho* test was also used to determine significant correlations between the PRE vs. POST Difference Scores and the non-linguistic variables.

Chapter 4 – Results

The results are organized by research question. The corresponding research question (hereafter RQ) is repeated at the beginning of each section.

4.1 Personal Narrative Thematic Analysis

RQ1) How do non-aphasic adults with acquired brain injury *personally narrate* (as thematically explored) their

- a. PRE-injury self?
- b. POST-injury self?
- c. experience of their (post-injury) speech, language, and communication (SLC)?

4.1.1 PRE-injury self-narrative. There was one central theme that emerged from PRE-injury narrative about the self, i.e. the theme *Cohesive lives: “I felt the way I felt”*. Despite the limited number of and comparatively brief references, I was able to identify a sense of personhood from each participant’s narrative about his or her PRE-injury self; cumulating in the theme that each participant experienced their own self as cohesive and rounded prior to their injury. This theme is also reflective of the diverse backgrounds and pre-injury experiences the participants brought to the study, contained in the six sub-categories and described in Table 6 below. Across all participants, differences in pre-injury successes, missed opportunities, relationships, and hopes for the future were evident. Participants were at different stages in their lives when they sustained an acquired brain injury, but each of them was their own person with a specific sense of self and who they were. Some participants had made friends, while others experienced

bullying. Some were not even adults yet, while others were in midst of a full and busy life. Some had travelled, while others were in long-term stable jobs. Some were focused on staying home, while others wanted to see the world. Some felt strong, while others felt confident, or accomplished, or lost, or angry.

Table 6. Theme and subcategories with sample statements PRE-injury self-narrative

Cohesive lives: I FELT THE WAY I FELT (<i>Walter</i>)	
<u>Subcategories</u>	<u>Sample statements</u>
Everybody had experienced some successes before the BI	I was the longest employed at that job. (<i>Joan</i>); I had travelled. (<i>Walter</i>)
Everybody was at a different stage in life before the BI	I wasn't even an adult yet. (<i>Tobias</i>); My life was always full and always busy. (<i>Joan</i>)
In retrospect, people missed or lacked different opportunities before the BI	I quit so many jobs before. (<i>Andrea</i>); I tried to do too many things. (<i>Walter</i>)
In retrospect, people reflect differently on their personality before the BI	I used to be super-woman. (<i>Doris</i>); I was very angry. (<i>Andrea</i>)
Relationships to others were diverse before BI	I had made friends. (<i>Water</i>); I was being bullied too much. (<i>Page</i>)
The imagined or hoped for future was different for everybody before the BI	I wanted to see everywhere in the world. (<i>Tobias</i>); I always wanted to just be at home. (<i>Andrea</i>)

4.1.2 POST-injury self-narrative. Four recurring themes were identified, each including two or more subcategories. The themes are described below and are summarized in Table 7.

The first theme *Pivotal differences: "It's just not the same"* captures the experience of change following the acquired brain injury. Participants were keenly aware that their personhood, lives, and circumstances had changed on a fundamental level: "I feel like I'm a different person" (*Doris*), and they shared that they struggled with the magnitude of the change brought on by the experience of acquired brain injury: "I don't want to be labelled as [...] head injury" (*Tobias*). The changes were experienced negatively as limitations, e.g. in their reduced abilities ("more often now, I don't even

try” – Joan), losses in all domains of life (“eventually you’re left with you know nothing” – Walter), or a sense of fragility (“I don’t want to get hit in the head” – Tobias).

Participants also felt that their acquired brain injury resulted in some potential positive changes: “Now all of the sudden I have this opportunity with BI” (Walter).

I noted that participants spoke about their experience of time and different stages of their lives – and their selves – since the injury, similar to how a person without an acquired brain injury might distinguish between when I was in college, when I got my first job, when I moved to England. The theme *Experience of time: “I’ve gone through different stages”* reflects how an acquired brain injury – and the impact of acquired brain injury – create time marks in a person’s life: “I have no recollection of the last year, year and a half, since the accident” (Doris). How acquired brain injury is experienced also depends on a person’s age, yet at the same time acquired brain injury can impact how age and the passing of time are experienced: “It just hit me, I’m an adult” (Tobias). Most participants also shared about the disruption of how they had envisioned their future and having to set new goals: “it’s re-evaluating your own life” (Walter).

With the third theme *Perspective as a choice: “Carrying on with what’s left”*, I recognize the tremendous mental efforts participants have put into reclaiming their lives and selves, and not giving up in the face of challenging moments following acquired brain injury: “I’m so happy I got through that, find my life, because it was pretty difficult, yeah, that [after the accident] was a really difficult time in my life” (Tobias). All of them shared in some way having to adjust their (pre-injury) perspectives in order to come to terms with the acquired brain injury and the resulting changes in their lives – and their sense of self. Some participants used mindful thinking strategies to help them identify

those skills or aspects of self they had not lost: “Okay, can’t do this, but what, what do I have now [...] and I have this” (Joan). Others practiced acceptance to overcome losses (“I have sort of like a rich attitude now” – Andrea). And most expressed the notion of good luck maybe having played at least a small role in either the extent of or outcome following their injury; in the words of Walter: “I got really lucky. Really, really lucky.”

Finally, the fourth theme ***Reclaiming self cohesion: “Everything that’s left, that’s you”*** reflects that participants did not entirely feel like a new person or that they had lost everything that had made them who they were before. Although aware of the changes within themselves – which they shared to experience – they also commented “I think I’m the same person, but now that I have limitations” (Tobias). This experience of having changed fundamentally, yet still also being the same person, appears to be at the core of the participants’ narrative of self post-injury. It is a contradiction within the self that requires much energy if not to tolerate, at least to navigate and demands care of and focus on the self: “I’m more self-centred, than I used to be” (Doris). In relation to others, all participants noted that “[...] people treat me differently” (Walter). In their interactions with others they often use strategies to help them function despite the internal contradiction within their sense of self: “I know how to appear interested” (Joan).

Table 7. Themes and subcategories with sample statements POST-injury self-narrative

Pivotal differences: IT'S JUST NOT THE SAME (<i>Joan</i>)	
<u>Subcategories</u>	<u>Sample statement</u>
BI - an opportunity	Now all of the sudden I have this opportunity with BI. (<i>Walter</i>)
Defined by BI	I don't want to be labelled as [...] head injury. (<i>Page</i>)
Everything (else) changed	I feel like I'm a different person. (<i>Doris</i>)
Limitations	More often now, I don't even try. (<i>Joan</i>)
Loss	eventually you're kind of left with you know nothing. (<i>Walter</i>)
Risks and fragility	I don't want to get hit in the head. (<i>Tobias</i>)

Experience of time: I'VE GONE THROUGH DIFFERENT STAGES (<i>Page</i>)	
<u>Subcategories</u>	<u>Sample statement</u>
Age	It just hit me, I'm an adult. (<i>Tobias</i>)
Before, after and since injury	I have no recollection of the last year, year and a half, since the accident. (<i>Doris</i>)
Future and time ahead	It's re-evaluating your own life. (<i>Walter</i>)

Perspective as a choice: CARRYING ON WITH WHAT'S LEFT (<i>Page</i>)	
<u>Subcategories</u>	<u>Sample statement</u>
Acceptance	I have sort of like a rich attitude now. (<i>Andrea</i>)
Luck	I got really lucky. Really, really lucky. (<i>Walter</i>)
Mindful thinking	Okay, can't do this, but what, what do I have now [...] and I have this. (<i>Joan</i>)
Not give up	I'm so happy I got through that, find my life, because it was pretty difficult, yeah, that [after the accident] was a really difficult time in my life. (<i>Tobias</i>)

Reclaiming self cohesion: EVERYTHING THAT'S LEFT, THAT'S YOU (<i>Page</i>)	
<u>Subcategories</u>	<u>Sample statement</u>
Focus on self	I'm more self-centred, than I used to be. (<i>Doris</i>)
I'm the same person	I think I'm the same person, but now that I have limitations. (<i>Tobias</i>)
Me in relation to others	I notice that people treat me differently. (<i>Walter</i>)
Strategies	I know how to appear interested. (<i>Joan</i>)

4.1.3 Speech, Language, and Communication (SLC) narrative. Three final themes were identified; the themes and subcategories are shown in Table 8 and described below.

The interview questions about speech, language, and communication deliberately did not include definitions for any of these terms. This allowed for participants to respond to those aspects of SLC that were most relevant to them. While some shared more philosophical thoughts about the inaccuracy of words, others revealed experiencing deep personal losses from no longer being able to tell stories or use humour. Across all participants, a recurring theme was that speech, language and communication were understood as essential human activities. Participants were motivated to regain lost or impaired skills: “If I’m going to be with them, [...] I want to be able to add to the conversation” (Joan). But the experience, captured in the theme *Recovery and SLC: “To function like a human being again”*, also revealed itself as an integral aspect of participants’ recovery after acquired brain injury. The participants shared that they relied on SLC skills during recovery (“Eventually, I uhm [...] spoke to them about whatever I was writing in my notebooks, and then they'd ask questions about that, so I learned how to uhm speak again, right” – Page) or that they noticed when SLC skills, including writing, were not available to them (“If it's not written down, I'll forget it, completely I'll forget it” – Tobias). Notably, participants shared how they experienced the interaction between cognition and SLC: “[...] and memory is so important for socialization” (Joan).

The participants’ comments were a reminder to others that it does not matter so much whether the source of a SLC “impairment” is linguistic or cognitive, but that the individual experiences the impact as real nonetheless. The second theme *SLC changes*

after brain injury are real: “I maybe sounded like I wasn’t drowning, but I was”

captured the participants’ lived experiences of changes in SLC. Speech changes (in the words of Page: “Stutter, I would pause a long time or forget it, you know”), changes in language (Doris: “Emotions, uhm, sometimes came out completely opposite of what I was thinking and feeling”) and in communication (Andrea: “I don’t so much guard what I say anymore”) were shared. Participants actively experienced losses related to SLC changes: “I can not be mature about some jokes or some situations that I get into” (Tobias) and feelings of isolation: “It’s very isolating, you know, because I can’t explain to you, to other people what’s going on” (Walter). The changes in their SLC after acquired brain injury crucially continued to impact their daily lives: “So I come home [from the doctor] and nothing had happened, because I couldn’t pick up the page, say the words, to tell him” (Doris).

A number of participants use strategies now to succeed in SLC. The third theme ***SLC Strategies: “I have key stories now, I practice”*** identified that participants try to adapt by planning ahead or using rehearsed content in their interactions (Tobias: “I just get little lessons from people and I just keep them on my mind, so I share those lessons that I know, which makes me seem that I’m smarter”). Participants also stated that they actively continue to practice their skills: “People kept saying my name, so then uhm, in my mind I just kept saying, my name’s Page, my name’s Page” (Page). Overall, this theme reflects that participants do not take their SLC for granted anymore since their acquired brain injury.

Table 8. Themes and subcategories with sample statements SLC narrative

Recovery and SLC: TO FUNCTION LIKE A HUMAN BEING AGAIN (<i>Page</i>)	
<u>Subcategories</u>	<u>Sample statement</u>
Motivation to (re-)gain SLC skills	If I'm going to be with them, [...]I want to be able to add to the conversation. (<i>Joan</i>)
The interaction of cognition and SLC	[...] and memory is so important for socialization. (<i>Joan</i>)
Use of SLC is integral during recovery & to moving on	Eventually, I uhm [...] spoke to them about whatever I was writing in my notebooks, and then they'd ask questions about that, so I learned how to uhm speak again, right. (<i>Page</i>)
Writing has a place during recovery too	If it's not written down, I'll forget it, completely I'll forget it. (<i>Tobias</i>)
SLC changes after BI are real: I MAYBE SOUNDED LIKE I WASN'T DROWNING, BUT I WAS (<i>Doris</i>)	
<u>Subcategories</u>	<u>Sample statement</u>
Experiences of speech changes	Stutter, I would pause a long time or forget it, you know. (<i>Page</i>)
Experiences of language changes	Emotions, uhm, sometimes came out completely opposite of what I was thinking and feeling. (<i>Doris</i>)
Experiences of communication changes	I don't so much guard what I say anymore. (<i>Andrea</i>)
Experiences of losses related to SLC changes	I can not be mature about some jokes or some situations that I get into. (<i>Tobias</i>)
Experiences of isolation as a result of SLC changes	It's very isolating, you know, because I can't explain to you, to other people what's going on. (<i>Walter</i>)
Experiences of living with SLC changes	So I come home [from the doctor] and nothing had happened, because I couldn't pick up the page, say the words, to tell him. (<i>Doris</i>)
SLC Strategies: I HAVE KEY STORIES NOW, I PRACTICE (<i>Joan</i>)	
<u>Subcategories</u>	<u>Sample statement</u>
Adaptive planning & strategies to succeed in SLC	I just get little lessons from people and I just keep them on my mind, so I share those lessons that I know, which makes me seem that I'm smarter. (<i>Tobias</i>)
Practice, practice, practice	People kept saying my name, so then uhm, in my mind I just kept saying, my name's Page, my name's Page. (<i>Page</i>)

4.2 Linguistic Performance

RQ2) How do non-aphasic adults with acquired brain injury *perform linguistically* in a spontaneous narrative task (as assessed through micro- and macro-linguistic measures), as elicited

- a. in a baseline spontaneous story task?
- b. in narrative about the PRE- and POST-injury self?

4.2.1 Baseline linguistic measure spontaneous story narrative. Overall, differences were observed across participants in all productivity measures (e.g. *Range* of Words = 175 – 1,071; *Range* of Complete Sentences = 17 – 89). Large variation in Speech Rate, i.e. words/minute, was also observed (*Range* = 109.38 – 186.27).

With regards to lexical processing, the scores for Percent Phonological Selection (hereafter % Phonological Selection) were evenly distributed ($M = 97.10$; $SD = 0.94$). This indicates that participants were equally able to retrieve phonologically well-formed words in this task.

The scores for the morpho-syntactic processing measure indicated different levels of ability in the area of grammatical organization; participants' scores of Percent Complete Sentences (hereafter % Complete Sentences) ranged from 47.30 to 80.00 ($M = 60.32$; $SD = 13.01$).

In terms of Informative Content, similar to the differences found in counts of Words and Units, counts of Lexical Information Units (LIU) indicated differences in the production of appropriate informative content, with a range of LIU from 152 to 852 ($M = 470.67$; $SD = 285.12$). The Informative Speech Rate results showed a wide range of

LIU/minute as well ($M = 135.26$; $SD = 24.31$). The communicative effectiveness of participants, i.e. Percent Lexical Informativeness (hereafter % Lexical Informativeness), was more consistent across individuals, ranging from 79.55 – 92.55 ($M = 86.62$; $SD = 4.55$). The results are summarized in Table 9.

Table 9. Individual scores baseline linguistic measure spontaneous story narrative

<u>Participant; Rotation</u>	Productivity					
	<u>Units</u>	<u>Words</u>	<u>Speech Rate</u>	<u>Utterances</u>	<u>MLU</u>	<u>Complete Sentences</u>
Walter; A	552	536	184.82	74	7.24	35
Page; B	182	175	109.38	25	7.00	17
Tobias; C	1,089	1,071	160.65	144	7.44	73
Doris; C	453	443	135.61	60	7.38	48
Joan; A	223	217	162.75	36	6.03	18
Andrea; B	929	891	186.27	135	6.60	89
<i>M</i>	571.33	555.50	156.58	79.00	6.95	46.67
<i>Md</i>	502.50	489.50	161.70	67.00	7.12	41.50
<i>SD</i>	369.65	360.75	29.67	50.02	0.54	29.41
<i>Min.</i>	182.00	175.00	109.38	25.00	6.03	17.00
<i>Max.</i>	1,089.00	1,071.00	186.27	144.00	7.44	89.00

<u>Participant; Rotation</u>	Lexical Processing	Morpho-Syntactic Processing	Informative Content		
	<u>% Phonological Selection</u>	<u>% Complete Sentences</u>	<u>Lexical Information Units (LIU)</u>	<u>% Lexical Informativeness</u>	<u>Informative Speech Rate</u>
Walter; A	97.10	47.30	460	85.82	158.62
Page; B	96.15	68.00	152	86.86	95.00
Tobias; C	98.35	50.69	852	79.55	127.80
Doris; C	97.79	80.00	410	92.55	125.51
Joan; A	97.31	50.00	196	90.32	147.00
Andrea; B	95.91	65.93	754	84.62	157.63
<i>M</i>	97.10	60.32	470.67	86.62	135.26
<i>Md</i>	97.21	58.31	435.00	86.34	137.40
<i>SD</i>	0.94	13.01	285.12	4.55	24.31
<i>Min.</i>	95.91	47.30	152.00	79.55	95.00
<i>Max.</i>	98.35	80.00	852.00	92.55	158.62

4.2.2 Semi-structured interview PRE- and POST-injury self-narrative.

Similar to the results from the participants' baseline linguistic measures, large differences were observed across participants in the range of count scores of productivity measures and counts of lexical information units (LIU). Additionally, an increase in the means of all count scores of productivity measures and counts of LIU across the two conditions PRE- and POST-injury self were found, corresponding with the observation that participants produced more narrative about their POST-injury self than about their PRE-injury self (without any time limit set by the researcher). The complete results for Means, Medians, *SD*, and *Ranges* are shown in Table 10.

Table 10. Means, Medians, Standard Deviations, and Ranges for linguistic performance of semi-structured interview PRE- and POST-injury self-narrative

	Units		Words		Speech Rate		Utterances	
	<u>PRE</u>	<u>POST</u>	<u>PRE</u>	<u>POST</u>	<u>PRE</u>	<u>POST</u>	<u>PRE</u>	<u>POST</u>
<i>M</i>	781	1,502	757	1,534	167.15	148.46	117	243
<i>Md</i>	845	1,519	826	1,523	163.65	153.28	125	259
<i>SD</i>	337	221	322	173	22.94	24.52	55	43
<i>Min.</i>	267	1,216	261	1,291	133.85	118.26	43	160
<i>Max.</i>	1,249	1,847	1,199	1,825	203.80	184.65	189	275

	MLU		Complete Sentences		% Phonological Selection		% Complete Sentences	
	<u>PRE</u>	<u>POST</u>	<u>PRE</u>	<u>POST</u>	<u>PRE</u>	<u>POST</u>	<u>PRE</u>	<u>POST</u>
<i>M</i>	6.60	6.44	54	101	97.15	97.84	46.93	42.83
<i>Md</i>	6.21	6.25	62	97	97.26	97.68	44.28	39.39
<i>SD</i>	0.91	0.91	24	15	1.05	0.84	9.08	9.20
<i>Min.</i>	5.80	5.59	17	88	96.00	97.04	39.15	33.96
<i>Max.</i>	7.88	8.07	78	130	98.62	98.81	62.00	59.38

	Lexical Information Units (LIU)		% Lexical Informativeness		Informative Speech Rate	
	<u>PRE</u>	<u>POST</u>	<u>PRE</u>	<u>POST</u>	<u>PRE</u>	<u>POST</u>
<i>M</i>	625	1,239	83.02	81.10	138.43	119.69
<i>Md</i>	695	1,206	82.51	80.27	141.84	118.56
<i>SD</i>	249	120	4.29	6.12	16.43	16.47
<i>Min.</i>	210	1,109	77.23	74.03	107.69	99.33
<i>Max.</i>	926	1,462	87.82	92.49	157.29	145.29

	% Cohesive Errors		% Local Coherence Errors		% Global Coherence Errors	
	<u>PRE</u>	<u>POST</u>	<u>PRE</u>	<u>POST</u>	<u>PRE</u>	<u>POST</u>
<i>M</i>	8.44	9.28	2.05	2.03	3.87	1.45
<i>Md</i>	9.26	9.47	2.01	1.94	4.01	1.25
<i>SD</i>	2.98	2.46	2.03	1.25	3.37	0.57
<i>Min.</i>	4.00	5.00	0.00	0.73	0.00	0.75
<i>Max.</i>	11.63	11.57	5.29	3.42	9.52	2.39

The Wilcoxon Signed Ranks test was used to determine significance and magnitude of differences between PRE- and POST-injury linguistic measures. The results are shown in Table 11, including *Z* statistics. The results from the test indicated no significant difference between participants' PRE and POST scores on the measures for MLU, % Phonological Selection, % Lexical Informativeness, % Cohesive Errors, % Local Coherence Errors, and % Global Coherence Errors. However, the Wilcoxon Signed Ranks test results indicated that participants produced significantly more Units ($p = 0.028$), Words ($p = 0.028$), Utterances ($p = 0.028$), number of Complete Sentences ($p = 0.028$), % Complete Sentences, and LIU ($p = 0.028$) in their POST narrative than in their PRE narrative. Finally, it is indicated that the Speech Rate ($p = 0.075$) is significantly slower in POST narrative ($Md = 153.28$) than PRE narrative ($Md = 163.65$). Even more significant is the slowing of the Informative Speech Rate from PRE narrative ($Md = 141.84$) to POST narrative ($Md = 118.56$) ($p = 0.046$).

Table 11. Wilcoxon Signed Test results linguistic measures PRE- vs. POST-injury self-narrative

Linguistic Measures	Z Statistics	p
POST Units - PRE Units	-2.201 ^a	0.028*
POST Words - PRE Words	-2.201 ^a	0.028*
POST Speech Rate - PRE Speech Rate	-1.782 ^b	0.075*
POST Utterances - PRE Utterances	-2.201 ^a	0.028*
POST MLU - PRE MLU	-.105 ^b	0.917
POST Complete Sentences - PRE Complete Sentences	-2.201 ^a	0.028*
POST % Phonological Selection - PRE % Phonological Selection	-1.572 ^a	0.116
POST % Complete Sentences - PRE % Complete Sentences	-2.201 ^b	0.028*
POST LIU - PRE LIU	-2.201 ^a	0.028*
POST % Lexical Informativeness - PRE % Lexical Informativeness	-.943 ^b	0.345
POST Informative Speech Rate - PRE Informative Speech Rate	-1.992 ^b	0.046*
POST % Cohesive Errors - PRE % Cohesive Errors	-.943 ^a	0.345
POST % Local Coherence Errors - PRE % Local Coherence Errors	-.314 ^b	0.753
POST % Global Coherence Errors - PRE % Global Coherence Errors	-1.363 ^b	0.173

Note. a. Based on negative ranks; b. Based on positive ranks; * p = significant at the 0.10 level (2-tailed)

4.2.3 Level of fatigue questionnaire. Two questionnaires were used to collect demographic data (age, age at injury, time since injury, and level of education (LOE)), as well as record self-rated changes in levels of fatigue. For completion purposes, I now report the results for the level of fatigue questionnaire, followed by the association between the linguistic performance measures and the demographic and level of fatigue variables.

Two of six participants reported no change in their level of fatigue between start and end of the first session, while the other four reported an increase in fatigue by 1

point. One of them began at level 2 = *I'm rested and alert*, and finished at 3 = *I'm getting tired*, while the other three participants began at level 3 = *I'm getting tired*, and finished at level 4 = *I'm very fatigued and should be resting*. On the second session, three of six participants reported no change in their level of fatigue between start and end (beginning and finishing either at 1 = *I'm well rested and fully alert* or at 2 = *I'm rested and alert*). The other three participants all began at level 2 = *I'm rested and alert*, and finished at level 3 = *I'm getting tired*.

4.2.4 Association of linguistic performance and demographic and level of fatigue questionnaire scores. The Spearman's *rho* test was used to detect associations between linguistic measures from PRE- and POST-injury self-narrative and the demographic variables age, age at injury, time since injury, and LOE, as well as the level of fatigue scores reported at the end of the second session (during which the semi-structured interview was conducted).

No significant correlations were found for the linguistic measures from narrative about the PRE-injury self and the variables age, age at injury, time since injury, level of fatigue. However, the test results ($r = 0.759$; $p = 0.080$) indicate a positive correlation between LOE and production of Units, Words, Utterances, and LIU, as well as Speech Rate. Participants with a higher LOE also had significantly lower scores on % Phonological Selection ($r = -0.955$; $p = 0.003$), i.e. retrieved fewer well-formed words. Table 12 presents the results with strength of correlation.

Table 12. Spearman's rho significant test results questionnaire variables vs. PRE-injury self-narrative linguistic measures

Questionnaire variable	Linguistic measure - PRE-injury self narrative	<i>r</i>	<i>p</i>
LOE	Units	0.759	0.080
LOE	Words	0.759	0.080
LOE	Speech Rate	0.759	0.080
LOE	Utterances	0.759	0.080
LOE	% Phonological Selection	-0.955	0.003
LOE	LIU	0.759	0.080

Note. LOE = Level of Education; *p* significant at the 0.10 level (2-tailed)

No significant correlations were found for the linguistic measures from narrative about the POST-injury self and time since injury. However, the test results indicate that participants who were older ($r = -0.886$; $p = 0.019$) or who were older at the time of injury ($r = -0.812$; $p = 0.050$) were less able to retrieve well-formed words (% Phonological Selection). Participants who reported higher levels of fatigue at the end of the session were also less able to retrieve well-formed words ($r = -.926$; $p = 0.008$). Additionally, the higher the participants' LOE, the more words ($r = 0.880$; $p = 0.021$) and Lexical Information Units (LIU) ($r = 0.759$; $p = 0.080$) they produced and the faster they spoke ($r = 0.880$; $p = 0.021$) about their POST-injury self. Significant results (and strength of correlation r) are shown in Table 13.

Table 13. Spearman's rho significant test results questionnaire variables vs. POST-injury self-narrative linguistic measures

Questionnaire variable	Linguistic measure - POST-injury self narrative	<i>r</i>	<i>p</i>
Age	% Phonological Selection	-0.886	0.019
Age at Injury	% Phonological Selection	-0.812	0.050
LOE	Words	0.880	0.021
LOE	Speech Rate	0.880	0.021
LOE	LIU	0.759	0.080
Level of Fatigue (End of session)	% Phonological Selection	-0.926	0.008

Note. LOE = Level of Education; *p* significant at the 0.10 level (2-tailed)

Finally, the Spearman's *rho* test was used to identify correlations between Difference Scores of linguistic measures, i.e. changes in POST-injury narrative scores from PRE-injury narrative scores of linguistic measures, and the demographic variables age, age at injury, time since injury, and LOE, and level of fatigue scores. No significant correlations were found.

4.3 Association Linguistic Performance and Non-Linguistic Assessment Measures

RQ3) In non-aphasic adults with acquired brain injury, how do linguistic performance of narrative skills and personal narrative about the self and SLC associate with:

- a. self-reported **functioning**, as measured by the Quality of Life in Brain Injury Questionnaire?
- b. self-rated current experience of **grief and adjustment**, as measured by Brain Injury Grief Index?
- c. assessed **cognitive performance**, as measured by the Cognitive Linguistic Quick Test?

- d. self-reported *communicative abilities*, as measured by the La Trobe Communication Questionnaire?

4.3.1 Non-linguistic assessment instruments. Four assessment instruments were administered to measure subjectively rated functioning (quality of life), perceived loss and adjustment, and perceived communicative abilities, as well as to assess cognitive-linguistic abilities. These instruments were not used for clinical assessment, rather to compare participants and to investigate potential associations between non-linguistic and linguistic performances. I first report the results of the four non-linguistic assessment instruments (see Table 14), followed by the results for associations between linguistic performance and non-linguistic assessment scores.

(a) Quality of Life in Brain Injury (QOLIBRI). The overall QOLIBRI score reflects a wide range of self-perceived functioning, i.e. Quality of Life (QoL) across participants (Range = 16.67 – 91.67; $M = 58.33$; $SD = 27.26$) at the time of assessment. A wide range in perceived QoL was found across all six separate domains of Cognition, Self, Daily Life Autonomy, Social Relations, Emotions, and Physical Problems. On average, participants reported lowest QoL in the domains of Cognition ($M = 55.95$; $SD = 14.58$) and Physical Problems ($M = 50.83$; $SD = 24.98$), and highest QoL in the domain of Emotions ($M = 70.83$; $SD = 20.84$) and Social Relations ($M = 65.97$; $SD = 12.75$).

(b) Brain Injury Grief Index (BIGI). Participants reported Loss scores ranging from 4.00 – 11.00 ($M = 7.67$; $SD = 2.80$) and Adjustment scores ranging from 7.00 – 16.00 ($M = 12.00$; $SD = 3.52$). In all but one participant, the Adjustment score was higher

4.3.2 Association between linguistic performance and non-linguistic

assessment scores. The Spearman's *rho* test was used to detect associations between linguistic measures from PRE- and POST-injury self-narrative and the non-linguistic measures from QOLIBRI, BIGI, CLQT, and LCQ scores. The results are again organized by assessment instrument.

(a) Functioning (QOLIBRI). Only one significant association between QOLIBRI scores and linguistic measures from PRE-injury self-narrative was found; during narratives about the PRE-injury self, participants who were more bothered by physical problems also made significantly more cohesive errors ($r = 0.812$; $p = 0.050$) (Table 15).

In contrast, a number of significant correlations occurred between QOLIBRI scores and linguistic measures during narratives about the POST-injury self (Table 16). The better participants felt about their thinking ability, the more Utterances they produced ($r = 0.829$; $p = 0.042$). The better they felt about themselves ($r = 0.886$; $p = 0.019$) and their daily life autonomy ($r = 0.812$; $p = 0.050$), the better they were able to retrieve lexically well-formed words (% Phonological Selection). The better they felt about their social relations, the less lexically appropriate and relevant content they produced ($r = -0.883$; $p = 0.020$) and the more cohesive errors they made ($r = 0.883$; $p = 0.020$).

The Difference Scores test result indicates that participants who were more bothered by physical problems were more likely to maintain a similar level of global coherence when speaking about their PRE-injury self and their POST-injury self ($r = 0.841$; $p = 0.036$) (Table 17).

(b) Loss and adjustment (BIGI). The results showed that participants who reported more strongly that they experienced Loss produced more lexically appropriate and relevant content ($r = 0.912$; $p = 0.011$) and made fewer global coherence errors ($r = -0.765$; $p = 0.076$) during narratives about the PRE-injury self (Table 15).

During narratives about the POST-injury self, participants who reported experiencing higher levels of Loss produced more complete sentences ($r = 0.853$; $p = 0.031$), produced more lexically appropriate and relevant content ($r = 0.853$; $p = 0.031$), and made fewer cohesive errors ($r = -0.853$; $p = 0.031$) (Table 16).

As for Difference scores (Table 17), participants who reported higher feelings of Loss were more likely to maintain a similar level of global coherence when speaking about their PRE-injury self and their POST-injury self ($r = -0.765$; $p = 0.076$).

Furthermore, participants who reported low feelings of Loss were more likely to speak at a similar speech rate about their PRE-injury self and their POST-injury self; or, put differently, the higher feelings of Loss participants reported, the more slowly they spoke about their POST-injury self compared to how they spoke about their PRE-injury self ($r = 0.883$; $p = 0.020$). Likewise, the higher feelings of loss participants reported, the slower their Informative Speech Rate was about their POST-injury self vs. their PRE-injury self ($r = 0.883$; $p = 0.020$).

(c) Cognitive performance (CLQT). During narratives about the PRE-injury self, higher scores in % Phonological Selection were associated with lower CLQT scores in Memory ($r = -0.877$; $p = 0.022$), Language ($r = -0.857$; $p = 0.029$) and the Composite score ($r = -0.893$; $p = 0.016$) (Table 15). No other significant correlations were found between linguistic measures and CLQT scores.

(d) Self-reported communicative abilities (LCQ). No significant correlations

were found between linguistic (PRE, POST or CHANGE) variables and LCQ scores.

Table 15. Spearman's rho significant test results non-linguistic vs. PRE-injury self-narrative linguistic measures

Non-linguistic measure	Linguistic measure - PRE-injury self narrative	<i>r</i>	<i>p</i>
QOLIBRI - Physical Problems	% Cohesive Errors	0.812	0.050
BIGI Loss	% Lexical Informativeness	0.912	0.011
BIGI Loss	% Global Coherence Errors	-0.765	0.076
CLQT - Memory	% Phonological Selection	-0.877	0.022
CLQT - Language	% Phonological Selection	-0.857	0.029
CLQT - Composite	% Phonological Selection	-0.893	0.016

Note. QOLIBRI = Quality of Life in Brain Injury Questionnaire; BIGI = Brain Injury Grief Index; CLQT = Cognitive Linguistic Quick Test; *p* significant at the 0.10 level (2-tailed)

Table 16. Spearman's rho significant test results non-linguistic vs. POST-injury self-narrative linguistic measures

Non-linguistic measure	Linguistic measure - POST-injury self narrative	<i>r</i>	<i>p</i>
QOLIBRI - Cognition	Utterances	0.829	0.042
QOLIBRI - Self	% Phonological Selection	0.886	0.019
QOLIBRI - Daily Life Autonomy	% Phonological Selection	0.812	0.050
QOLIBRI - Social Relations	% Lexical Informativeness	-0.883	0.020
QOLIBRI - Social Relations	% Cohesive Errors	0.883	0.020
QOLIBRI - Overall	% Phonological Selection	0.943	0.005
BIGI - Loss	% Complete Sentences	0.853	0.031
BIGI - Loss	% Lexical Informativeness	0.853	0.031
BIGI - Loss	% Cohesive Errors	-0.853	0.031

Note. QOLIBRI = Quality of Life in Brain Injury Questionnaire; BIGI = Brain Injury Grief Index; *p* significant at the 0.10 level (2-tailed)

Table 17. Spearman's rho significant test results non-linguistic vs. linguistic Difference Scores

Non-linguistic measure	Linguistic measure - Difference Score	<i>r</i>	<i>p</i>
BIGI Loss	Change Speech Rate	0.883	0.020
BIGI Loss	Change Informative Speech Rate	0.883	0.020
BIGI Loss	Change % Global Coherence Errors	-0.765	0.076
QOLIBRI - Physical Problems	Change % Cohesive Errors	0.841	0.036

Note. Difference Score = Change; *p* significant at the 0.10 level (2-tailed)

Chapter 5 – Discussion

The discussion of the results in this chapter is structured in the order of the research questions, which are, once more, listed first in abbreviated form.

- 1) How do non-aphasic adults with acquired brain injury *personally narrate* their PRE-injury or POST-injury self, or their experience of their (post-injury) speech, language and communication (SLC)?
- 2) How do non-aphasic adults with acquired brain injury *perform linguistically* in a spontaneous narrative task as elicited in a baseline spontaneous story task or during a semi-structured interview about the PRE- or POST-injury self?
- 3) In non-aphasic adults with acquired brain injury, how do linguistic performance of narrative skills and personal narrative about the self and SLC associate with self-reported *functioning*, experience of *grief and adjustment*, assessed *cognitive performance*, and self-reported *communicative abilities*?

5.1 PRE-Injury and POST-Injury Self-Narrative Themes

Everyone is at risk for brain injury (Cahill, Rotter, Lyons, & Marrone, 2014; Demir, Rowe, Heller, Goldin-Meadow, & Levine, 2015; Godwin, Lukow, & Lichiello, 2015), an observation that is reflected in this study by the varied backgrounds of the participants. Participants' narratives about their PRE-injury self did not contain many similarities in terms of goals, achievements, relationships, or experiences. However, each participant thoughtfully depicted an image of a grounded individual with a rounded sense of self, reflected in the theme *Cohesive lives: "I felt the way I felt."*

From the narratives about the POST-injury self, four themes emerged, each reinforcing or expanding on findings from earlier published studies about the subjective experience of acquired brain injury and sense of self following acquired brain injury.

The first theme *Pivotal differences: “It’s just not the same”* relates to the experience of changes in the self following the acquired brain injury; several previous studies have established change in or loss of pre-injury sense of self as a central topic for individuals during recovery and beyond (e.g. Muenchberger et al., 2008; Nochi, 1998, 2000). Page captured this sentiment when saying, “It’s just not the same.” Some participants in this study found the experience of brain injury had provided them with unexpected opportunities; for example, Doris stated that “it makes me feel [...] like I’m a different person,” while Andrea shared the changes had granted her a “sense of freedom.” Overall, however, the changes were described as fundamental, defining, limiting, and marked by (great) losses in different domains of their lives; for Tobias it means that “I can’t be into team sports anymore,” while Doris commented that “more than anything, I’d like [my short-term memory] back.”

A second theme, *Experience of time: “I’ve gone through different stages”* captures the participants’ comments about going through different stages following their injury. This experience of time in distinct sections subsequent to the injury has been described similarly by Morse and O’Brien (1995) in a study with patients who had survived serious traumatic injuries and where the authors noted that individuals tended to go through a four-stage process during their recovery. The demarking of the life story into a pre- and post-injury phase was of course accentuated by the interview questions in this study; additional temporal points of reference came from participants’ reflections

about their own age, such as Tobias who noted that “my mind still feels like I’m 18 [time of injury],” as well as a recognition of having “gone through different stages” (Page), including the phase of immediate recovery since the injury to now, the post-injury phase of their lives. Doris for example stated, “I have no recollection of the last year, year and half, since the injury,” but was also looking towards the future, “I want to go back to work,” pointing towards the next stage of living with acquired brain injury. In the context of recovery, individuals appear to benefit from having opportunities to explore their own personal trajectories, rather than be held to a linear path of medically defined timeframe markers (Muenchberger et al., 2008).

Participants in the present study also shared what different strategies they employed to “carry on with what was left” (Page), the third theme identified, “*Perspective as a choice: Carrying on with what’s left.*” A number of different mental attitudes were employed in order to move forward, and individuals relied on acceptance, considering the possibility that there was fortune in misfortune, the use of mindful thinking and reframing, as well as maintaining a positive outlook. Using, or adapting previous coping strategies is central during recovery and often a prerequisite to achieving success following the injury (Fraas & Calvert, 2009). The participants in this study stated, “I’ve accepted things, so that helps a lot” (Page), but also that, “I can have like a better life almost” (Andrea). They remained vigilant about “continuously [...] changing every [negative] thought” (Andrea) and staying focused on “what do I have now” (Joan), so that they could reach a point of saying “I’m so happy I got through that, because [the first few years after the accident] was a really difficult time in my life” (Tobias).

Finally, participants described an experience of being the same, yet fundamentally changed person, captured in the theme “*Reclaiming self cohesion: Everything that’s left, that’s you.*” In the words of Walter, “everything around me changed, but I still feel the same.” Rather than just being contradictory, this theme embraces two meaningful insights. First, it captures that despite the potentially life-altering impacts, individuals can and do recover and experience positive outcomes and a sense of wholeness after acquired brain injury (see also Muenchberger et al., 2008). Vital to that appears to be a sense of “continuity in the core” (Gelech & Desjardins, 2011, p. 67) and stability in the participant’s perception of who they were before, across, and since the experience of their injury. Most participants directly commented on the need and desire to focus on the self, in terms of “do[ing] things on my own more” (Page), “speaking up for myself” (Andrea), and “trying to figure out where I fit in” (Doris).

The notion of being changed, yet still the same also alludes to the active, ongoing process of living with the experience of acquired brain injury. Davis, Gemeinhardt, Gan, Anstey, and Gargaro (2003) suggested that reaching a resolution of the crisis experience brought on by the injury leads to the achievement of a “precarious homeostasis” (p. 373). This delicate stability is further suspended in the existing relations between the individual with others: “I see that they look at me differently” (Doris), but “I’m at the age and stage that having somebody always there holding my hand, and always protecting me, is not always a good thing” (Page). In the end, recovery for the participants in this study compares to a continuous engagement, or ongoing story, between the POST-injury self and others (see also Tasker, 2003).

A final observation: with no time limits set during the interview, all participants in this study produced more narrative about their POST-injury self than narrative about their PRE-injury self. This is noteworthy because of a lingering bias encountered sometimes where individuals with brain injuries are perceived to “[maybe] idealize their former pre-injury self [...], impacted by poor memory” (Ponsford, Kelly, & Couchman, 2014, p. 147). The thematic analysis of PRE-injury vs. POST-injury self-narratives in this study however shows participants neither idealized, nor perseverated on speaking about their pre-injury self.

5.2 Speech, Language, and Communication (SLC) Themes

While the subjective experience of living with aphasia (e.g. Niemi & Johansson, 2013; Rohde, Townley-O’Neill, Trendall, Worrall, & Cornwell, 2012; Sjöqvist Nätterlund, 2010) or other speech, language, and communication needs (e.g. Baylor, Yorkston, & Eadie, 2005; Bricker-Katz, Lincoln, & Cumming, 2013; Markham et al., 2009) has been documented widely, there is a distinct paucity of similar documentation about the lived experience of cognitive-linguistic communication deficits (CLCD) following acquired brain injury. The findings of the present study therefore complement the available clinical and experimental literature on CLDC.

The first theme, “*Recovery and SLC: To function like a human being again,*” captures that linguistic abilities contribute to our sense of being capable: “[it] was my motivation, for people to understand who I am, what I’m doing.” Those are the words of Page, speaking about how she experienced the changes in SLC following acquired brain injury. With a persistent lack of effective assessment tools for CLDC, non-aphasic

individuals are often left alone with their experiences, quietly redirected to focus on other rehabilitation goals. A shared experience among participants however was that SLC skills were in fact integral during their recovery. Importantly, SLC changes were challenging to tolerate, regardless of whether the source of the impairment was cognitive or linguistic in nature from a clinical perspective; language is a fundamental human tool, and its absence or changed functioning was noted as a distinct lack in the participants' lives. Each participant shared experiences that underline how integral SLC skills are to an individual's sense of functioning, not only in his or her interactions with others, but also inadvertently in the context of rehabilitation and recovery. Joan for example shared that, "after they left my office, I had no knowledge of what we really talked about," while Page explained, "I just kept going, trying to get a spark, until one day, I remembered my name and just said, my name's Page."

With regards to using SLC in rehab settings, writing (and reading) stood out as particularly relevant skills that could be employed as strategies, such as for Doris, who said, "I know this because I reread some diaries," while Joan shared, "He told me [some trick] and I've got it written down," a strategy used by Tobias as well, "if it's not written down, I'll forget it, completely forget it." The focus of this study is primarily on spoken narrative; however, Barwood and Murdoch (2013) recently identified reduced general language performance in writing to dictation and copying of information following mild traumatic brain injury.

A second theme common among participants was how their brain injury affected their SLC abilities and performances, despite not having received a formal diagnosis of SLC deficits: ***"SLC changes after BI are real: I maybe sounded like I wasn't drowning,***

but I was.” The lived experience of the diffuse interaction between acquired brain injury and speech, language, and communication is captured in the words of Doris, “I maybe sounded like I wasn’t drowning, but I was.” All participants commented that their injury impacted their SLC in one form or another, like forgetting what they have heard, needing strategies to remember names of others, feeling left behind in conversations due to difficulties processing, not being able to participate in conversations due to difficulties joining at the right time or forgetting the stories they wanted to share, or generally feeling limited in their abilities to conceptualize their thoughts and experiences. The impacts resulted in a sense of separation from others, as Walter shared, “it’s very isolating, you know, because I can’t explain to you, to other people what’s going on.” Clinicians and others involved, during or after the rehabilitation process, ought to be careful when interacting with individuals with “subtle” or less overt SLC challenges, as they are at risk of not receiving the care they actually require, as exemplified by Doris, “So I come home [from the doctor] and nothing had happened, because I couldn’t pick up the page, say the words, to tell him.” Studies with other populations have found that unattended to SLC impairments can result in barriers to accessing appropriate services (Sanger, Moore-Brown, Montgomery, Rezac, & Keller, 2003) or a breakdown in the client-service provider communication, such as mismatched goals between speech and language pathologists and people with aphasia (Rohde et al., 2012).

Finally, participants shared that they are using different SLC strategies when interacting with others, captured in the third theme “*SLC Strategies: I have key stories now, I practice.*” Coping strategies to manage discourse and communicative interactions have been previously documented for various SLC conditions not related to acquired

brain injuries (e.g. McCormack et al., 2012; Plexico et al., 2005; Walsh, 2008).

Participants in this study noted the importance of practicing speaking, listening, understanding, or writing, because “it doesn’t come simply anymore” (Joan), and to remain patient, as “the more I talk, the more it improves” (Page). However, most also continue to having to adapt, either by making explicit efforts to be specific in their responses, or by staying vigilant about their moment to moment state of being, such as in the words of Tobias: “for me joining conversations and stuff like that, I have to really decide on where I am, the current stage of where I stand.” While some rely on a collection of key stories or anecdotes to share in order to maintain pace during a conversation, others draw on their professional experiences from before their injury to participate: “I know how to appear interested” (Joan).

5.3 Linguistic Performance – Baseline Spontaneous Story Task

A modified version of the conversational map technique (Biddle et al., 1996; Peterson & McCabe, 1983) was used to determine a baseline measure of linguistic performance. Participants differed widely in their baseline productivity measures and in their effectiveness in grammatical organization, i.e. number of complete sentences produced. However, they were similarly able to retrieve phonologically well-formed words and comparatively able to produce lexically appropriate and relevant well-formed words while spontaneously telling a story about a past experience. In their study, Biddle et al. (1996) observed that the group of participants with traumatic brain injury showed large *SD* on several measures of narrative performance, while the healthy comparison group did not. The findings from the baseline task of spontaneous story telling in this

study support the notion that diffuse acquired brain injuries result in complex, heterogeneous impairments (Williams et al., 2012), including linguistic performance.

5.4 Linguistic Performance – Interview about PRE- and POST-Injury Self

Similar to the baseline results, the analysis of linguistic performance during the semi-structured interviews also shows differences across participants with regards to their individual productivity. Again, this is in line with findings from other studies that revealed the pattern of linguistic narrative performance is more varied across individuals in participant groups with acquired brain injuries compared to healthy control groups (Lê, Coelho, Mozeiko, & Grafman, 2011; Lê, Coelho, Mozeiko, Krueger, et al., 2011).

However, the focus of this study is the within-group comparison of linguistic performance during spontaneous narrative about the PRE-injury self vs. the POST-injury self, elicited during a semi-structured interview. The results from this study differ therefore from those generated from standardized CLDC assessment tools, which tend not to evaluate spontaneous speech (Blyth et al., 2012), as well as results from studies on narrative following brain injury that use other more controlled elicitation methods (e.g. Biddle et al., 1996; Lê, Coelho, Mozeiko, & Grafman, 2011; Marini, Galetto, et al., 2011).

In this study, participants spoke longer about their POST-injury self, as well as produced significantly more units, words, utterances, complete sentences, and lexical information units (LIU) during their POST-injury self-narratives. Furthermore, they also maintained similar levels of % Lexical Informativeness, meaning the higher productive output did not result in empty chatter, but remained meaningful and relevant. Yet, all

participants also spoke significantly slower when talking about their POST-injury self. Both, the Speech Rate ($p = 0.075$) and Informative Speech Rate ($p = 0.046$) were significantly slower during POST- compared to PRE-injury narrative.

Narrative segments about the PRE- and POST-injury self occurred throughout the interview, with the bulk of POST-injury narrative occurring at the beginning of the interview, while most narrative about the PRE-injury self occurred towards the middle of the interview (the third part generally covering speech, language, and communication experiences). Also, only half of the participants rated their level of fatigue to have increased by the end of the entire second session during which the interview took place. A slowing down of the speech rate is therefore difficult to explain by only assuming fatigue as a factor. Instead, it appears that narrative about the POST-injury self, while produced generously, may be more taxing to generate and therefore results in a reduction of the speech rate. Marini, Galetto, et al. (2011) found that participants with traumatic brain injuries had significantly slower speech rates compared to a healthy control group ($p < 0.001$). Results from this study show that the speech rate of individuals with acquired brain injuries may also vary depending on what participants speak about.

Unlike when talking about the PRE-injury self, an individual can indeed not rely on a previous version of their self-narrative when talking about their POST-injury self; the POST-injury narrative about the self only commences *after* the injury, and any detail about the self since the injury is new information to be integrated into the narrative. Galetto et al. (2013) observed reduced speech rates in adults with mild traumatic brain injury compared to a healthy control sample during an elicited picture narrative task. In the absence of additional phonological or lexical deficits, the authors hypothesized that

the reduced speech rate resulted not from articulatory or linguistic difficulties, but rather a more general reduction of the cognitive resources available during narrative. It is plausible that in the present study, in order to maintain a relatively steady % Lexical Informativeness throughout the interview, participants slowed down their speech rate during POST-injury narrative segments to offset the increased toll the encoding and integrating of relatively newer information about their POST-injury self took on their cognitive resources. This interpretation is in line with the “High Level Language Hypothesis” (Hinchliffe, Murdoch, & Chenery, 1998), which proposed that communicative deficits following diffuse (mild) traumatic brain injury are the outcome of more general cognitive difficulties, rather than a primary linguistic deficit. In other words, even mild cognitive impairments following acquired brain injury might influence higher-order linguistic functions (such as lexical-semantic access and manipulation, verbal fluency, non-linear expression) (Barwood & Murdoch, 2013), and may account for the reduction in speech rate during POST-injury narrative of self.

5.5 Linguistic Performance, Self-Narrative, and Functioning (QOLIBRI)

Participants reported a wide range of perceived functioning, or Quality of Life (QoL) in all domains of the QOLIBRI questionnaire, i.e. Cognition, Self, Daily Life Autonomy, Social Relations, Emotions, and Physical Problems. The observed variation in standard deviations are typical of Health-related QoL instruments (Truelle et al., 2010).

On average, participants reported that they were most bothered by their changed thinking abilities and ongoing physical problems. Cognition and Physical Problems are the two domains within the QOLIBRI that directly and intimately relate to the *bodily*

event of acquired brain injury. In their metasynthesis of studies documenting lived experiences of recovery following traumatic brain injury, Levack, Kayes, and Fadyl (2010) identified the enduring experience of a mind/body disconnect, including being slower in cognitive activities. Similarly, the QOLIBRI scores in the domains of Cognition and Physical Problems appear to be reflected in the POST-injury self-narrative theme *Pivotal differences: "It's just not the same"*; participants were fully aware of and most deeply experience the fundamental physiological changes that occurred due the acquired brain injury.

During PRE-injury self-narratives, QOLIBRI Physical Problems scores correlated significantly ($p = 0.050$) with the linguistic variable % Cohesive Error scores.

Participants who were more bothered by physical problems were also more likely to maintain a similar level of cohesion ($p = 0.036$) when speaking about either their PRE- or POST-injury self. However, cohesive error counts include abrupt interruptions of utterances, where the next utterance completes the previously introduced information. Marini, Galetto, et al. (2011) have in their own reporting suggested that interruption errors may not be due to specific linguistic deficits, but rather reflect dysfluency in cognitive processing. Interruption errors made up the majority of counts of cohesive errors in this study; when interruption errors were excluded, the correlation with Physical Problem scores disappears for both the % Cohesive Errors ($p = 0.471$) and Change % Cohesive Errors ($p = 0.868$).

A number of two-tailed correlations were found between QOLIBRI scores and linguistic measures from POST-injury self-narratives that have not been discussed in the literature previously. For one, higher scores in Cognition correlated with higher numbers

of Utterances produced ($p = 0.042$). This may indicate that the more utterances participants produced, the better they perceived their thinking abilities. Also, higher scores in Self ($p = 0.019$), Daily Life Autonomy ($p = 0.050$), and Overall QoL ($p = 0.005$) correlated with higher % Phonological Selection scores. This may indicate that when participants are more able to select phonologically well-formed words while talking about themselves now, they rate their view of self, autonomy in daily life and overall QoL more favourably. Scores in Social Relations also correlated positively with the measure % Cohesive Errors ($p = 0.020$), but again, the significant correlation disappeared when interruption errors were discarded.

Finally, scores in Social Relations correlated negatively with % Lexical Informativeness ($p = 0.020$). The Social Relations variable ($M = 65.97$; $SD = 12.75$) is calculated from answers about how satisfied participants are with their ability to feel affection towards and in their relationships with family, friends, and partners, and the attitudes of other people towards them (Truelle et al., 2010). The variable % Lexical Informativeness adequately measures communicative effectiveness in people with neurological or neuropsychiatric disorders (Marini, Andreetta, et al., 2011). Taken together, the results indicate that the better participants are able to provide pragmatically relevant information when speaking about their POST-injury self, the more sensitive they are to the quality of their relationships with people in their social network (family, friends, partners). Put differently, participants who provided more detailed POST-injury self-narratives may comparatively be more susceptible to whether their expectation for reciprocity is met during conversations or not. Such an interpretation could account for observed negative effects of traumatic brain injury on social interactions, which are

understood to be rooted at least in part in the subtle communicative challenges associated with brain injury (Johnson & Turkstra, 2012; Nichols & Kosciulek, 2014; Turkstra, 2008). In the context of this study, participants themselves may have provided their own clarification in the themes from their POST-injury self-narrative and their SLC narratives: while participants explicitly use strategies when communicating with others to enhance the interaction (*SLC Strategies: "I have key stories now, I practice"*), all but one participant also directly stated that they felt people treated them differently now or noted a change in their relationships with others (*"Reclaiming self cohesion: Everything that's left, that's you"*; sub-category *"Me in relation to others."*)

5.6 Linguistic Performance, Self-Narrative, and Grief (BIGI)

The results from the BIGI reflect a complicated relation between feelings of loss and experiences of adjustment. High ratings of adjustment did not consistently correlate with low levels of loss. Two participants with the highest Adjustment scores also had the longest Time since Injury (14;1 years and 10;3 years, respectively). However, while one of them also had the lowest Loss score (*score = 4*) of all participants, the other had the highest Loss score (*score = 11*). The participant with the highest Loss score was the individual who most recently sustained an injury. Nevertheless, a number of novel and interesting correlations emerged, discussed as follows.

In the PRE-injury narrative, Loss scores correlated positively with % Lexical Informativeness ($p = 0.011$) and negatively with % Global Coherence Errors ($p = 0.076$). Actual counts of Global Coherence Errors were low (*Range = 0 – 18*), making interpretation of the correlation of those errors to Loss scores vague. The significant

correlation between Loss and % Lexical Informativeness, i.e. communicative effectiveness, was also found in the POST-injury narrative results ($p = 0.031$). This may indicate that the better participants are able to provide pragmatically relevant information when speaking about their self, the more sensitive they are about their perceived losses.

Aside from a correlation with % Lexical Informativeness, Loss scores also correlated positively with the measure % Complete Sentences ($p = 0.031$) and negatively with % Cohesive Errors ($p = 0.031$) in the POST-injury self-narratives. Again, cohesion correlations were no longer significant once interruption errors were removed ($p = 0.922$). However, participants with higher Loss scores not only provided more relevant information, but also produced more complete sentences. The finding suggests that a relation may exist between the ability to produce comparatively detailed and fluent narrative about the self and an experience of Loss or, alternatively, an awareness of Loss that may be amplified through the process of more precise articulation. In a previous study with individuals with traumatic brain injuries, higher levels of depression and grief were found to be associated with greater perceptions of change in identity (Carroll & Coetzer, 2011). Indeed, other studies, including Cooper-Evans, Alderman, Knight, and Oddy (2008) found that higher levels of awareness of deficits were associated with lower levels of self-esteem and greater levels of psychological distress. Taken together, these findings have implications for clinical settings, in that those individuals who provide more detailed accounts of their POST-injury self may be at risk of experiencing higher levels of grief, a possibility that must not be overlooked during rehabilitation of individuals presenting with higher levels of self-awareness.

Finally, the BIGI Loss score also correlates significantly with Change in Speech

Rate ($p = 0.020$) and Change in Informative Speech Rate ($p = 0.020$). As previously discussed, talking about the POST-injury self appears to put different demands on the speaker compared to when talking about the PRE-injury self. In addition to the earlier noted factor of cognitive processing resources, changes in speech rates appear at least in part also to be related to feelings of loss. During the interviews, all participants spoke about feelings of loss or painful changes or limitations experienced since their injury, culminating in the theme *Pivotal differences: "It's just not the same."* Remarkably, participants who reported lower feelings of loss in the BIGI were more likely to speak at a similar speech rate about their PRE-injury self and their POST-injury self; or, put differently, the higher feelings of loss participants reported, the more slowly they spoke about their POST-injury self compared to when speaking about the PRE-injury self ($r = 0.883$; $p = 0.020$). Likewise, the higher feelings of loss participants reported, the slower their Informative Speech Rate was about their POST-injury self vs. their PRE-injury self ($r = 0.883$; $p = 0.020$). Notably, no significant correlation was found between Loss scores and Time since Injury. Taken together, these findings indicate that feelings of loss following acquired brain injury are not always lessened with an increase of time since injury; rather, feelings of loss may persist and continue to affect the individual and remain reflected in the rate of speech when speaking about their POST-injury self.

5.7 Linguistic Performance, Self-Narrative, and Cognition (CLQT)

All participants scored within normal limits in the domains of attention, executive function, and visuospatial skills, and all but one were within normal limits in the clock drawing task. However, only one participant scored within normal limits of the memory

domain, while three received mild and two received moderate severity ratings. Also, while four participants reached normal limits in the language domain, one participant earned mild severity rating and one earned moderate severity rating. These findings suggest that the participants in this study performed at comparative, and also normal levels, with regards to their attention, executive function, visuospatial, and clock drawing skills, but differed in their memory and language performances.

Memory ($p = 0.022$), Language ($p = 0.029$) and Composite ($p = 0.016$) CLQT scores all correlated negatively with the linguistic measure % Phonological Selection in the PRE-injury narrative. In other words, higher Memory, Language and Composite scores correlated with lower scores in the ability to retrieve well-formed phonological words. The direction of this correlation is at first surprising, as it could be expected that memory and language scores would positively correlate with word retrieval (Crawford, Knight, & Alsop, 2007). A closer look at the sub-components contributing to the respective scores shows that the CLQT Memory score is calculated based on scores from four individual tasks: a) retrieving personal facts, b) retelling a story, c) generative naming, and d) remembering designs. The CLQT Language score is calculated based on scores from the four tasks a) retrieving personal facts, b) story retelling, d) generative naming, and d) confrontation naming (Helm-Estabrooks, 2001). All five separate tasks are in fact highly structured and where language skills are involved, provide some form of cue. The *story retelling* task assesses working memory, auditory processing, and verbal production following a cue of listening to a structured story, and in that differs from the act of retrieving well-formed phonological words during spontaneous self-directed narrative. The *generative naming* task evaluates the ability to systematically

search for words according to specific rules, i.e. animal names and word starting with *m*, the *confrontation naming* task involves a picture, and *personal facts* are retrieved in response to a specific question (e.g. “when were you born?”); all of these tasks again differ from the act of retrieving well-formed phonological words during spontaneous self-directed narrative. Hinchliffe et al. (1998) posited that using single language measures, such as generative naming, are not adequate to provide information on higher-level language functioning. Hence, the correlations noted between the CLQT scores and the variable % Phonological Selection score must be considered with caution; at best, they indicate that there is a difference between linguistic performance during cued tasks in a structured context and spontaneous narrative production. No significant correlations were found between CLQT scores and linguistic measures from the POST-injury narrative, nor did participants explicitly share any thoughts about cognition when speaking about their PRE- or POST-injury self.

5.8 Linguistic Performance, SLC Themes, and Communicative Abilities (LCQ)

No significant correlations were found between any linguistic measure scores (PRE, POST or CHANGE), demographic variables and LCQ scores. However, a significant negative correlation was found between LCQ scores and the QOLIBRI Social Relations measure ($p = 0.059$). All participants reported experiencing some communication impairment on the LCQ test, but all scored just or well below the test median score of 75 ($Range = 45 - 72.50$; higher scores reflect worse perception of abilities). Taken together, the findings indicate that while all participants notice difficulties when talking to others in their daily lives, the better they perceive their

communicative abilities, the better they perceive their social interactions and relations to be. When asked during the interview to elaborate on whether they experience their speech, language, or communication to have changed after the acquired brain injury, all participants shared that the injury has affected their SLC and that they experience these changes as impactful. As earlier discussed, each participant was affected in at least one domain (speaking, grammar, communication with others, writing, or reading), and most stated they continued to rely on adaptive strategies to deal with residual difficulties.

5.9 Implications

5.9.1 Methodological. This study was able to conduct novel within-group analyses by taking advantage of the PRE- vs. POST-injury conditions. Additionally, the use of different non-linguistic assessment instruments to measure perceived functioning, feelings of grief, and communicative abilities allowed for a more nuanced understanding of how acquired brain injury affects the individual and his or her narrative skills. Taken together, the results suggest that mixed-methods approaches may be particularly suitable to investigate cognitive-linguistic communicative disorders following acquired brain injury.

5.9.2 Empirical. The absence of conclusive or informative findings between the CLQT and the linguistic measures used in this study is in line with results from other studies that have also failed to disentangle specific linguistic and cognitive variables contributing to cognitive-linguistic communication disorders following acquired brain injury (Body & Perkins, 2012; Marini, Galetto, et al., 2011). Nevertheless, this study is based on the broadly accepted view that cognitive impairments affect linguistic skills

(Angeleri et al., 2008, 2012; Barwood & Murdoch, 2013; Blyth et al., 2012; Body & Perkins, 2012; Lê, Coelho, Mozeiko, Krueger, et al., 2011), and the findings of this study suggest a relation exists between a person's cognitive capacity, their sense of loss, and how fast they speak about their PRE- vs. POST-injury self. Participants spoke more slowly during POST-injury narrative of self, with those participants with higher loss reducing their speech rates comparatively more. It is possible that increased cognitive demands to speak about the POST-injury self required a reduction in speech rate in order to maintain a similar level of lexical informativeness. However, the more articulate participants spoke about their POST-injury self, the more susceptible they appeared to feelings of loss, while time since injury did not correlate significantly with BIGI Loss scores.

5.9.3 Practical. This study has shown that neuro-typicals ought to be careful when interacting with people with subtle, or non-clinical, SLC challenges following acquired brain injury, as non-aphasic adults with acquired brain injury are at risk of not receiving the support, care, and interaction outcomes they seek and deserve. Their difficulties when interacting with others may be as unremarkable as a significant slowing of their speech rate when speaking about their POST-injury self, but the change in response from others are nevertheless noted by them.

However elusive SLC changes might be, knowing that a difficulty may exist can provide an individual attempting a communicative task or interaction in a real-world scenario with just the means to plan ahead accordingly. For example, if the person can declare upfront that articulating a POST-injury narrative of self, i.e. sharing how he is doing now or how she is viewing her self, is more challenging than talking about the past,

can give him or her better control over the outcome of the conversation.

5.10 Limitations

5.10.1 Sample. This study was designed to be exploratory. The inclusion criteria were selected for high-functioning participants, while the sample size was kept small to accommodate the data collection and manage the integration of data during the mixed-methods analysis. The results from the study are therefore not intended for generalization.

5.10.2 Methods. While the Spontaneous Narrative task provided a baseline for participants' linguistic performance, the method used to elicit that data differed in format from the semi-structured interview. Because of this, a comparison of PRE-injury and POST-injury linguistic performance during self-narrative to linguistic performance when speaking about a generic topic was not possible.

5.10.3 Comparison of results. This study used a novel approach not only in response to the literature review, but more importantly to address the posed research questions. And while the results suggest that the design and methods used have yielded relevant insights, the novelty of the particular approach makes it difficult to compare the findings to other previous studies. This could be perceived as a limitation, particularly with regards to the linguistic analysis of narrative elicited during the semi-structured interviews.

The non-linguistic instruments used in this study were selected based on a) whether they measured patient-reported outcomes (QOLIBRI, BIGI, and LCQ), and b) their appropriateness to be used by a non-clinician (CLQT). Although established in clinical practice, these instruments differ from the measures used in previous

experimental studies, making a direct comparison of results impossible.

5.10.4 Quality of research. A number of efforts were made to strengthen the trustworthiness of the qualitative aspects of this study: engagement over two sessions; rapport building; intra-coder checks; thick and detailed descriptions; member checking during the interview; researcher bracketing; and journaling for audit trail. Similarly, measures were taken to ensure rigour in the quantitative portions of the research, including data triangulation, transcription checks against recordings, intra-coder checks, as well as strict adherence to a script established to administer the four non-linguistic assessment instruments. However, additional steps could have been taken in the form of additional member checks during and following the thematic analysis, as well as using a second coder for establishing inter-coder reliability of the scoring of linguistic measures. Both these steps were omitted due to time constraints.

5.11 Future Research Directions

While this study was not designed to determine causality, the findings of higher feelings of loss correlating with slower speech rate and informative speech rate during POST-injury narrative of self call for additional research to determine the exact relation – and direction of such a relation – between cognitive capacity, loss, and PRE- vs. POST-injury self-narrative speech rates.

While time since injury was not significant in this study, future research on the linguistic performance following acquired brain injury could benefit from ongoing consideration of the “other” temporal dimension, i.e. the PRE- vs. POST-injury condition. A relevant follow-up inquiry would be whether individuals can draw on PRE-

injury experiences to complete a task, or not. SLC tasks that rely heavily on or occur in a POST-injury context may be broadly more difficult to complete. It would also be interesting to see if differences emerged in writing about the PRE- vs. POST-injury self, as well as to conduct a comparative study with individuals who experienced a traumatic event without a cognitive injury to further address the topic of loss. Additionally, a comparison of linguistic performance during PRE-injury and POST-injury self-narrative vs. when speaking about a generic topic could provide more precise insights into how acquired brain injury may affect individuals' linguistic performance. Finally, the results from this study warrant exploring whether acquired brain injury also affects PRE- vs. POST-injury speech rates when the individual speaks about concepts *related* to the self, such as a person's wellbeing and health now vs. before the injury.

Future research that is redirected from comparing non-aphasic people with acquired brain injuries with healthy control groups towards identifying how acquired brain injury affects those individuals in their day-to-day communicative interactions can potentially also offer (direct) ways to improve functional outcomes in this area and strengthening individuals' perceived quality of life. Aims to understand the potential connection between communicative effectiveness and functioning in social relations are imperative, especially given that long-term outcomes following brain injury are acknowledged to be tied deeply to the well-being and resilience of the whole family or related intimate relationships (Godwin et al., 2015).

With regards to using speech, language, and communication in rehab settings, writing (and reading) stood out as particularly relevant skills to the participants. In the context of the self-identified importance of (oral) speech, language, and communication

(SLC) skills overall along with writing during the recovery process, further research to attain insight into the behavioural implications of SLC changes following acquired brain injury, during rehab and beyond, is considered necessary. Any such research should also consider the matter of self-narrative.

Chapter 6 – Concluding Remarks

In this thesis, I set out to better understand how acquired brain injury affects narrative of self. Specifically, I wanted to answer three questions: 1) what can we learn from the narratives from non-aphasic adults about their PRE-injury and POST-injury self and their speech, language, and communication following acquired brain injury; 2) how does acquired brain injury affect the linguistic performance during spontaneous narrative about the PRE-injury vs. POST-injury self; and 3) how do insights from questions 1) and 2) link with psycho-social and cognitive aspects commonly associated with acquired brain injury?

Regardless of where the participants were at in their life, acquired brain injury impacted their sense of self – and demarked their self-narrative into a PRE-injury and POST-injury chapter. And although none of the participants had been clinically diagnosed with a language impairment, each one of them had experienced and continues to deal with changes in their speech, language, and communication needs and abilities POST-injury. These changes play out in private, as well as in interactions with others.

At the level of linguistic performance, acquired brain injury affected one feature of self-narrative in particular: participants' speech rates were slower when talking about their POST-injury self, compared to when speaking about the PRE-injury self. And while the exact interaction between speech rate, feelings of loss, and cognition remains to be more fully explored, the implication of this main finding is noteworthy: Re-creating a cohesive narrative of self is integral to the recovery from acquired brain injury, yet (even) for high-functioning adults, the exact act of speaking about their POST-injury self will

continue to involve an added demand for patience and persistence and differ from talking about the PRE-injury self.

The findings also demonstrate the interconnectedness between language as a cognitive-linguistic capacity and as a human behaviour used to create meaning. By looking at *self-narrative*, this study illustrates how language can be more wholly understood by research approaches that address in their purpose and methods that language is both, subjectively experienced and objectively measurable.

The impetus for this inquiry grew out of the conversations I have been privileged to have with adults who had sustained an acquired brain injury. Countless times, my clients have reminded me over the years that our ability to meaningfully connect with and interact in the world is essential to our sense of self. Through their trust, they have also given me a glimpse of the raw fragility of this very sense of self. Regardless of the otherwise extensive literature on the potentially substantial impacts of acquired brain injury, brain injury itself is often described as an invisible disability. Brain injury also bears a risk to render the individual voiceless, their narratives of self untold, or worse unheard. By using this thesis as an instrument to bring awareness to the topic of self-narrative following acquired brain injury, I above all else hope to make right by Tobias, whose words have remained with me when I summarized his thoughts back to him during our interview: “I wish I would have said that. That took [me] so, that took [me] so long to say what you just told me.”

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Appendix A

Background Questionnaire

Full name _____

Age _____

Age at BI _____

Date of BI or time since injury _____

Type of injury (MVA, illness, etc.) _____

Rehab/support past (OT, physio, SLP, CBT, etc.)

Rehab /support current _____

Current living situation (alone, with spouse/partner/room mate, with family)

Current occupation _____

Level of education completed at time of injury _____

Level of education completed since then _____

Appendix B

Level of Fatigue Questionnaire

Before we get started, I would like you to rate your level of fatigue on a scale of 1 to 4, with

- 1 = well rested and fully alert
- 2 = rested and alert
- 3 = getting tired
- 4 = very fatigued; I should be resting

Appendix C

Baseline Spontaneous Story Task

For this part, I will tell you four short stories about things that I have experienced. I'll ask you after each if you've ever experienced something similar and to tell me about it. There is no right or wrong answer to this; just talk freely about what comes to mind. I'm recording this so I have an example of your speech when you just talk to someone about something. Do you have any questions? Alright,

1 – “A few years ago, my father-in-law had a spare ticket and he took me to a hockey game in his hometown. It was the first game I got to see. There was so much going on. Have you ever been to a live sports event?” (if not, do you watch sports on TV?)

2 – “I have a dog. Last week he ran away in the woods and we had to look for him for hours. Another hiker found him and returned him to us. Have you ever had a pet that ran away?” (if not, have you had an adventure with a pet?)

3 – “When I was young, I was a girl guide. We got to go on many camping trips together, like long sleep-overs. Have you ever been on a sleep over as a kid?”

4 – “Once, I stood in the living room of my house at the time and was looking out the window. Then a car came chasing down the street, followed by several police cars. The car had lost a tire and came to a screeching halt right in front of my window. Have you ever seen something like that?”

Appendix D

Semi-Structured Interview Guide

Introduction

During our meeting today, I would like to learn more about how your brain injury may have affected you. I'm interested in your personal experiences, as individual as they may be. I have some questions that we can use to guide our conversation, but there are not right or wrong answers.

Questions

I'm trying to get a picture of how you view your self at present. Could you tell me a bit about you and describe to me who you are now, after your brain injury at this stage in your recovery?

Prompt: can you tell me more (about...)?

Can you talk about how you experience your self in your daily life now?

I'm also trying to understand how your life was before your injury. Could you describe to me who you were before your injury?

Can you talk a little about how you experienced your self in daily life before your injury?

While keeping in mind everything you've shared so far, I'd like to better understand the impact of brain injury on a person's sense of self.

How would you explain to someone who does not have a brain injury or who has very little understanding of brain injury in general, what can happen to someone who had an injury?

For example, could you describe whether there are some differences between how you view your self, as a person, now compared to how you viewed your self before your injury?

Some people find that after having a brain injury their speech, language and/or communication changed. How would you describe your speech, language and communication now?

Regarding the things that have changed in your speech, language and communication since your injury, how do you feel about them?

Is there anything you would like me to know about your self or your speech, language and communication that we didn't mention?

Appendix E

Quality of Life in Brain Injury Questionnaire (QOLIBRI)

QOLIBRI - QUALITY OF LIFE AFTER BRAIN INJURY

In the first part of this questionnaire we would like to know **how satisfied** you are with different aspects of your life since your brain injury. For each question please choose the answer which is closest to how you feel now (including the past week) and mark the box with an "X". If you have problems filling out the questionnaire, please ask for help.

PART 1

A. These questions are about your thinking abilities now (including the past week).

	Not at all	Slightly	Moderately	Quite	Very
1. How satisfied are you with your ability to concentrate, for example when reading or keeping track of a conversation?					
2. How satisfied are you with your ability to express yourself and understand others in a conversation?					
3. How satisfied are you with your ability to remember everyday things, for example where you have put things?					
4. How satisfied are you with your ability to plan and work out solutions to everyday practical problems, for example what to do when you lose your keys?					
5. How satisfied are you with your ability to make decisions?					
6. How satisfied are you with your ability to find your way around?					
7. How satisfied are you with your speed of thinking?					

B. These questions are about your emotions and view of yourself now (including the past week).

	Not at all	Slightly	Moderately	Quite	Very
1. How satisfied are you with your level of energy?					
2. How satisfied are you with your level of motivation to do things?					
3. How satisfied are you with your self-esteem, how valuable you feel?					
4. How satisfied are you with the way you look?					
5. How satisfied are you with what you have achieved since your brain injury?					
6. How satisfied are you with the way you perceive yourself?					
7. How satisfied are you with the way you see your future?					

C. These questions are about your independence and how you function in daily life now (including the past week).

	Not at all	Slightly	Moderately	Quite	Very
1. How satisfied are you with the extent of your independence from others?					
2. How satisfied are you with your ability to get out and about?					
3. How satisfied are you with your ability to carry out domestic activities, for example cooking or repairing things?					
4. How satisfied are you with your ability to run your personal finances?					
5. How satisfied are you with your participation in work or education?					
6. How satisfied are you with your participation in social and leisure activities, for example sports, hobbies, parties?					
7. How satisfied are you with the extent to which you are in charge of your own life?					

Appendix F

Brain Injury Grief Index (BIGI)

The Brain Injury Grief Inventory
Coetzer ©, Vaughan & Ruddle, 2003.
<p>This questionnaire is designed to help your clinician to know how you feel. Read each item below and underline the response which comes closest to how you have been feeling in the past week.</p> <p>If you find it difficult reading and filling in the items, you can ask someone else to read each question out to you.</p> <p>Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long, thought-out response.</p>

Name: _____	Date: _____
-------------	-------------

<p>Please rate each statement below as 'never', 'sometimes' or 'mostly'. Please underline one only.</p>

1. I try to avoid thinking and reminding myself about having had a brain injury
 Never Sometimes Mostly
2. I am able now to think through what the brain injury means to my life
 Never Sometimes Mostly
3. I feel angry that I had a brain injury
 Never Sometimes Mostly
4. Although life has changed for me, I feel able to get on with my life now
 Never Sometimes Mostly
5. I am upset by things that remind me about my injury, e.g. the anniversary
 Never Sometimes Mostly
6. I have stopped comparing how things were before my brain injury
 Never Sometimes Mostly
7. I have found myself longing for the time before my injury occurred
 Never Sometimes Mostly
8. I am less preoccupied with the effects of my brain injury now than I was before
 Never Sometimes Mostly

Appendix H

La Trobe Communication Questionnaire (LCQ)

LA TROBE COMMUNICATION QUESTIONNAIRE		by Jacinta Douglas, Christine Bracy & Pamela Snow	
LCQ-Self: Frequency and Change			
Name or ID #: _____	Age: _____	Gender: <u>M</u> <u>F</u>	Date: ____/____/____
Date of Birth: ____/____/____	Occupation: _____	Education: _____	

Instructions: The following questions ask you about aspects of your communication. For **every** question please circle the response which best answers the question, where:

1 = Never or Rarely 2 = Sometimes 3 = Often 4 = Usually or Always

The questions also ask you about **change** in these aspects of your communication since _____.

For **every** question please circle the response which best answers the question, where:

+ = happens More 0 = No change - = happens Less since _____.

Make sure you consider **all** the communication situations you meet in your daily life (e.g. family, social and work situations).

WHEN TALKING TO OTHERS DO YOU:	FREQUENCY				CHANGE		
	1	2	3	4	+	0	-
1. Leave out important details?	1	2	3	4	+	0	-
2. Use a lot of vague or empty words such as "you know what I mean" instead of the right word?	1	2	3	4	+	0	-
3. Go over and over the same ground in conversation?	1	2	3	4	+	0	-
4. Switch to a different topic of conversation too quickly?	1	2	3	4	+	0	-
5. Need a long time to think before answering the other person?	1	2	3	4	+	0	-
6. Find it hard to look at the other speaker?	1	2	3	4	+	0	-

Appendix I

Consent Form

Participant Consent Form

Narratives about the Pre- and Post-Injury Self after Brain Injury

As a Master's student, I am required to conduct research as part of the requirements for a degree in Linguistics. I will be supervised by Dr. Su Urbanczyk, Associate Professor in the Department of Linguistics at UVIC during this project. You may contact her by phone at [REDACTED] or by email at [REDACTED]. My contact information is Barbara Jenni, [REDACTED] / [REDACTED].

Funding

I have received a fellowship from the Social Sciences and Humanities Research Council of Canada, commonly known as SSHRC, to support my research project.

Purpose and Objectives

- To learn more about how people with a brain injury speak when they talk about themselves before the injury and themselves after the injury.
- To find out if there are differences in how people speak, what kind of sentences they use, how many words, etc. because brain injury can sometimes affect the communication and language skills of a person.
- To better understand how people with brain injury experience how brain injury has affected their speech, language, and communication.

Importance of this Research

- No one has looked at how subtle difficulties with language might affect a person in their ability to tell their story about their self after a brain injury.
- No one has looked into how following brain injury people (without aphasia) describe how brain injury affected their speech, language, and communication.

Participants Selection

- You are being asked to participate in this study because you have sustained a brain injury in the past.

What is involved

- You would meet twice with me in person at a location that you feel comfortable and where we could talk in confidence.
- First meeting (~1.5 hours):
 - Consent process;
 - Basic background questions and current living situation;
 - Mark answers on a questionnaire about your subjective quality of life experience (QOLIBRI);
 - Answer questions of a short questionnaire on cognitive and linguistic skills (I will write down most answers, but you will also make some drawings and mark answers on a sheet) (CLQT);
 - Circle your answers on a short questionnaire about the emotional impact the brain injury may have had (BIGI);
 - Circle your answers on a brief questionnaire about how you perceive your communication skills to be now (LCQ);
 - Your answers to the four questionnaires will be written down;
 - Your answers to these questionnaires will only be used for research purposes, and not for diagnostic or clinical purposes;
 - A brief talk about a topic of general interest;

- The brief talk at the end would be audio-recorded; I will later transcribe the recording.
- Second meeting (~1.5 hours):
 - A semi-structured interview, with questions on:
 - How would you describe has the brain injury affected your speech, language, and communication?
 - How would you describe has the brain injury affected how you talk about your self and who you are?
 - Can you talk a little bit about who you are now? And you who you were before your injury?
 - The interview would be audio-recorded;
 - I would later transcribe the recording.

Inconvenience

- Travel time and time to attend the two meetings

Risks

- Fatigue: if you become too tired, we can take a break or reschedule to complete the session at another time;
- Emotional discomfort talking about your experiences following TBI: if you become too upset, we can take a break or reschedule to complete the session at another time if you still want to continue. I will be available to debrief with you at the end of our meetings and refer you to appropriate resources if you would like. You can also bring along someone you trust to support you after the sessions.
- As far as I know, there are no other risks for you in participating in this project.

Benefits

This project will help document the subjective experience of those living with brain injury. It will also help better understand how subtle language

difficulties after brain injury can affect a person in their recovery from brain injury. This might result in more specific supports made available to those with brain injury.

Compensation

As a way to compensate you for any inconvenience related to your participation, you will be reimbursed for your travel expenses to meet with me, such as bus fare or parking fees. As a way to thank you for sharing your experiences with me, you will also receive a small cash gift of \$30.

If you consent to participate in this study, this form of compensation to you must not be coercive. It is unethical to provide undue compensation or inducements to research participants. If you would not participate if the compensation were not offered, then you should decline.

Voluntary Participation

I do not want you to feel any pressure to participate in this project. It is up to you to join or in this project or not. If you do decide to participate, you may withdraw at any time without any consequences or any explanation.

If you decide to withdraw, you can contact me or my supervisor, Dr. Su Urbanczyk. Your data will only be used in the project if you give me permission to do so. You will be reimbursed for any travel expenses you incurred to meet with me, and you will also receive your gift.

On-going Consent

At the beginning of the second meeting, I will ask you if you consent to continue to participate in the project. You can decide to withdraw then or at any time during the second meeting.

Anonymity

If you choose to participate in this project, I will use a pseudonym instead of your real name, and I will not disclose any identifying information about you in my writing and presentations.

Confidentiality

If you choose to participate in this project, I will ask you questions about your background and current living situation. Only I will have access to this information and any other data collected from you. All of your information will be stored on a password-protected computer only accessed by me. I will not disclose to anyone whether you decided to participate in the study or not, including anyone at the Victoria Brain Injury Society; however, since members of VBIS are aware of the study, they might conclude that you are a participant.

Dissemination of Results

I would use the results from my project to write my Master's thesis; my final thesis would be published online on the UVIC Space website and available to the public. I also plan to write articles on the project for academic journals and present the results at conferences. At any time during or after the project, you can request a copy of your personal data. Please note that none of the data are intended to make a diagnosis about you, your skills or abilities.

Disposal of Data

The data collected for this project would be stored electronically for five years after completion of the project, on my personal computer hard-drive, for possible future analysis in my Ph.D. project. After that time, the data would be destroyed.

Contacts

If you have any questions or concerns, before, during or after participating in this project, you can contact me, Barbara Jenni, the researcher of this project, by phone at [REDACTED] or via email at [REDACTED], or you can contact my supervisor, Dr. Su Urbanczyk, by phone at [REDACTED] or by email at [REDACTED].

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
----------------------------	------------------	-------------

Future Use of Data

I consent to the use of my data in future research: _____ (Participant to provide initials)

I **do not** consent to the use of my data in future research: _____
(Participant to provide initials)

I consent to be contacted in the event my data is requested for future research: _____ (Participant to provide initials)

Ongoing Consent

I consent to continue to participate in the study: _____
(Participant to provide initials at the beginning of the second meeting)

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix J

Community Resources

COMMUNITY RESOURCES

You may want to talk with someone about your experiences in this study or about your experience of having acquired a brain injury. Here are a few resources that you can access for support:

TO TALK ABOUT BRAIN INJURY

- CITIZENS' COUNSELLING
PHONE: 250-384-9934
- VICTORIA BRAIN INJURY SOCIETY
Units D & E, 830 PEMBROKE STREET, VICTORIA
PHONE: 250-598-9339 (OFFICE)
WWW.VBIS.CA
- VANCOUVER ISLAND CRISIS LINE:
PHONE: 1-888-494-3888
WWW.VICRISIS.CA

TO ASK QUESTIONS ABOUT THE STUDY

- UVIC HUMAN RESEARCH ETHICS OFFICE
250-472-4545
ethics@uvic.ca
- DR. SU URBANCZYK