Exploring Women's Visual Narratives of Brain Injury

by

Jacquelyn Roer
Bkin., University of Alberta, 2011

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We acknowledge and respect the lək̓ʷəŋən peoples on whose traditional territory the university stands and the Songhees, Esquimalt and W̱SÁNEĆ peoples whose historical relationships with the land continue to this day.

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Supervisory Committee

Dr. Nevin J. Harper, (School of Child and Youth Care)
Supervisor

Dr. Mandeep Kaur Mucina, (School of Child and Youth Care)

Departmental Member

Land Acknowledgment

I respectfully acknowledge with gratitude and humility that my research was conducted on the unceded traditional territories of the lək̓ʷəŋən peoples, the Songhees and Esquimalt nations and the W̱SÁNEĆ unceded traditional territories.

Abstract

This qualitative exploratory study centres on the identity, relationship and experiences of six women who have survived a brain injury, as told through their narratives and photographs. Situated in a critical feminist disability framework, and using a visual narrative methodology, this study utilized photo-voice inspired methods with semi-structured individual and focus-group interviews to combine visual and narrative dialogues. The focus of this research is on how the body plays a role in identity, relationships and being in the world after the challenge of surviving a brain injury. This research invites the reader into the intersections between public spaces, cultural norms and societal expectations, and the private worlds, perspectives and identities of the participants.

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Gratitude

With heartfelt gratitude, I wish to thank and acknowledge all those who have supported me in my journey to completing my masters’ thesis. Thank you to my supervisory committee, Dr. Nevin J. Harper, Dr. Mandeep Kaur Mucina for each of your diverse skill sets and conversations and care in supporting and guiding me through my thesis process. Thank you to Dr. Annalee Lepp for being part of my thesis defence and asking critical and thoughtful questions and insight. To my colleagues and loved ones, your support, kindness, and in the many ways you have shown up means the world to me: Amira, Alina, Julia, Michele, Jenn, Sylvia, Jessica, Lindsay, Jennifer, Nancy. A big cuddly thank you to all my four-legged friends who reminded me the importance of making time for sunshine, food, naps, walks and play: Kitten, Miss Kitty, Lola, Oscar, Brew, Brutus, and Gunther. Finally, thank you to all the *mentors* who have played a role big or small in supporting me along the way to arrive at this point in my story.

Dedication

To the participants who took part in this research journey with me and shared their time, experiences, and spirit, it was an absolute honour, thank you for sharing your gifts of insight and knowledge. To the many survivors who have been misunderstood, silenced, or ignored, I hope this research can add to bringing more support, communication and change in understanding the diverse experiences of brain injury.

Floating and moving along

“I just thought of this log as kind of like the world of a brain injury. You can just be floating on the water, and it can be really peaceful and then all of a sudden there’s a wave! and you don't know when it's going to come and how many days there are and maybe the next moment is quiet and your just kind of floating on it and you have no choice, and you just have to take it as it comes.” **Pearl**

Chapter 1: Introduction

According to Bach (2012) visual images are a way of sharing experiences of common or unique events through narratives to capture certain meanings. The image above was submitted by Pearl (participant) in which she describes the lived experience of Brain Injury (BI) as having to navigate the dynamic and unexpected changes that occur and to adapt along with them as best as one can. I wanted to begin with the starting point of my thesis research by centering the voice of participants (women) alongside their imagery that speak to their experiences of BI. In this chapter I introduce my thesis research and situate myself within the research. It also includes my rationale for this study and the frameworks I will draw from. It finishes with a summary outlining the rest of the chapters in my thesis.

Embodied Experience

My research is concerned with the *embodied experiences* of women who have survived a brain injury (BI) and particularly their relationships with their bodies, their socio-emotional and physical environments and gender as aspects of their identity. The term embodiment stems from the work of Merleau-Ponty (1962), a French philosopher who contributed significantly to phenomenology. Merleau-Ponty wrote about the lived body as a social agent, that all our experiences and perceptions are embodied. In other words, we cannot understand the world we live in, nor can we interact with each other or act on the environments around us, without our bodies (Chrisler & Johnston-Robledo, 2018). For this thesis, I will be exploring women's narratives of embodied identity after a BI and the role certain environments play. My analysis is informed by a critical feminist disability (CFD) framework which centers the concept of the body and identity as fluid while exploring the role of disability, gender, and other embodied differences over time and place (Garland-Thomson, 2001, 2002; Wendell, 1989).

Since we live, grow, work, and play in the world through our bodies, this means we experience our worlds through our senses and perceptions alongside constant feedback from our external worlds. As embodied beings, the intersections of both our social locations and physical, and socio-emotional, political environments further shape and influence our own understanding of ourselves and our identities. For BI survivors, lived experience in an altered body can dramatically shift their worldview, experiences and identity. Understanding embodied experiences creates the possibility of common ground for meaningful communication between health care professionals and survivors and opens the possibility for better client-centered rehabilitative programs for overall wellbeing.

Background of Research

Acquired brain injury (ABI) or Brain Injury (BI) is well recognized as a serious public health concern (International Brain Injury Association, IBIA, 2021). BI is documented as one of the leading causes of death and disability in children, youth, and adults under 40 years old in Canada (Haag et al., 2016). In Canada, there are 165,000 serious ABIs per year, not including concussions, military injuries, or unreported cases (Brain Injury Association of Canada, n.d.). A BI is a life altering experience at any age and for any survivor, and the trauma of this event is complex and multistoried. BI does not discriminate based on sex, gender identity, ethnicity, race, social economic status, age or ability. Yet, some of these social locations, visible or invisible, will dramatically affect the outcome for the survivor, their family, and communities (Villa et al., 2020).

Much of what is known about ABI/BI comes from preclinical and clinical studies of males, leaving large gaps in the understanding of women and sex or gender-related differences in epidemiology, prevention, neuroprotection, secondary injuries, and specific outcomes related to rehabilitation, timing, and effective therapies (Valera et al., 2021). The bulk of BI literature has also focused on understanding how masculinity affects recovery, postinjury life, and conceptions of self, while research that considers injured women's lived experiences is still relatively rare with only a few studies in the last decade (Fabricius et al., 2020). This means there is a lack of research concerning women and girls surviving BI related to their long-term outcomes and lived experiences. Additionally, the dominant perspectives in BI research have been that an injured person's cognitive and vulnerable status reduces their capacity to think abstractly and be objective, thus yielding a large volume of scholarly work that has sought out the perspectives of relatives and clinicians, rather than the perspectives of BI survivors themselves (Howes et al., 2005b).

A common theme in the aftermath of BI is a loss, change, or a disruption to one's identity. The concept of changes in identity has been used to refer to disruption in the continuity of a person's subjective sense of who they are post-injury and is a key aspect of BI (Villa et al., 2020). Research literature on BI and identity has primarily focused on the loss of self and one's identity; however, one of the many adjustments individuals with ABI must make is addressing the changes in the functioning and appearance of their body.

Situating Myself in the Research

Embarking on this research has been shaped and informed through my lived experiences as a white, cisgender female, a former youth in care and BI survivor alongside my collective academic and professional background in visual communications, exercise sciences, psychology and child and youth care. My worldview is based on the idea that we are not a single story nor aiming to arrive at a single identity or outcome; rather, that we are all complex and multistoried beings. That our identities and worldview are shaped by our own lived experiences, social locations, and our relationships with our physical, socio-cultural, and political environments. Throughout my life, I have been guided towards the pursuit of knowledge, experientially and collectively, in and outside of academic institutions. I believe that seeing the world through this lens allows me to come to the belief that there are multiple truths, theories, and ways of seeing and being in this world.

Growing up, I had two diverse interests: the visual arts and biological sciences. I have been fortunate to follow my pursuit of knowledge in both paths. My studies in visual communication and design, have helped inform my way of seeing the world in a visual language, what is visible and not and what might be left out of the picture. My interest in biological environments led me to the study of the first environment that we have come to know intimately: our bodies (Erikson,1968). This interest led me to complete my undergraduate degree in exercise sciences with a focus on adapted recreation (supporting individuals with diverse abilities or barriers to experiencing recreational activities in various environments).

Learning about the body from a physiological standpoint alongside studying the sociology of identity started to further increase my curiosity. At that time, however, most studies focused heavily on white male bodies in sport and their identity after retiring from sport at a relatively young age or due to injury. I remember wondering at certain points why my curriculum did not spend time focusing on diversity in sport and rehabilitation particularly of women and girls alongside intersections such as race, ability, sexuality, religion, and class.

In contrast to my theoretical studies, my practice-based courses granted me the opportunity to work alongside children, youth, and adults with neuro and physically diverse abilities as an activity facilitator. These opportunities allowed me to witness, in a limited timeframe and capacity, what these individuals *might* experience daily. In this role, I operated from a clinical lens focusing on observation and assessment while building relationships. While this experience planted a small seed in developing my lens, it did not paint the full picture of an individual's lived experience and narrative. At the time, I knew I wanted to move beyond a reductive notion of the body defined by Western medical diagnosis and physiology and focus on more holistic connections between body, mind and identity of a person. I wanted to understand the complex relationships between ourselves and our bodies, our identities, and what role our sociocultural, political, historical, and physical environments play in this.

While my academic and work experiences contributed to my curiosity of the body and the many relationships involved in shaping identities, I admittedly had very little knowledge of what a BI is and how this it affects the individual, their family and surrounding community. At that point in my life in 2012, I was unaware of the events that would substantially shift the trajectory of my worldview and experiences. Over the course of a year and a half, I survived the cumulative effects of multiple concussions from motor vehicle and workplace accidents. At the time, I was not aware of my concussion symptoms, what they meant and or the lingering post-concussive syndrome that I would experience following my accidents.

When I believed I was able to move forward in my life, away from the narrative of accidents and BI diagnosis, I decided to go back to school. I started taking psychology courses on the brain and behaviour at the University of Victoria and accepted a position as a community support worker for a local BI service program in January 2015. Working alongside BI survivors in a supportive capacity only further increased my curiosity about BI, diversity in symptoms, experiences, the recovery process and how it is acquired. I became more aware of the process of diagnosis, the identity of a disability and a BI, acquiring access to funding and the way in which it not only affects the survivor, but also their family, their community and the larger systems involved such as government, healthcare and other affiliated helping professionals.

The combination of my work, academic, and personal experiences led me to delve deeper into the research on BI. I embarked on this thesis topic for my graduate studies while reviewing current gaps in BI literature and reflecting on my professional and personal experience. With all my insights over the years I still had had many questions. Why was the dominant discourse often heard from the public and colleagues in other helping organizations the assumption that BI is primarily a male issue? Where is the BI research that focuses on women's experiences? Or what affect does a BI have on ones' lived experience of their body?" These unanswered questions felt important to examine and frame the focus of this research.

Purpose and Rationale

The purpose of this research is to explore the diverse experiences of six women who have survived a BI, and specifically exploring their embodied perceptions and narratives about their relationships with their bodies, identity, and the influence of certain environments. The rationale for this thesis is to gain an in-depth understanding of women's lived experience of self, identity, and body since their injury. My research goal is to add to the literature on women and BI, specifically, centering the voices of survivors in the research, how embodied experiences are related to identity, and the role that environments may play. Additionally, this research may also contribute to a better understanding of the value that rehabilitative and therapeutic programs that address body in relation to identity can have, as well as what environments may be more supportive for these programs. The following questions guide my research:

- How do the bodily/embodied experiences of BI survivors play a role in shaping their identity after brain injury?

- How might specific environments influence the experiences of women who survive a brain injury?

Thesis Outline

To help further contextualize the research pursued and the findings, Chapter 2 will focus on a review of the literature focusing on a general overview of what ABI/BI is, what is known, defining sex and gender, and examining the gaps in BI research. Chapter 2 will also introduce theories on the body and its' relationship to identity, embodiment, and critical feminist disability theory. Chapter 3 includes my theoretical framework, methodology, recruitment procedures, ethics, data collection and analysis methods, ethics, validity and reliability, and reflections on my reflexivity process. In Chapter 4, I present and include some of the dominant themes and sub themes emerging from participants narratives form photos, focus groups and one-on-one interviews. Finally, Chapter 5 provides a discussion of the findings and how it relates to the literature. This final chapter will also include practical implications of this research, limitations, recommendations for practice and further research including the voices of the participants.

Chapter 2: Literature Review

In this chapter I discuss literature regarding Brain Injury (BI), sex and gender, identity and the body and embodiment. I will start by defining what BI is, its aetiology, epidemiology and effects. The symptoms discussed below are generalized for the purpose of this brief literature review although every survivor of BI may have diverse and nuanced symptoms unique to their injury. This chapter will also include common affects that may occur to a survivor, as well as the important research trends emerging in BI regarding sex and gender. In addition, gaps in BI research and common misconceptions about survivors (stigmas, stereotypes) will be highlighted. I will also discuss what the literature presents about brain injury and identity, and embodiment.

Acquired Brain Injury: What is it?

Many terms in the research literature are used to describe BI. For this study, I will draw on the terms Acquired Brain Injury (ABI) or BI, which is a general umbrella term used in the biomedical sciences to categorize the types of brain injury: traumatic and non-traumatic (Haag et al., 2016). A traumatic BI is described in the literature as occurring from outside the body when there is an external force such as a fall, motor vehicle collision, or penetrating injury such as a concussion, while a non-traumatic BI is described as occurring inside the body, for example, an aneurysm, anoxia, stroke, or tumour (Kolakowsky-Hayner & Goldin, 2020).

BI's are often classified as mild, moderate, or severe. Regardless of injury classification, they may result in persistent physical, cognitive, mental, or emotional challenges and possible long-term or permanent disability (Kolakowsky-Hayner & Goldin, 2020). Regardless of classification, every BI is unique to the individual and may lead to one or more symptoms occurring at the same time or episodically.

Physical changes to the body’s movement or function may occur post BI. For instance, some may experience hemiplegia, a partial body paralysis, or apraxia, a condition that affects balance and coordination, creating significant challenges with bodily movements (Howes et al., 2005). Changes in physical areas may also affect speech and communication such as aphasia, word-finding abilities, word meanings, tone, timing, and affect. Vision related concerns such as eye tracking and eye movement might be affected, which also cause issues with reading and processing information, movement, light and noise and other sensory sensitivities (Berthold Lindstedt et al., 2019). Visual and sensory changes may affect a survivor’s ability to navigate different environments such as brightly lit or crowded grocery stores and these changes are also linked to increased mental fatigue, depression and anxiety.

Changes to cognition may also be present and create challenges with reading, writing, memory (short or long term), organization, planning, focusing and attention, task initiation, decision making, and/or cognitive fatigue (Pallesen, 2014). Other symptoms such as fatigue or changes in eating and sleeping patterns are also common with BI but are hard to predict when and for how long they will occur (Mollayeva et al., 2013). Struggles with mental health and emotional regulation are also noted in the research or further exacerbated if they were present pre-injury, with many individuals experiencing both anxiety and depressive symptoms regardless of injury severity (McIntyre et al., 2020). For instance, Kwako et al. (2011) report that anxiety and depression, suicidal ideation and PTSD all correlate with an ABI. In addition to these challenges, addictions may also be present or used as a coping mechanism for symptoms associated with BI.

Recovery and Life After Brain Injury

The transition from a BI event to recovery is affected by a plethora of factors, including environmental attitudes at the local, family, and societal levels and possible economic deprivation. In the aftermath of a BI, those who can access proper medical attention will often go through a process of rehabilitation and recovery. Phases of recovery generally include acute medical treatment to stabilize, as well as subsequent physical and cognitive rehabilitation. This process may include seeing various specialized rehabilitation professionals depending on injury classification and individual needs. Survivors frequently experience a loss of self or identity associated with their former professions, relationships, and physical capabilities, personal and social autonomy, self-confidence, and a 'sense of *self'* (Tasker, 2003).

Brain Injury and Identity

Identity and sense of self play a variety of roles for individuals with or without a BI. Identity enables one to have a sense of continuity in life, and to experience the world through the lens of a "me" that remains relatively constant through the flow of events and changes in life circumstances (Ylvisaker et al., 2008). A meta-analysis of BI research by Thomas et al. (2014) found that previous literature on BI and self-identity is unclear and complex. Their findings note that survivors reported *a felt sense of loss* or change in their identity, yet there is no universal definition or understanding of what self-identity is and this terminology has been used interchangeably with sense of self, self-concept, and self-identity. In a recent review of BI and identity literature, Villa et al. (2020) defines self-identity as encompassing our knowledge and understanding of ourselves, relationships and social roles, and self-evaluation or perceptions. They add that numerous factors contribute to a sense of self, including understanding our personality (relatively stable and consistent patterns of thinking, feeling, and behaving);

motivations (goals, preferences, and values); abilities, limitations, and potential; knowing the roles we play within social environments and social connections with others; and knowing our personal history.

Previous research has focused on the changes in identity after a BI, especially the loss of self. Individuals with a BI may experience problems with attention and focus, concentration, memory, problem solving, and emotional stability and in some cases, it is not always obvious depending on the severity of injury. For instance, Pallesen (2014) notes that over a prolonged period, survivors are challenged by a range of bodily, emotional, and mental changes to try to find their present sense of self. Gelech and Desjardins (2011) further specify losses to include: functional performance, behaviour, roles, status, relationships, employment as well as self-definitions, individual traits, emotional tendencies, and spiritual beliefs simultaneously. This is primarily based on a comparison between their lives before and after a BI, with the desire to return to their previous self, alongside the frustration at themselves and the slow rate of perceived recovery progress. Adding further complications and confusion to a survivor's relationship with self is their relationship with family members and peers. Specifically, when a BI survivor experiences invisible symptoms yet *appear to be highly functioning*, meaning they can maintain daily living activities and return to their previous self and roles, they may still experience emotional repercussions.

Significant research has discussed and theorized identity in the literature. Dominant theories looking at identity changes and/or a *loss of self* primarily focus on cognition and mental health or mental concepts. For instance, *ambiguous loss*, a theory termed by Boss (2010, 2016) is described as unclear loss that defies resolution or closure and creates prolonged confusion which blocks areas of coping within a family or support system and perpetuates the grief process.

Ambiguous loss manifests either as the physical absence but psychological presence of a loved one, such as with a service member missing in action, or as the psychological absence but physical presence of a family member, such as a family member with dementia (Kreutzer et al., 2016).

Boss (2010) further notes that in a society that places a focus on productivity as equating to success, not being able to find closure is criticized as malingering. For BI survivors, it may also feel as though the inability to resolve the loss is itself a personal failure. While this is false, dominant discourse in Western society places higher value on having solutions and tangible outcomes, and this leaves many survivors (and their communities) with the notion of having to pretend everything is fine and move on. Thus, a BI, regardless of severity, can cause major life changes, with losses affecting survivors, their families, and the surrounding community (Masel & DeWitt, 2010).

Public Perceptions, Educators and Professional Knowledge

Myths and misconceptions about BIs lead survivors to doubt themselves or not share what might be happening to them, fearing stigma, isolation from friends and family, and not being believed, which can influence their perceptions of self and identity. It is imperative to contextualize this process thus including common public perceptions and knowledge, to better appreciate what a survivor may internalize, as well as what is known about BI. McKinlay et al. (2011) note that the terminology used in relation to BI is varied and contradictory. This lack of consistency regarding definition and criteria creates confusion for the public regarding what the different terms mean and what steps to take following an injury, what symptoms to be concerned about and when to seek medical attention. Public uncertainty or lack of knowledge about specific symptoms related to BI can result in individuals not accessing appropriate healthcare.

A systematic review by Ralph and Derbyshire (2013) analyzed twenty studies (sampled from the UK, US, Canada, and New Zealand) on the public's knowledge and attitudes towards BI survivors between 1988-2011. They highlighted that while public knowledge of BI, particularly of mild BI, has grown over the years, common misconceptions about BI continue to be prevalent. One misconception is that the speed of recovery is completely dependent on the survivors' efforts. In addition, the expectation is that all survivors could achieve complete recovery, regardless of injury severity. This has significant implications for those who continue to experience persistent difficulties post-injury, given they are likely to be perceived as not trying hard enough or lazy due to the public's misunderstanding of recovery. Further, the authors noted that these findings also correlated with stigma from the public, meaning that individuals who hold these negative beliefs and stereotypes are likely to display prejudice and discrimination towards BI survivors (Ralph & Derbyshire, 2013).

In addition to public perceptions and misconceptions, little research has been undertaken to identify and validate clinical procedures specifically designed to assist survivors with identity rehabilitative processes. Ylvisaker et al. (2008) suggest that certain language used by therapists, focusing mostly on an individual's impairments or deficits, tends to further contribute to a survivors' narrative regarding self and identity. This may lead helping professionals to unintentionally influence survivors' identity post-injury that undermines the rehabilitation and recovery outcomes they are intending to achieve. The loss of self remains a dominant discourse in BI rehabilitation practice and study, implying an overwhelming loss of continuity in personhood and the disruption of a previous perception of self. Yet uniqueness, intersubjectivity and contextual factors are often lost in the medical narratives that may overshadow subjective accounts and homogenize and simplify post-injury experiences (Gelech & Desjardins, 2011).

Given the uncertain nature of a BI and recovery along with public perceptions and accessible and appropriate healthcare services, it is no surprise the combination of these pose challenges to a survivor's overall quality of life. The ability to be perceived as *normal* or go back to pre-injury activities is also related to quality of life, identity, and the ability to reframe a new *narrative of self* (Alston et al., 2012). This might indicate why survivors may resist claiming the identity of a BI or disability due to the oppressive and stigmatizing associations often tied with static, socially constructed ideologies and a lack of understanding and awareness from others, specifically public perceptions (Garland-Thomson, 2002).

Research Gaps: Sex, Gender, and Brain Injury

BI is a condition that is has been highly gendered in the research literature (Colantonio, 2015). Sex refers to a set of biological attributes in humans and animals that are dependent on chromosomes, hormone levels and reproductive anatomy. Gender refers to behavioural expressions, socially constructed roles, and identities (Mollayeva et al., 2018). Gender is a socially constructed framework, and it speaks to what it is to perform as *female or male* at a particular point in time and in a particular context or place. The way women and men perform gender is often related to heteronormative and culturally constructed ways of being and performing gender (Alston et al., 2012). While the term gender has since become more fluid and is starting to be reflected in some research literature, the socially constructed binaries of men and women are still current in research sectors and in many parts of the world.

Historically, males are believed to have higher rates of BI due to certain perceptions about *masculine* gender, such as being involved in more risk-associated activities like extreme sports, physical labour such as construction work, military service, and motor vehicle accidents. Women are generally assumed to be more susceptible to BI due to physical violence in interpersonal relationships, sports injuries, motor vehicle accidents and workplace incidents (Colantonio, 2015; Mollayeva et al., 2018). These research disparities may also be attributed to differences in beliefs or biases around gender norms and role expectations and social cultural discourses. This is supported by the higher rates of male athletes on a measure of conformity to dominant ideas of masculine norms, specifically risk-taking.

While previous research has noted that the overall rate of BI has been higher in men than in women, a ratio of 2:1, the overall frequency of injury means that many women and girls are also injured annually. This is because BI studies are rarely stratified by sex (Colantonio, 2016) or the terms sex and gender are often conflated with potentially unexplored sex and gender factors skewing the data in either direction (Fabricius et al., 2020; Mollayeva et al., 2018). For instance, hospitalization rates for BI, particularly traumatic BIs are problematic, and highly susceptible to underestimation, as not all individuals will present symptoms of a BI at a hospital. Additionally, a survivor’s care-seeking behaviour might be influenced by the proximity and accessibility of available services, as well as their own knowledge and awareness of BI symptoms.

If the epidemiological data only captures the injuries that lead to hospitalization, which are often the most severe, men are likely to be overrepresented owing to their increased propensity to sustain severe BIs (Mollayeva et al., 2018). In comparison, other research has reported that girls and women who display more *masculine gender roles* are more prone to risk-taking behaviours and may continue playing in sports activities despite symptoms (Mollayeva et al., 2018).

Overall, it is still unclear from the research whether the difference in seeking medical attention is higher in women after injury due to disparities in symptoms and behaviours, or the influence of socially constructed gender roles. From a physiological standpoint, Mollayeva et al.

(2018) argue that women may sustain mild concussions more often than men, experience more neurological challenges, and display a different pattern of post-injury symptoms as well as having a delayed recovery response. For example, the reason for the higher incidence in concussion rates in females might be due to differences in head and neck physiology and stability, as well as differences in hormone levels and hormone response rates (Colantonio, 2016).

In summary, sex and gender-based research is critically important to consider in all areas of the public health system, including research, programs, and policies. Understanding the relationships between sex, gender, and the other social determinants of health and how they influence health opportunities, accessibilities, risks, and outcomes is critical to achieving optimal health and well-being for all individuals (Colantonio, 2015).

Brain Injury and Intimate Partner Violence

A significant research gap gaining more attention in the last five years are BI's occurring from Intimate Partner Violence (IPV) a term commonly used in Canada, or Domestic Violence (DV) in the United States. In Canada, IPV affects 1 in 4 women over their lifetime and international estimates are higher (Colantonio, 2020). A recent review by Haag et al. (2019) highlighted that BI is a serious consequence of IPV and often goes unnoticed (by healthcare providers or survivors) or is misdiagnosed. IPV includes physical, sexual, and emotional harm, and controlling behaviors, inflicted by an intimate partner (World Health Organization, 2021). IPV- BI occurs from a blow to the head, strangulation or choking. These injuries have a debilitating long-term effect on a survivor's overall function and independence and may include higher levels of depression, anxiety, worry, and post-traumatic stress (Campbell et al., 2018). Post-injury symptoms may present as several other physical, social, and mental health issues and prevent survivors from receiving appropriate access to rehabilitation and health support from professionals (Kwako et al., 2011). When survivors are not able to access appropriate supports, this is also evident in other sectors of BI. There is a greater chance of homelessness or unstable housing, substance abuse and addiction, and or involvement in the criminal justice system. Valera et al. (2021) affirm that research and guidance for professionals working with IPV- BI is still limited, despite the call throughout the literature for increased awareness of this population across diverse fields of practice and education.

The Missing Voices in BI Research

Another gap in BI literature is research that centers the voices of women who are navigating multiple intersections of vulnerability. For instance, research involving the voices of Indigenous (First Nations, Inuit and Metis) women in Canada exposed to IPV-BI or who have experienced stroke (Heart & Stroke, 2018) is still lacking. In Haag et al.'s (2019) research seeking to address IPV-BI service gaps within Indigenous communities, participants spoke of the lack of culturally sensitive care and specific systemic barriers to service provision, including adequate communication technology and a lack of shelters in remote and rural communities.

There is a need for increased education and awareness to address the serious health consequences for IPV-BI survivors among direct service providers such as health care professionals, legal professionals, child protection agencies, and Indigenous and settler government bodies, as well as survivors, families, and communities. Haag et al.'s (2019) research also emphasized the need to explore the complexity of IPV-BI in Indigenous communities and focus on developing culturally sensitive and community-based supports in partnership or led by Indigenous communities. Furthermore, service design and delivery require critical considerations of the complexity of marginalization, shame, stigma, racism and the ongoing colonial violence affecting Indigenous women and girls and communities (Baumann et al., 2019; Colantonio, 2020).

An emergency summit report by Toccalino et al. (2022) touched on several key concerns needing to be addressed regarding IPV-BI in Canada and the lack of inquiry to date considering intersections such as gender, race, ability, socio economic status and geographical locations. This report highlighted that woman with other disabilities face an even greater risk of experiencing IPV-BI. Women and transgender women who engage in sex work are also at a greater risk for IPV-BI, another understudied area (Baumann et al., 2019). Additionally, there is a lack of research on IPV-BI in immigrant and refugee communities, as well as the lack of culturally safe and accessible healthcare in rural and remote communities.

When discussing the missing voices in BI research, considerations of systemic racism experienced by Black and Indigenous women within the healthcare system and by service providers needs to be addressed (Omar et al., 2021; Toccalino et al., 2022). Women who identify as Black, Indigenous, women of colour, immigrants or refugees, are often not seen, believed or are dismissed, discouraging them from seeking care. Racist assumptions by service providers create further barriers to access and contribute to negative experiences with the healthcare system. Furthermore, in some cases, survivors’ symptoms of BI might be weaponized against them to reinforce systemic racism further impacting a survivors’ access to care; for example, assuming intoxication when a survivor presents with the symptoms of a BI.

In Omar et al.’s (2021) research, based in the US, the authors note that one of the main challenges and limitations of rehabilitation and care pathways is a one-size-fits-all approach that overlooks intersecting vulnerabilities based on race, racialization, racism, disability, gender, culture, and socioeconomic disparities. Noting that previous reviews to date have not challenged or explicitly recognized the pervasive nature of structural violence in BI care. Toccalino et al. (2022) and Omar et al. (2021) both emphasized the need for trauma-informed, anti-racist, and equitable care systems. Toccalino et al. (2022) and Omar et al. (2021) also highlight the barriers for survivors accessing care in the current system including: retraumatizing experiences, systemic racism and discrimination, and navigating financial or bureaucratic hurdles.

Research on the effects of BI on women's health, long term outcomes and the complexity of intersecting vulnerabilities is still limited. Women with disabilities often lack sufficient access to medical care compared to women without a disability. In these instances, women have reported not being believed or taken seriously about their symptoms or concerns by medical professionals (Colantonio et al., 2010). In other clinical settings, healthcare professionals have been shown to have a diversity in preferences regarding patient care, decision-making on preventive, rehabilitative therapies and or special areas and training, leading to gaps in consistent care for survivors. Such differences have the potential to influence the trajectories, outcomes and needs of survivors and require further investigation and knowledge translation across the healthcare, social services, and other helping professions (Mollayeva et al., 2018).

The invisibility of disability itself, such as a BI, often decreases the perceived impact of injury on overall quality of life or the seriousness of symptoms. When symptoms of a BI are not visibly obvious, or linked to sufficient research practices, survivors are often misunderstood or not believed. When individuals, in this case women, are not seen, heard, or believed to have a disability or illness, it may be more difficult for them to secure support and accommodation required to function in their day to-day lives (Davis, 2005). Further inquiry on the lived experience of BI will aid in developing relevant recovery planning, rehabilitation practices and supportive research.

Women, Brain Injury and Identity

Mukherjee et al. (2003) suggests that the long-term psychosocial outcomes for women include those directly related to their injury and the socio-cultural experience of living as a woman with a BI, as well as the *loss of self*. A loss of self, in this case, means a loss of identity or clear understanding of who they are as an individual after surviving a BI. For instance, losses might be experienced in areas such as the perception of control over one's life, or a loss of having a sense of time or bodily control and awareness. For many survivors, some of the most enduring changes after a BI relate to their subjective experience of who they are and their identity (Carroll & Coetzer, 2011).

Women and girls who have survived a BI are more likely to be affected differently due to societal, gender and power differentials and because their bodies are the site of cultural and socially sanctioned behaviour (Alston et al., 2012). For example, physical appearance is often perceived as important for women because of the heavy societal importance placed on the ideal female body. This *ideal body image* represents youth, beauty, vigour, ability and health and there is likely to be a resulting increase in insecurity and anxiety, as well as decreased self-esteem among those who differ from this ideal (Howes et al., 2005a).

A BI can dramatically change the relationship with one’s identity and with their body. Women who have survived a BI, whose bodies do not respond as they did before their injury, may feel that their bodies have betrayed them. One of the many adjustments after a BI is addressing the changes in the functioning and appearance of their body. Howes et al. (2005a) research on female survivors and their body image, suggested that internalized feelings related to appearance and overall health increased feelings of depression and anxiety, consequently decreasing their self-esteem.

Haag et al. (2016) interviewed female survivors of BI. Some women discussed their struggles with fulfilling caregiving (unpaid labour) and other domestic tasks that are often assumed as women's roles. Survivors reported having difficulties in their daily lives because of fluctuations in cognition, memory, mood, attention span, overall energy levels and fatigue, and heightened anxiety, further impacting their ability to perform meaningful activities many years post injury. Overall, they expressed feeling overwhelming stress and frustration trying to fulfill complex tasks involved in these caregiving and domestic roles, along with balancing their own self-care.

Alston et al. (2012) examined gender bias which can further impede the recovery process for women. For instance, power imbalances between men and women are key features of gender that affect how women negotiate the world post-injury. Women may often navigate health concerns from a subordinate social position which undermines their own self-advocacy and credibility. Additionally, navigating power imbalances in relationships becomes even more difficult post injury as survivors must deal with injury-related challenges.

The Body, Identity and Embodiment

While much has been written on the theory of identity, qualitative studies are limited, and very little is known about how the body is salient to identity. Discovering the diversity of the body's salience to people's identities versus focusing on identity problems in relation to negative perspectives about the body may uncover new ways to understand body, identity and overall well-being (Kling et al., 2018). The concept of embodiment supports the understanding of the interconnectedness of the body and identity. Goldberg (2011) elaborates on Merleau-Ponty’s

(1962) view of embodiment by describing that, as the core principle of human existence, the body is uniquely both subject (the lived experience) and object (the physical entity that admits to objective assessment and scientific examination) at the same time. In other words, embodiment encompasses a holistic view of a person by including both subjective and objective notions of the body and experience. Goldberg (2011) also notes that this framework is ideal to better understand the experience of injury and illness, which are often associated with a long-term shift or altered embodiment.

Lived embodiment does not only involve subjective and individual experiences of one's body, but also the meaning of a shared world. This means that embodied experience cannot be isolated from an external view of one's body. Thus, understanding lived experience must not only delve into the way one's body is experienced internally, but simultaneously looks at how it manifests itself in a world shared with others (Slatman, 2014).

Historically, in the Western medical model of healthcare, there has been a suggestion of mind-body separation. This approach to the body was advocated by philosopher Rene Descartes in his theory of Cartesian dualism where subjective and objective experiences were separate (Goldberg, 2011). While the prevalence of this concept is apparent in the division of health and helping professions with either the body or the mind, the theory of mind-body dualism has been mostly rejected. However, this view of the body as a biological entity separate from the self is still apparent in Western medical and healthcare frameworks. Although medical practice is increasingly engaging in more holistic person-centred care, embodiment does not yet feature in theoretical social determinant models of health (Slatman, 2014). Rather, the body is still represented within education, practice and literature separated into dis-embodied compartments and systems versus holistic interactions. Yet our bodies play a significant part in our experiences of ourselves and worlds.

While Merleau-Ponty's theories on embodiment are well known, they have also been criticized by feminist scholars for failing to pay attention to crucial gender, race and disability concerns and instead points to a universalized and generalizability of lived experience. Weiss (2015) highlights these critiques, but also argues that Merleau-Ponty's insistence that our bodies, not our consciousnesses, are how we directly engage with the world, encourages attentiveness to how an individual's or group's gender, race and bodily abilities differentially affect how their bodies are responded to by other bodies, and in doing so, directly influences the meaning of their (inter) actions within that situation.

More recently, embodiment has been explored in relation to several other chronic health conditions. It reveals that physical illnesses, pain, discomforts, disabilities, or chronic conditions shift a person's perception of their world, and their possibilities of engagement in the world (Slatman, 2014). The unity of body and self is thought to be frequently disrupted in other chronic health conditions as has been described after a BI, such as stroke, traumatic BI and other chronic illnesses that may lead to permanent disability. Drawing from the lived experiences of individuals with chronic illnesses, Charmaz (1995) suggests that bodily alienation or dis-embodiment caused by an illness or injury disrupts a person's assumptions of the relationship between their body and self, therefore disrupting their sense of wholeness or sense of self.

Most studies exploring the embodied experience of BI and other health conditions have been conducted by scholars in social psychology or health philosophy (Timothy, 2015). Research looking at embodiment, identity, and the body post injury has focused on female survivors of stroke. For instance, Kitzmüller et al. (2013) sought to understand the long-term effects and significance of bodily changes on the perception of self after stroke. In their research, 13 female stroke survivors perceived their bodies as fragile, unfamiliar and unreliable, tending to objectify them. Additionally, survivors with invisible symptoms such as fatigue, disorientation and speech difficulties, criticized the public’s hegemonic understanding that only visible disabilities are worth taking seriously.

Similarly, Kvigne and Kirkevold (2003) interviewed women who survived stroke and they described their bodies as strange, unreliable and embarrassing, and that regaining familiarity with the body takes time. The authors also explored social expectations and femininity, arguing that this experience may be more pronounced for women because the appearance of the body may be culturally more significant. These studies support the concept that embodied experiences of health conditions are deeply connected to self-identity and social relationships.

Biology and the environment are in a constant dynamic interaction over the human lifespan, as reflected in the post-injury experiences of individuals (Mollayeva et al., 2018). Zitzelsberger (2005) argues that relationships between cultural representations of bodies and people's experiences are fundamental to understanding the conditions that shape the lives of people with differences in Western societies. Consequently, meanings attached to bodies and their lived experience occur in interactions with social and built environments in everyday life.

Bodily ability has been shown to influence individuals' perceptions of the world around them and has been discussed in previous studies of BI. Kitzmüller et al. (2013) suggest that knowledge of one's own body and shared engagement in the world opens the possibility to understand other human and non-human beings. This could mean that an awareness of the interconnectedness between the world, body and self would contribute to a better understanding of how bodily or embodied experiences post injury also influence identity and sense of self.

Having a better understanding of embodied experience, especially post injury may help in creating more accessible recovery and rehabilitative services that consider the environment and specific needs to increase well-being and positive long-term outcomes for women.

Chapter 3: Methodology

This chapter provides an overview of my research methodology. I utilized a visual-based narrative methodology situated in a Critical Feminist Disability (CFD) framework to explore women's experiences of Brain Injury (BI). More specifically, I approached this study with a particular interest in participant's relationships with their bodies (embodied experience) and the influence of certain *environments* on them. My use of the term environment encompasses both physical such as natural or built and socio-cultural such as attitudes, beliefs or people. I will discuss in detail my theoretical framework, methodology, data collection methods, participant recruitment and an outline of my research process and procedures. Last, I conclude with a brief discussion of ethical considerations, validity and reliability, reflections on my reflexivity and process.

Theoretical Framework

My research draws from a CFD framework using a qualitative methodology to offer rich and diverse descriptions of the lived experiences of participants. Over the last two decades, CFD studies emerged from feminist philosophy, disability studies and the critical social sciences. The merging of these theories has opened a framework that offers a space for new perspectives on the intricate relations among bodies, identities and worlds. When thinking about the body, a specific focus of CFD is feminist material disability theory, which centers on embodied experience in relation to the social and material world. This framework seeks to recognize the complexity of deeply rooted social practices, expectations and discourses in shaping and defining our bodies and their capacities. Moreover, it conceptualizes the body as dynamic, not as something that *is* but as something that is always in the process of becoming (Rice et al., 2021).

According to Zitzelsberger (2005), a CFD perspective articulates the role of disability, gender, and other embodied differences in a women's corporeality. Garland-Thomson (2002) expands on this perspective adding that it addresses concerns such as: socially constructed norms of behaviour, gender, the lived body (bodily/embodied), the complexities of appearance and the medicalized body, sexuality and the social constructions of identity. Disability, like gender, is a social construction that pervades all aspects of culture: it structures institutions and systems, social identities, cultural practices, political positions, power dynamics and the shared human experience of embodiment (Garland-Thomson, 2002; Wendell, 1989). This framework plays an important role in understanding the social construction of gender, disability and identity as well as analyzing the dominant narratives along these lines that might be revealed in the data analysis.

Visual-based Narrative Methodology

Visual-based narrative methodology originates from qualitative narrative inquiry which is rooted in history, literature, and sociolinguistics, and traditionally has assumed that speaking and writing are forms of meaning making (Padgett, 2008). Narrative inquiry is based on a relational framework and is the study of experience as story (narrative) and a way of thinking about experiences (Clandinin, 2007). John Dewey's (1958) philosophy of experience is often cited as the theoretical premise of narrative inquiry and describes experience as relational, temporal and situational. Thus, it is only when experience is reflected on, and re-storied, that it can potentially reveal identity constructions and one can derive meaning, or further meanings, from engaging in this inquiry (Lindsay & Schwind, 2016). The essence of a narrative approach is to promote awareness, insight, and give meaning to a particular issue that has not been represented in a similar way at a certain point in time (Kuntz, 2010). In addition, highlighting that story is how humans come to know, understand and make meaning in their social worlds (Tuck & McKenzie, 2015).

A visual-based narrative inquiry incorporates intention, reflection and active processes in which researchers and participants explore and make meaning of experiences, both visually and narratively (Bach, 2012; Hunter, 2017). Incorporating visual images as part of the narrative, as described by Lorenz (2010) is a powerful tool for understanding and illuminating the lived human experience, while attempting to decenter power differences between researcher and participants. Using photographs in qualitative research also promotes creativity in individuals by stimulating critical thinking and reflection with images (Simmonds et al., 2015).

I specifically chose to use a visual-narrative methodology to experiment with alternative ways to engage participants in a deeper conversation and meaning making processes through what can be said or not said with visual images (Given, 2008). Overall, I selected a visual arts-based method to generate conversation with the hope it would also offer agency and autonomy for participants as to what and how they wanted to share and make meaning of their worlds in relation to my research focus.

A visual-based narrative inquiry is valuable when conducting gender-based research because it focuses on narratives as experiences lived and told (Simmonds et al., 2015). It creates space for the meaning making process and offers an opportunity for shared knowledge of multiple identities, perceptions of self and physical bodies through conversation and use of visual images. Bach (2012) emphasizes that experiences are always our own but shaped by the social, cultural and institutional narratives in which individuals are embedded. Participants tell stories of what matters to them and for the researcher, it is an invitation to look, listen and write about the story’s participants tell. From a relational perspective, having conversations about the photographs taken connects the psychological and physical realities for both the participants and the researcher (Bach, 2012). In this regard, the knowledge and meanings that emerged throughout this research process was co-constructed by the researcher and participants during a certain time and place.

Data Collection Methods and Process

For my data collection methods, I used semi-structured focus groups and one-on-one interviews integrating visual (photos), spoken and written narratives as well as my own reflective journaling and note-taking processes. Photovoice is a method that was originally developed by Caroline Wang and is often associated with community and Participatory Action Research (PAR) methodologies, although more recently been used in narrative and other qualitative research methods (Bach, 2012; Simmonds et al., 2015).

All focus groups and interviews were audio recorded for data collection and then transcribed for analysis. Focus groups and interviews are useful for exploratory research when little is known about the topic of interest and to gain a better understanding of the experiences and beliefs expressed by the participants (Berg & Lune, 2017; Pinnegar & Daynes, 2007). My reason for giving the choice of participating in a focus group or one-on one interview was to acknowledge that some participants might be more comfortable one-on-one than being in a group setting. This ensured that participants were comfortable in sharing their experiences and images.

I chose a photovoice-inspired activity as a data collection method with the hope that it would allow participants to focus and engage in a creative medium to express their personal experiences. In addition, to create a space for further dialogue and explore the connection to specific images that reflect their unique thoughts around identity, their bodies and worldview

(Butler-Kisber, 2010). This method included a combination of photo-taking and interviews/focus groups and/or writings about the content of the images used (Dassah et al., 2017).

Participant Recruitment

Recruitment of participants took place following approval from the Human Research Ethics Board (HERB) at UVIC. Purposeful sampling of potential participants was done by the community coordinator/BI advocate at a local community BI services program and recruitment lists were derived based on participant criteria, and who might be a potential *good fit* for the research study. A good fit meaning that they would fit the research criteria: having at least one year of recovery post injury (formally diagnosed or discovered), able to provide consent for themselves, feel comfortable carrying on conversations for at least one to two hours, and have been involved actively in the community (e.g., volunteer, work, social engagements). For further context, most clients involved with the community BI services enter the program with mild to moderate BI's and participate in activities of daily living independently or semi-independently depending on symptoms and recovery states. Clients also engage in one-on-one or group programs that are two hours in duration, volunteer and/or work in the community.

This sampling involved making two lists of eight women, with an age range from 28-55, who had acquired a BI in adolescence or as an adult. Once the lists had been discussed and decided, all potential participants were then sent an email invitation by the community coordinator/BI advocate (see Appendix A) that outlines the purposes of the research, the activities involved, time required and location of focus groups/one-on-one interviews. Initially, the first list of eight potential participants all expressed interest in the research study, but due to the timing of the focus groups commencement, two were unable to participate.

Six participants were able to generously give of their time and energy, take photographs and share their experiences. This included two women who engaged in the one-on-one interview sessions and four who took part in focus groups. Once a participant responded to the invite, I followed up with a more detailed description of the research aims and thorough explanation of the study's voluntary consent information (see Appendices B and C). I informed each participant that they were welcome to ask questions regarding the consent form before making any commitments as well as reviewing it again during the first focus group and interview sessions. Participants were given the option to use a pseudonym to protect their identity and anonymity in the research. Ongoing consent was also discussed to ensure that participants knew they could stop at any time with no questions asked.

Research Process

To ensure transparency and authenticity, I have outlined the procedural details of my research below in the gathering and interpreting of participant narratives; a crucial component of ensuring rigor (Padgett, 2008). My data collection methods and procedures included three semi-structured focus groups that integrated visual imagery from participants and their narratives using a photovoice-inspired approach as a data collection method.

Focus Groups

The purpose of choosing three focus groups and/or three interviews for my research was to create community and rapport among participants and myself, and to ensure enough time to process and reflect on the activity. All focus groups were held in Victoria, British Columbia. The focus groups involved three meetings, each one-two hours in length over the span of a month, all were audio recorded and transcribed for data collection.

During the first focus group, I discussed the purpose of my research and the data collection activities involved. I reviewed the consent, confidentiality, and voluntary participation for transparency and understanding, and in case there were any questions. I incorporated a short activity (see photo below) that involved participants choosing an image to answer the question: what image represents you right now?

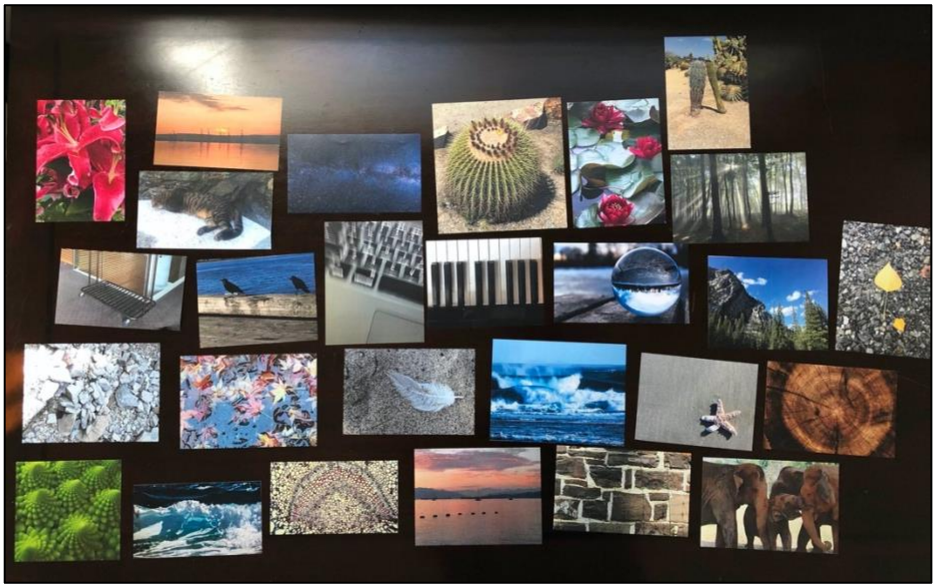


Figure 1. Mini photo activity (Source: Jacquelyn, 2019).

I used this activity to introduce participants to the idea of taking photos and reflecting on their own meanings. They were asked to complete this before the next focus group/interviews, two weeks away. I discussed using a photo release form that would need to be signed if they wanted to take a photo of a person/group of people (see Appendix D). I also reviewed the guiding questions (see Appendix E) with participants to make sure they understood the photovoice activity. Participants were asked to choose 3-6 images that reflected their experiences based on the guiding questions. Participants chose to submit their images via email as it was most convenient for them. Additionally, we decided it would be best to showcase them on a larger screen and discuss them at the next focus group. One-on-one participants discussed their chosen images as I displayed them on my laptop.

The second focus group involved participants sharing and speaking about their images and experiences in connection to body and environments and how it might influence identity and societal influences. In this focus group, I uploaded the photos that participants sent via email during the week and displayed them on a large monitor. Participants spoke about each of their photos based on what it represented for them and how it fit with the guiding questions provided. The final focus group was a follow-up to the photovoice activity and a chance for reflections and feedback on the process of sharing images and stories of experience for research and alongside other survivors. This session also included gathering recommendations.

Interviews

Two of the six participants opted for interviews instead of participating in the focus groups, which were held at the participants' homes as it was a comfortable and convenient option for them. Similar to the focus groups, I met with participants three times over a month, with the first and second interviews being 60-90 minutes in length, and the final interview being under 60 minutes. Interviews were audio recorded and transcribed.

Data Analysis Method

This research utilizes inductive thematic analysis to uncover patterns within the data and seeks to recognize larger overarching themes in relation to the body, identity and environment. Braun and Clarke (2006) define thematic analysis as a method for identifying and analyzing patterns (themes) within the collected data. Themes capture something important about the data in relation to the research questions and represent an implicit level of meaning within the data (Ryan & Bernard, 2003). According to Dudley (2011) thematic analysis of focus groups and interviews with participants are useful when the researcher is trying to identify common themes in their responses as well as differences in relation to the research inquiry. For the process of thematic coding in this analysis, I followed a step-by-step process: the first step involved is familiarizing myself with the data (O'Connor & Gibson, 2003).

According to Bach (2012), a visual narrative methodology includes listening to the stories participants share about their photographs of their choice. Bach notes that it is not about using a particular set of skills or techniques; rather that narratives around images, places the researcher directly in the study of experience while simultaneously recognizing that there is no *single truth*. It also includes reviewing participant transcriptions and drawing connections between participants experiences alongside theories. Overall, the goal of visual narrative research is to centre the narratives and images of participants while also making theoretical connections with participant experiences.

Familiarizing myself with the data took place by listening to the audio recordings and transcribing them while identifying any codes and quotes for potential themes, noticing patterns within the data, mapping the data (themes) and reviewing them. Reviewing the transcripts alongside the visual images was repeated multiple times to make connections between the narratives shared while applying a CFD framework. Drawing from a CFD framework, my analysis includes considerations of the complexities of altered embodiments, binaries, roles and expectations, social and material environments, and the dynamic of the body in process that may be reflected in participants narratives.

Ethical Considerations

A key ethical consideration in research work is to do no harm (Berg & Lune, 2017). When speaking of doing no harm, I mean that I am working from an ethic of care, respect and reciprocity. This involves building trust and rapport with participants, structuring *enough* safety throughout all aspects of the research process, and honouring participants for giving their time and energy for my research aims (Harrison et al., 2001).

Bach (2012) highlights that an ethical consideration that needs to be addressed will be who will have access, rights and ownership of the data after the research is completed. This is important considering that visual images will be used and as they will be part of a narrative and documented in academic research. This led me to seriously consider what it would mean to use participant photos as data, and how their data could be used by me, and once disseminated, possibly used by others. Even though the University's ethical requirements to be approved to carry out this research are rigorous, I still grappled with what images might be shared in a static document.

While participants appeared to convey a solid understanding of their privacy rights connected to this research and to the photographs and narratives they shared, the fact that I could be presenting their photographs and narratives in ways they may not have thought about or agreed with was hard to guarantee with full certainty. My decision about which data should remain private/personal and which data shall be publicized was made after careful contemplation. In addition, photos with participants' faces included within the thesis have been altered to maintain anonymity.

While this research was not funded, I wanted to provide participants with a gift to symbolize my appreciation of their time, energy, and expertise. Gifts for participants were purchased from a local Indigenous artist from the Tla-o-qui-aht First Nations in the Tofino area. Gifts were presented to participants while wrapping up the final focus group and interviews.

Validity and Reliability

To strengthen the validity of a qualitative methodology, Polkinghorne (2007) suggests the researcher needs to clearly demonstrate how interpretations of the data have been achieved and integrate participant quotes and images from the data. This allows the reader to judge whether the evidence supports a level of trustworthiness and credibility in what is being *claimed* in the research. Fereday and Muir-Cochrane (2006) add that researchers need to clearly demonstrate how interpretations of the data have been achieved and illustrate findings and participant reflections with quotations and images from the data, to strengthen the validity and credibility of the research.

For this research, I have carefully considered how I expose and share the voices of my participants. Having a say or voice implies that there is an audience and, in the case of visual narratives, viewing participants' voices are expressed through their images and quotes (Lorenz, 2010). During my interviews and focus groups, I often clarified participants' narratives by paraphrasing (i.e., member-checking) what they said to make sure I understood their perspective (Lincoln & Guba, 1985). This has been captured in my audio recordings and transcriptions to ensure I have conveyed the overall meaning and essence of what was shared. This is known as member-checking and is a means of ensuring trustworthiness (Harrison et al., 2001). More importantly, I wanted to center participants' voices with respect and authenticity (Kennelly et al., 2017) and thereby strengthen the reliability of the findings.

Reflexivity and Insights

Reflexivity, as described by Kirby et al. (2006), is the ability to recognize my social location and experiences openly and honestly and “deeply consider the implications of power during analysis and interpretation of research participant's narratives” (p. 39). My reflexive practice includes reflective journaling and note-taking either written or audio recorded. I also made reflexive notes while reading and re-reading the focus group and interview transcripts (Kennelly et al., 2017) and referred to them often to help me remain aware of my biases and if my own understandings were evolving in the process of data analysis and documentation.

This research is exploratory and deeply personal. I have carried my own awareness of holding myself accountable to recognize where some of my biases might appear during this thesis process. From the onset, and prior to ethics and data collection, I have carefully considered how my own assumptions may show up in how I engage with participants and influence the data and research process (Polkinghorne, 2007). During all phases of my research, I strived to maintain a reflexive practice by documenting some of my initial thoughts before, during and after data collection stages and analysis. This was done through journaling and note taking. While hoping to become more aware of some of my assumptions, I also recognize it is impossible to see or completely shelf all my biases or beliefs. In the following section I discuss my insider/outsider status in relationships.

Insider research refers to when researchers conduct research with populations of which they are also members so that the researcher shares an identity, language and or experience with participants (Dwyer & Buckle, 2009). Reflecting on my role as insider, I include both my personal experience of surviving BI and my experiences of supporting survivors in various capacities. In both, I have recognized the value and uniqueness of my own experience as well as the individuals I have met while playing a supportive role. Both have afforded a certain level of understanding and appreciation so deeply embodied it is hard to capture in written words. I shared in my focus group briefly my experiences with motor vehicles and workplace accidents and the changes they brought to my body and my world at the time. I didn't always share this information in my interviews or work position as the focus was not about me but rather my research or being in a supportive position. I don't always think of myself as belonging to a certain group and perhaps that is because I find the nature, onset and trajectory of BI quite diverse. However, when I reflected on why I sought out this research, it was to focus on giving space to those unique and valid experiences that are often homogenized and generalized in a few sentences or left out of the academic research space.

I acknowledge that while it is easy to capture possible power imbalances within the writings of this study and formal documents, it is hard to catch them in the moment and day to interactions that occur working alongside survivors in a supportive capacity. I have been a Community Support Worker (CSW) with a local BI services program for over five years and have supported some of the participants due to their association with the service program. As a CSW, we focus on building rapport and trust with clients and engage in a client-centered approach. Some of our roles might be supporting clients with recreation, scheduling and organizing, memory cuing, self-advocacy, employment, housing, goal setting, socializing and building a support network in the community. I am fully aware that my dual relationship as researcher and community support worker with the BI services program presented an imbalance of power in my relationships with participants. However, I believe that my supportive role aided in building familiarity and rapport in my relationships, which possibly helped some participants feel more comfortable in engaging in my research.

According to Mazzei and Jackson (2012) even though qualitative researchers have incorporated participants' voices in their research, we need to acknowledge that as researchers we are always shaping those exact words through the unequal power dynamics in the research participant relationships. For instance, the language, structure and sequencing in which I asked questions could have led participants to answer them in a certain way. Also, the language used in the structuring of my thesis and findings all hold power in the narrative that I created about participants. Over the journey of the analysis and editing process, I tried to ensure to not convey findings in a specific narrative or mislead the reader about participants' accounts.

In addition, sometimes the title of researcher or support worker gives a position of power, even when you believe you have the best intentions. After reflecting on my very first interview with a participant, I was implicitly reminded of how my power shows up in relation to my role and how easily that can be embodied. In this moment of conversation, I felt a visceral experience of how I could easily sway the conversation depending on what I chose to say next. I have discussed the role of power imbalance within my thesis ethics, within my graduate level courses and in my own self-work. Yet, experiencing it within a moment alongside a participant reminded me of how easy it is to take an imbalance of power for granted even if you may not intend it, but symbolically it is embedded within your role.

Chapter 4: Findings

This chapter presents findings from my research focusing on the following research questions:

- How do the bodily/embodied experiences of BI survivors play a role in shaping their identity after brain injury?
- How might specific environments influence the experiences of women who survive a brain injury?

Thematic analysis (Braun & Clarke, 2006) was used to identify some of the dominant themes and sub themes emerging from the data. The analysis process consisted of listening to participants' recordings from interviews and focus groups alongside their submitted photos, transcribing the audio recordings and reading and re-reading the transcripts of their narratives around their chosen images and discussion. From this process, it was possible to develop insights into how they expressed their own unique narratives, embodied experiences and identities and their relationship to environments. Ongoing conversations with the participants about their images provided an opportunity for them to reflect on and discuss how their photographed images represented parts of their identities and their worlds living with Brain Injury (BI).

When I began analyzing the data, I used my research questions to tease out themes and subthemes in relation to my research inquiry. Two overarching themes were identified: (1) Is it me or is it the BI? and (2) Relationships, along with multiple subthemes. Within the theme of Is it me or is it the BI? were the subthemes: invisible/visible, disabled/not disabled, bodies marked by experience and being/becoming. Within the theme of Relationships were the subthemes: what is my body telling me, family, I feel like I'm part of…, and having a safe space. Table 1 displays these themes and subthemes and provides brief descriptions.

Table 1. *Themes, subthemes and descriptors: Overview of findings*

Themes	**Subthemes**	**Descriptors**
Is it me or is it the BI? included a myriad of aspects of self: labels, social constructs, emotions, roles, changes in self, dominant and less dominant aspects of self.	*Invisible/visible*	Aspects of self/identity that are not seen such as having to prove what can't be seen or objectively measured or what is visible inviting unwanted attention, staring, standing out, misconceptions
	Disabled/not disabled	Disability/BI identity, used for medical, economic means, or part of self? How does it show up or not?
	Bodies marked by experience	Includes aspects of bodily/embodied self, marked by pain, memories, physical changes and communication, clothing items.
	Being/Becoming	Diverse narratives center around the process and discovery of "who am I" after BI
***Relationships*:** included narratives around important connections to self, others, and environments.	*What my body is telling me*	Participant understandings of their relationships with their body/self
	Family	Importance of family (human/non-human) relationships and connection, being a parent/caregiver
	I feel like I'm part of…	Focuses on relationships in community and belonging, fitting in while still feeling different
	Having a safe space	Narratives included being present, feeling connection, peace, and safety in relation to specific environments.

It is important to note that these narratives are captured at a certain moment in time. They are symbolic of the participants pasts and present moments during the data collection and are not definitive nor static representations of their identity. I also acknowledge this as much of the literature on BI often presents a narrative that survivors are perceived or presented in a fixed manner or with a deficit-based outcome. While survivors have added barriers to navigate since their pre-injury self, they still adapt and change and lead dynamic lives.

Participants

The following introductions are based on what participants chose to share about their positionalities, identities and if they wanted to use a pseudonym or their real name. Some participants used their own name, chose their own pseudonym or gave me permission to choose one for them. Introductions and backgrounds were part of the first focus group or interview to get a chance to know and understand participants better. Additionally, two follow up emails were sent to participants after transcriptions and during data analysis to finalize names or pseudonyms as well as other identities they wished to identify with in the research such as gender, race or other identities not mentioned during data collection that they wanted acknowledged. The age range for participants in this research is 28-55.

Erika

Erika is a creative interdisciplinary artist with experience in the dance and physical theatre. She has survived a series of concussions since childhood, noting lots of migraines. Erika spoke of more recent concussions occurring while rehearsing for a show in 2009 that changed her life. She is a mom of a daughter, in grade five. Currently, she continues to perform dance and teach physical theater.

Angela

Angela has moved to Victoria from San Antonio, Texas, in 2007 with her partner and son. She had a brainstem aneurism, a stroke, in 2009, on her birthday. After her stroke she spent three months in rehabilitation “trying to remember how to walk and talk. I had to learn everything all over again and it's the hardest thing I have ever done.” Angela’s son is now 15 years old.

Pearl

Pearl describes herself as an active and outgoing person, a varsity athlete in soccer, and a fitness trainer. During a soccer game she hit her head hard resulting in a concussion. Three weeks later while training to obtain her massage therapy license her neck was hyper extended resulting in another injury. The effects of her injuries are cumulative, and she is currently working towards stabilizing her recovery efforts and focusing on life after injury.

Sara

Sara described her injury as starting when she couldn’t feel her leg while getting out of the bathtub. An MRI showed that she had a cyst, but it was too deep in her brain to operate. In 2010, she had another bleed and had brain surgery to remove it. Sara is a mom of two young boys and a wife. At the time of her surgery her boys were ages 3 and 5; they are now 12 and 13 years old. She identifies as having a disability not a brain injury as her changes after brain surgery are physical rather than cognitive.

Sophie

Sophie grew up in Victoria, B.C. Her ancestry is a mix of Indigenous and European. Sophie shared that while working as a social worker in New Zealand she got sick. Her mom brought her back to Victoria, B.C. and she was diagnosed with Autoimmune Encephalitis. Autoimmune Encephalitis currently does not have a cure but is treatable when symptoms are severe or in remission.

Diane

Diane was born in Australia but has resided in Canada for the last 20 years. Diane is a survivor of intimate partner violence and BI, also sharing that she struggles with addiction and

PTSD. She is a mom of two boys in their late teens. She is currently working on recovery and maintaining safe, stable housing with her animal companion.

Is it me or is it the BI?

The theme of *Is it me or is it the BI* encompasses the subthemes from participant discussions that addressed aspects of themselves in relation to navigating the fluid and dynamic spectrum of identity post BI. In this case, participants shared through images and narratives what they saw as their dominant identity or aspects of their experiences and perceptions around their identities. In some cases, they embraced their BI's as part of them or separate or it would change based on the day and what they experienced. Additionally, narratives shared by participants centered on how they wanted to identify. Subthemes that emerged within this overarching theme included invisible/visible, disabled/not disabled, bodies marked by experiences and being/becoming.

Invisible/Visible

A subtheme around invisible/visible emerged from both focus group discussions and interviews. In the research literature, a BI, depending on the type and symptoms is considered an 'invisible disability' (Ralph & Derbyshire, 2013). When discussing BI, visible differences that stand out can often draw unwanted attention while invisibility can also leave an individual to have to *prove* that something is going on or different while they are perceived as being *normal* or *high functioning*. In both cases it may contribute to a lack of understanding from society, from family, and the outside world which all influence a survivors' perception of self and identity.

Diane shared she felt like she had to prove to others, especially medical professionals who hold the power of being able to diagnose and affirm that something is not quite right. Diane also acknowledges the difference from her previous self and the struggle of trying to explain it to people when it’s not always visible or evident to medical and or rehabilitation specialists, especially when her MRI scans showed no *abnormalities* leaving her to justify and feel she must prove herself to receive supports.

> **“**I even had an MRI done on my head right because there was concern about the pain, I was feeling in my head that came back clear like what does that say? I'm still having problems, but I've got nothing to prove what's going on. So… you know, I automatically think people...people are thinking I'm lying or something I guess...I feel like I have to prove myself. It's the same with pain, you can't see it. And it's so hard to explain to people what that feels like and where the pain is and what it feels like you can't explain that.” **Diane**

Similarly, in a focus group session Sophie had expressed that **“**the health care system there let me down.” I had asked Sophie what she meant, and she elaborated further on what was happening around the time she started to feel symptoms while she was in New Zealand.

> “My condition presented with psychiatric symptoms, so I was like getting really confused and lost going to work, and not recognizing people and they just thought I was having a breakdown and my mom was like "No, it's something *more* than that". But yeah, women’s intuition? I was like how did you know?? (laughing) So she came and was like really advocating for me to get an MRI and they wouldn't do one they just did bloodwork I guess, and my bloodwork was fine...” **Sophie**

Sophie also shared that it was not until her mom had brought her back to Canada, she was able to get an MRI and given a diagnosis of autoimmune encephalitis. Autoimmune Encephalitis is a condition in which the bodies’ immune system attacks the brain causing inflammation (Brain institute/auto-immune-encephalitis, n.d.). While Diane and Sophie have diverse experiences of their BI, they share similar experiences of the medical system. Both have had to prove something is going on beyond what can be seen on an MRI or due to presenting psychosocial psychiatric symptoms which are often interpreted as mental health diagnosis for women and girls (Hamberg, 2008). Additionally, Valera and Kucyi (2017) maintain that MRIs are not the gold standard of measure when trying to detect more subtle changes in the brain such as a mild traumatic BI or concussions.

Sara and Angela discussed the barriers with having visible differences that stand out and garner unwanted attention. In the excerpt below, Sara discusses the visibility of the changes in her physical movements and the challenges it presents for her own identity.

Figure 2. I used to be a fast walker now I feel as slow as a snail (Source: Sara, 2019).

> “Like this is me when I'm just by myself. That's it. I move at a snail's pace, that's what's so frustrating because I just feel like what's going on inside doesn't match up outside. So, I think it’s really hard to exist when they don't match. It's really frustrating when my body or my mouth can't keep up.” **Sara**

The visibility of difference or something outside of what might be considered normative within a particular culture often invites undesirable attention such as staring or certain assumptions made based on appearances and or behaviours. Sara and Angela both shared their experiences in receiving this kind of attention. In the excerpt below, Sara’s narrative describes her discomfort in receiving more attention due to the changes in her pace and using supportive aids.

> “I think that I get more attention I guess and positive or negative. I don't think it's necessarily...I wish I was invisible sometimes (laughs). I have a walker; a mobility scooter and I think that kind of throws people. I get that double take. I get that extra second stare or something like that…You can ignore them (people looking at you) for only so long, but you would have to be inhuman for it not to get to you after a while. It's hard not to internalize how you see yourself when other people stare for not necessarily positive reasons” **Sara**

Angela also expressed frustration with certain assumptions, about the tracheostomy (trach) in her neck as well as some of her other behaviours that might be misunderstood or misinterpreted when in public.

> **“**If I could get it tattooed across my forehead. I would. I would because um this invisible injury they say or visible whatever but um sometimes stuff falls out of my mouth (laughing) and if I just had something that said you know BRAIN INJURY. Maybe people wouldn't look at me as goofy as they do. And I get some *really funny* looks, but this is me... I got a brain injury. It’s like my trach, if I'm on the bus oh my god...people are looking at me and I had a lady ask me "Can I talk to you about that thing in your neck?" I said sure. You know what, I appreciate that. I would rather you talk to me about it than just stare at me. Yeah, I say some weird stuff sometimes. But don't just go “this woman’s crazy!” No, I've got a brain injury, talk to me. Ask me. *Talk. To. Me.* That's all I want is... just talk to me.” **Angela**

The theme of invisible/visible is important to unpack because it illustrates the lack of understanding that outsiders including medical professionals may hold for survivors who have invisible symptoms. On the other hand, having more visible physical or behaviour differences that stand out garner unwanted attention. This may include staring or a lack of understanding from others; all which influence their identity and how they engage with the outside world.

Disabled/Not Disabled

Disability is an identity that is socially constructed and may be claimed for a variety of different reasons. In some instances, it may be for the purpose of acquiring eligibility to access funding supports and accommodations within a medical or social welfare system. Additionally, it may also be an aspect of identity that provides a sense of agency to the person who claims it. During interviews and focus groups, I had asked participants if they identified with having a disability and or a BI. The answers to my question varied and depended on many factors. For example, Pearl shared that it depends on the day; it’s not a fixed identity for her, nor something she acknowledges as her main identity.

> “I feel like I'm a different person every single day. Like some days I don't identify with having a disability and I don't know maybe I'm just in denial that day or not honoring it. I've literally had days where I think that I made this whole thing up. You know...um, and then there's other days where I'm pushing myself, I'm actually going to work more and it's so in my face...it's very evident. It's embarrassing because nobody knows, and I will make dumb mistakes or even in front of my parents I had a couple of panic attacks. And that's part of what I'm going through right now and so on those days I'm like “Yeah, I have this but then on other days I don't.” **Pearl**

Erika and Sophie also shared narratives around having to acknowledge having a disability in a formal document for work and funding purposes. There was something so uncomfortable about putting it on official documentation, having to acknowledge and accept it on some level along with possible risks of sharing it with others. Erika said that she does not see herself as having a disability; however, the one time she did was when applying for grant funding as shared below.

> “So, I basically wrote on a form I am brain injured and it was like life changing to say that right” **Erika**

Sophie also reflected on a moment when she was filling out a form for work and the feelings that occurred in disclosing her diagnosis.

> *"*I had to fill out this sheet at my new job and my boss emailed me the emergency contact info that I had to fill out and one of the questions like "are you on any medications" "Do you have any chronic conditions" and I put my auto-immune encephalitis and then I deleted it and then I put it down again and then I deleted it and I was like…"Why am I so like ashamed of it?" **Sophie**

In both narratives, Erika and Sophie shared about the possible fears that arise with disclosing a label that invites the possibility for discrimination and stigma while wanting to be seen as capable alongside acknowledging it for themselves in a formal piece of writing. Pearl and Angela discussed the experience of disclosing in a public setting and reflecting on the notable reactions from strangers while also navigating their own tensions with acknowledging having a disability at the time.

> **"**So, I'm filling it out and there's one extra page where it's like "do you have a disability?" And there's a big group of us filling out this form and I get to that page and I'm not comfortable with that. I don't have a disability, *but I do right now*. Finally, I go to the guy in front of everyone "so I have a disability and I just was wondering what needs to be done with this?" and the whole demeanor in the room changed. I know no one did it on purpose but they all just looked at me differently and the guy, the HR guy started talking to me sloooowly." (everyone laughs) **Pearl**
>
> **"**People have done that to me too! They start talking slooow. It's like you know what, I'm not stupid. I have a brain injury but *I'm not stupid*. Talk to me, just talk to me. So, you know I just really come to terms with fact that people aren't going to understand because they don't have it. They don't have a brain injury and they're going through their life. They're doing their thing. So that's kind of what I feel like *I have* to do. I have to go through my life and do my thing." **Angela**
>
> **"**I think a lot of times it's their own (other people) discomfort. The unknown. I try not to like feel ill towards them. It's like it's their journey and their nature or whatever and that's okay, but it is hard in the moment." **Pearl**

This also led to a discussion point around navigating between pre-self and post self-identity post injury. In other words, this was about noticing when symptoms or behaviours show up and wondering if this is an aspect of self or lingering effects of BI. Erika comments below about how this occurs for her daily.

> “All the time... Each day it's like this percentage of like “oh I feel 99 percent the way I used to feel”. I'm okay and then on other days or other situations or other moments it's “Oh this is the brain injury playing in” and sometimes I don't remember that this is the brain injury playing in until I've exploded at my family right.” **Erika**

Bodies Marked by Experience

Another subtheme that emerged was bodies marked by experience. In this subtheme, participants discussed how their bodies are marked by the experience of BI in differing ways such as in the form of pain, memories, changes in speech or clothing. Similar to the theme of visible/invisible, how the body is marked will be diverse and unique to the survivor. For example, pain is a way for the body to communicate to us that something is going on, pain is what gets us to notice, act on and or listen to what we need to do. Angela described her relationship with her body and the scaling work she does each day to check in with herself and figure out what kind of day it will be.

> **“**I'm to the point now where I wake up in the morning and I've got chronic pain in my head and neck from all the surgeries that I had. I get up in the morning and I sit on the side of the bed, and I say "thank you universe for another day. But what's my pain level like today? I can sit there and go uh it’s about a five. And I'm going to get up and move. If it's 8 or 9 or 10 then I'm staying home and I'm going to take care of myself and try to try to get back to the point where I can get out of the house. I just made it a point in my life to make sure I can get out of the house at least a little bit every day so I'm not stuck. I just felt so stuck for such a *long* time. I don't want to feel that way anymore.” **Angela**

Diane also discussed her relationship with pain in her body in her photo and narrative below and how it related to feelings and memories of being stuck in her previous relationship.

Figure 3. Scattered, anxious and stuck (Source: Diane, 2019).

> **“**That’s how I feel… like I'm stuck in that relationship, I guess. I'm still stuck feeling pain and hurt and it hasn't gone away right. Like I know it's going to take time and I feel like I struggle every day....” **Diane**

In this interview, while we were looking at her photo, I had asked Diane if she could elaborate on what she meant when she spoke of still feeling stuck in her previous relationship and feeling pain. In the quote below, she discusses her bodily experience of what her pain feels like and what happens when it manifests in different areas of her body.

> **“**I'm wearing the trauma and I don't know if that's why I feel pain in different parts of my body and it's random pain. But the emotional side of stuff like I know I'm wearing it. I feel it's like this heavy weight on my shoulders right. And just feeling the pain takes me back to the situation because I have PTSD. So, this shoulder (pointing to shoulder) was damaged to the bone from being shoved into a wall. This one bothers me a lot and every time it hurts it takes me back to the times that he threw me into the wall. And this is when I find myself um… how do I explain it... I go out of reality into my head, and I'll be gone, and people would be talking to me, and I won't hear a thing because I'm out there somewhere.” **Diane**

In Sara’s case her photo and narrative below illustrate how her body has been marked by the experience of her physical change in speech and ability to type. Her narrative holds both the internalization of this change as well as her experience of outsiders. In the excerpt below she shares how using email levels the playing field and she has more freedom to express herself without worrying about what people might be thinking when they hear her voice.

Figure 4. Keyboard (Source: Sara, 2019).

> “I can’t type with my left hand anymore. While that is frustrating, it’s really nice to type things because then people cannot hear my speech impediment. I feel judged very much based on my voice” **Sara**

> “When people talk to me it's initially very hesitant and they’re trying to suss me out and same with me talking on the phone I hate talking on the phone because ...well I sound like I'm drunk or they don't know exactly who they're talking to. But when I e-mail, they don't hear that at all they focus on more of what I'm asking or my thoughts versus what I'm saying. So, in that sense the identity I like much better when the print communication

> versus the phone or when I don't speak at all. So that just gives me the power to express myself and people hear the ideas and not the voice. People can't see me when they write, and I think that makes a huge difference because ...it takes away everything and I can express myself and see more who I am... They don't see all this and get distracted by it. It levels the playing field.” **Sara**

Another way we are marked by experiences that shape us, is through clothing items that hold specific memories. Sophie used this photo to talk about a particular shirt that held memories and experiences of where she first had symptoms associated with her BI in New Zealand. In the quote below she speaks to the significance of how an item such as a shirt can hold many memories and stories of experience.

[redacted]

Figure 5. That shirt (Source: Sophie, 2019).

> “That's my ex-boyfriend’s shirt from New Zealand and you can't really see it but, I was in the hospital there and this is the little mark from the **S** that they did on there that does not seem to come out because I washed this shirt, that was from 2 years ago, um… Yeah I feel like this shirt in this picture kinda means like, grief to me, everything that I lost

> there. Like some people think clothes are just to cover your body but, I feel like I have like an emotional attachment to a lot of my clothes. I don't really feel I had closure from my time in New Zealand because my mom just came and got me and I left... **Sophie**

Being/Becoming

This subtheme speaks to the diversity of participant narratives when reflecting on the question “who am I?” When viewing identity from a Critical Feminist Disability (CFD) approach/framework it speaks of a person’s identity as being fluid versus static and comprising of multiple aspects of identity. When we add the complexity of change that may occur after a BI it invites a diversity of identity narratives with each being distinct to the participant on their own journey of recovery, transition and transformation.

In the excerpt below, Sara describes the many changes that occurred after her surgery, noting the difference of before surgery and after and what changed and what stayed the same. There is one thing that Sara sees that hasn't changed is her cognition and intellectual capacities. She identifies with having a disability but not a BI because of the physical changes to her body and speech.

> **“**I can't think of how it didn't change because I don't speak the same. I don't see the same. I don't hear the same. I don't move the same, I don't feel the same, so everything has changed except one thing I guess I'm still a mom and a wife (both laugh quietly) that hasn't changed but it's totally different. I think before the surgery my identity was really connected in a healthy way to my physical presence. Like I take a lot of pride in that, and I felt very strong and capable, and I don't anymore...It's really, I really have to recreate/appreciate my identity because there’s more to me than my body. So, it's really made me focus, and one of your questions "Who are you" I thought out of all the questions that was the hardest” **Sara**

Diane's narrative also addresses the changes of who she is after injury and not recognizing “who” she is in this moment or time. Her narrative depicts the challenges of these changes occurring and not being able to recognize aspects of herself or a loss of her sense of self.

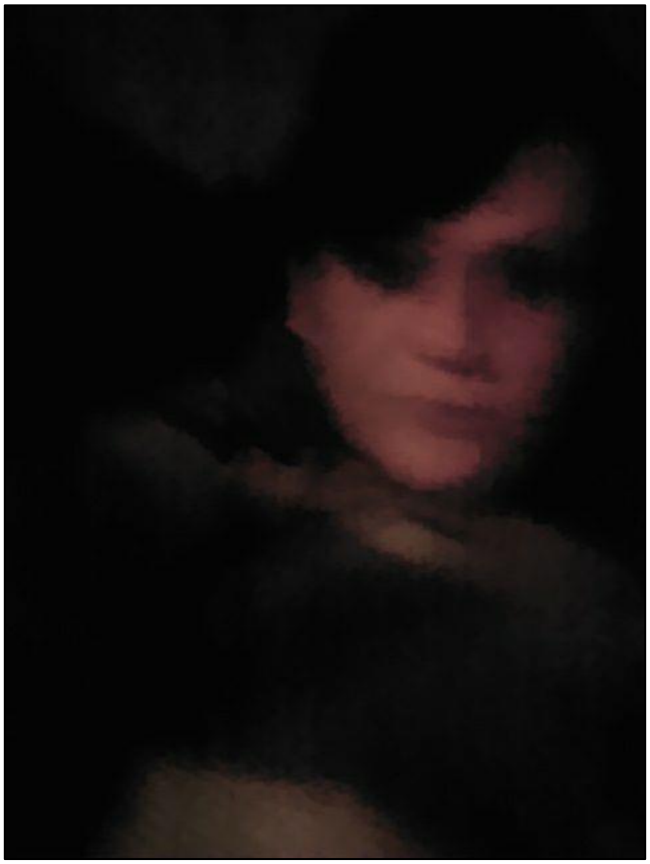


Figure 6. I am a blurry mess (Source: Diane, 2019).

> "The fact that there's certain things I was able to do I can't do now like multitasking. I can't do that anymore and that's really frustrating for me. And then like you know having a conversation with somebody and just not finding that word it happens to me all the time, I find it embarrassing. I don't feel like anybody that I was and now I'm completely different... who is this person? And trying to explain that to people is *really hard*. Even trying to explain to the medical people right, what I'm feeling and what I'm going through. It's hard because it's in my head you can't diagnose, you can't see it right." **Diane**

Another identity that was discussed in the focus group was a work identity. The next few excerpts from Sophie and Angela are their narratives about work and the adjustments to their identity after injury regarding employment. Sophie discusses her position at the senior centre as being connected to her previous work as a social worker. This is her first job back in the social work field after her diagnosis. In her photo below at her office she describes some of the changes and transitions that she is noticed or experienced while engaging in work that is connected to her identity before her diagnosis.

Figure 7. My office (Source: Sophie, 2019).

“So, I go around to places and do information sessions for seniors, and I'm just constantly need to keep organized and stay up to date on papers... so That's me, I'm kind of organized but … my work has always been a pretty big part of my identity. And I couldn't do my work for a couple years because of my brain injury. So, this is kind of my first job back in the Social Work role. yeah, I feel like this photo is kind of organized but kind of chaotic which I feel like represents me. a lot of my job is time management and planning which used to come really easy to me and now it's pretty challenging. I had to fill out that form for work and ended up saying that I have autoimmune encephalitis, but it's been in remission for 2 years. But I've never talked openly to anyone about my health struggles. I’m like afraid people will see flaws and then blame it on that. I'm pretty reserved about it. I guess it's that thing of like is it the brain injury or... I know there are some notable differences with the time management, and I have to look at my calendar over and over and over again and say am I giving myself enough time here? **Sophie**

Angela described the experiences of navigating her new/altered self after her stroke. In the photo below she discussed her experience working at a grocery store and while she loved the company, they didn't understand some of her needs based on capabilities. Before her BI, Angela used to work as a surgical technician delivering babies; after her stroke she was not able to do the same type of work.

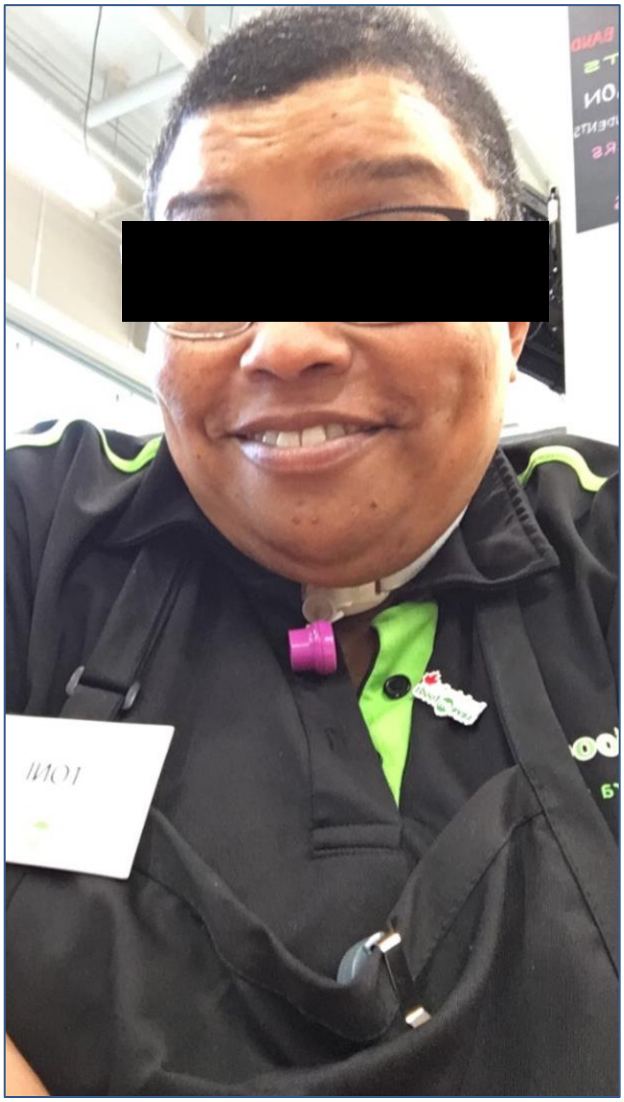

[redacted]

Figure 8. At work (Source: Angela, 2019).

“Unfortunately, I'm not working there anymore because it was just a little too much. Yeah. But it was great, while I was there it was fun. They wanted me to work full time, so the 35 to 40 hours a week, too much, and it's a huge store. So, a lot of up and down, a lot of walking. If I could do like 20-25 hours a week. Sure. Plus, standing working on the cash register. I'm like You know guys, since my brain injury I don't really count that well… I said you guys want me to work the cash register?? And their like “well you know, you don't have to worry about it, it's not a lot of money..." I was like... "well when I give away enough of your money, you'll take me off the cash register!" (laughing) all I can say! and they did, I said "See I told you!" **Angela**

After Angela had shared, I asked her if she was not afraid to disclose to possible employers about her injury. This invited a dialogue around identity and in Angela’s case her acceptance of her BI, as she states below.

> “No, not at all! yeah, to me It's....I try not to hide who I am, and my brain injury is who I am. So, you accept it, accept me or don't. Take it or leave it. To be really honest with you I don't give a shit. I don't care because this is me. This is the way it is, and this is how it's gotta be. So, you know, yeah, I'm very very honest about that kind of stuff.... I’m to the point now where I'm getting older, and I don't want to lie. I don't want to have to remember what I said, what I didn't say...” **Angela**

Angela’s narrative also displays her upbeat sense of humour, which Erika also commented on: “and you have a sense of humour about things”, a strength which appears to help her navigate through challenging situations with ease.

> “I try to be a happy kind of chick... But definitely after the brain injury. Yes, it has helped me tremendously to try and have that positive outlook on everything and to find the humor in it. Then every now and then that gets me in trouble (laughing) ...” **Angela**

In Pearl's photo (empty nest) and narrative below she describes the complexity of emotions that occur while navigating life changes, as a survivor and a woman. Often, sociocultural discourses continue to perpetuate certain pressures on woman to have a family and a stable life, to be nurturing caregivers and mothers along a projected timeline. All of this alongside the personal changes after a BI create an immense pressure to act and perform gender roles in a socially prescribed way. While pointing out these pressures, I want to emphasize that Pearl desires to be a mom and have her own family. In her narrative below, she shares the challenges of grief and loss while also acknowledging the insights she gained during the process of recovery.

Figure 9. Empty nest (Source: Pearl, 2019).

> **“**This one for me represents my maternal instincts. I always wanted to be a mom (her voice is shaky and holding emotion) and maybe I will… just before my brain injury, I had a home and a partner, and a life and we were talking about a having a family and... that's all gone... and I lost my home and so it's just sometimes I feel like... do I have the ability to be a mom? Because a struggle I have is just taking care of myself. And I never doubted that before and I just feel like I might have an empty nest. It's so beautiful but at the same time I just felt like such grief when I looked at it. I have a heart condition and my doctor the other day said I'm going to be a high-risk pregnancy already. If you're going to have kids, you should really be thinking and doing it now and I'm like...you know that was just kind of like...just being a woman I guess!? and the brain injury I think has in a good way really made me be my own best friend and I've never spent so much time alone. I've had so much going on around me and I've been on sports teams, and I've never had downtime before, and I spend a ton of time on my own now and I think it's been a beautiful gift, but it's been really challenging. So, it's been a gift, like I've been forced to really get to know myself and I love myself and I never had something so true...It's this little mess that is a blessing but also, it's painful.” **Pearl**

Sara shared a similar narrative of grief and loss with her physical changes, noting that it’s the little things that are missed, such as being able to go for a walk with her husband and hold his hand. It’s a struggle to not focus on that loss of independence.

> “It's just small stuff like this morning I had this person over who I consider more of a friend, we were talking about marriage and all that and that stuff and like I need both my hands for my walker and she's talking about her brother and his wife, and she's like “they still hold hands." I couldn't even do that do that if I wanted to because I have to be sitting down or have to...I need both my hands for walking. it's like little stuff that. I can't bring him a glass of wine, I can't. I don't know, the list is kind of endless really. It's hard, it's hard not to have that stuff change in your mind of who you are. When our relationships change from what you can't do and again that’s hard not to internalize. I think it's like impossible not to kind of internalize that you're more dependent.” **Sara**

Relationships

Relationships were the second of the two overarching themes that appeared clearly across the data. As stated in Table 1, the theme relationships centered around aspects of being able to relate, understand and listen to themselves and their bodies post BI. Participants also spoke about those who matter to them such as family members (human and non-human) and the meaningful roles they play in their lives in the context of family. Discussion around where they felt comfortable and tension within certain community environments both physical and social was another subtheme that was discussed. Additionally, participants discussed the importance of specific places or environments play in supporting their sense of self.

What My Body is Telling Me

One of my main curiosities of my research was the relationships participants had with themselves. In the Western world the body often seems to be the site of productivity and performance with a lack of promoting awareness on the intelligence and expertise our bodies hold. When thinking about women’s bodies, it is heavily focused on physical image and ideals of beauty, motherhood and youth.

Pearl discusses her struggles with the disassociation of her body in the photo below. Disassociation often occurs as the body’s nervous system responds to trauma as a way of protecting itself from becoming completely overwhelmed depending on the context and situation

(Hartney, 2020). In Pearl’s experience, she also shares how she has worked hard to understand and see her body’s coping response with compassion.

Figure 10. Hand shadow (Source: Pearl, 2019).

> “One of the things that I've really struggled with is disassociation of my body. And so, there's two things, like my left side I have some neural feedback that happened. And like I said I used to be an athlete, personal trainer very very in tune with my body. So, I have a hard time with coordination so it's just difficult sometimes to kind of adjust to this new body I guess... And I have struggled with a lot of depression and anxiety since my injury. I don't tell a lot of people this, but I will feel like "this is not my hand, this is not my arm” so this is symbolic of like "it's not my body. This is not me.” I will see my physical hand, but I feel like I'm a shadow looking at my hand. I've been told that it's a trauma response and a coping mechanism for your brain. So, if your brain is tired and overwhelmed it's like “Okay I'm going to take you out of this environment”. I think after you've had an injury your body starts talking to you in different ways. I think when your whole identity is gone and then you're looking in the mirror it's like, that's not me! this is not me I'm so ungrounded what’s going on?? So, I'm getting to know myself again and I'm a new me.”
> **Pearl**

When asking Sara what her relationship is like with her body presently, she shared some of the resistance she had with her relationship to her body now while also acknowledging that she doesn’t want to feel this way or focus on it in such a negative way in the future.

> “It's pretty bad, I get pretty mad that it doesn't do what I want and that's hard because from this...I know it doesn't want to feel like this and so I 've got to be a little more patient with it because if it could do what everyone did it would and I ... I don't want to live like this for the rest of my life, I don't want this to be such a big part of my thoughts and my conversations and all that. I kind of want it to be on the back burner …it's like right here all the time and I want to be able to talk about things without getting teary as much or giving it as much attention.” **Sara**

In the narrative below, Sara commented on how she felt after her surgery and feeling like a part of her died. She also discusses the changes that occur daily to her body and with this in mind, she notes that the rehabilitative testing she undergoes at the hospital is not an accurate reflection of the constant fluctuations in her daily physical abilities.

> “I feel like I died. I feel like a really good part of mine died and now I don't know…I remember, I was saying to my dad once I felt like I'd died on that operating table, and he said to me "why can't you think of it as a birth versus a death?" and I'm like because I really liked... that person before. It's really frustrating and quite honestly, I don't see it as an achievement. So, one of the tests at the hospital was standing for two minutes and one day I could stand for five and then the other day I can't stand for 30 seconds. So, it's so arbitrary. What they used to measure and it's so different every day and that's why it's hard I think to have it knock down your day, so it always is changing. I think your relationship with your body shifts and nothing is constant. It's sure not necessarily who you are as a person. I think the way you perceive yourself from the way you perceive your body, and your abilities is very different than last week even, like it's just in flux all the time. And not necessarily always moving forward because to me it's more like dips and then you come back up and whether it's five years or nine years down the road. So, I don't think you're always moving forward.” **Sara**

Sometimes it’s not always obvious how our bodies are trying to protect us. The image Erika shared included her narrative around her concussions and the messy chaotic feelings that occurred during the times of her injuries.

Figure 11. Messy chaos (Source: Erika, 2019).

> "This one I think is like the ugliest and the most about my concussion experience because when I was concussed for like the third time when it was really bad and we were painting the house and this was taken so…all the messy emotion like garbage comes up with it. But it just brings me right back there, the chaos" **Erika**

As we discussed this image further Erika relays her other experiences around concussions and not listening to her own inner knowing to slow down or stop.

> **"**Well usually just before I was concussed. For instance, I was tubing with this friend. He was three times my weight and his wife was driving. And we had a great time, and it was sure fun. And then it was just kind of like I just feel like we should be done, right. Like cut the boat, cut the engine, like literally. OK I'm done. I'm ready to get in the boat and then she just makes one more turn and we go flying across the lake. And because of his weight I catapult through the air, and I smash into the water on my head and so ...I knew I was done, and I didn't call it right. And he was having the best time and I was like oh he's having such a good time and I'm not listening to myself. Yeah, and like I go back to the other previous two as well and I go "oh yeah." One, I was trying to follow the rules and I was trying to be good, and the second one, I was like done, I'm done! but I kept going right and then I got hurt uh that was a total like I knew it was time to stop and yeah that instinct.**"** **Erika**

When Erika describes the events leading up to her experiences with her concussions, she discusses her internal narrative of knowing she needed to stop and listen to what her body was telling her. Erika talks about the tension of feeling resentment towards herself, and Angela shares her feelings of self-blame around not taking better care of herself.

> "There's something that came up for me last week. Which was around resentment, and you know like I kind of look at my situation and I suppose I think "well I only really blame myself and ...and not right". I mean there's this level of acceptance like *it is what it is*…I'm meant to be here for some reason. And yet it really sucks." **Erika**
>
> "For me it's because I know that if I lived my life a bit differently and taking care of my body better. Then I probably wouldn't have had the stroke. So, I have been living with a lot of resentment to myself and blaming myself for everything. I mean for my stroke, for my slow recovery, for the fact that my marriage ended. I can't do a lot of the things I used to do before and it's all my fault. And that's the way I look at it, but yeah, it was my fault. Yeah, I probably should've done a lot differently, but what can I do about it now. I can't do anything about it now." **Angela**

In the excerpt below Sophie shares her process and thoughts around love and acceptance of her body. This includes an understanding her autoimmune encephalitis from a bodily perspective.

[redacted]

Figure 12. My body (Source: Sophie, 2019).

> “I can point out a lot of what I see as flaws in this photo, but I am trying to reframe it and to love my body, to accept my body. My condition is autoimmune encephalitis so it’s my immune system attacking my brain cells and I sometimes ask myself “why is my body doing this?” it makes me sad sometimes but I also try to reframe it as my body doing its best, thinking that its helping but just getting confused along the way and I imagine these little cells thinking that there like going into a fight and trying to get rid of bad things in my body. But oh well, it's very misguided.” **Sophie**

Angela shares a similar narrative to Sophie in that she is trying to listen to her body and have acceptance for the way it is.

> “I have a very rocky relationship with my body, very rocky relationship. It's getting better, it's getting a lot better actually. I'm actually listening to my body now and trying to get along with my body I guess I'm not quite sure about it but I'm definitely trying to listen to my body more. I've had to learn how to not only listen to my body but taking what my body is telling me and trying to change my outlook, my perspective on my body…and just listening to my body and seeing my body and seeing the way it is. It's been so freeing because this is me but listening to my body as it is it's been a very much a learned experience. The only thing that I can do now is go on and try and make whatever life that I have left. Yeah, my brain exploded, yeah, I'm going to have a trach for the rest of my life but I'm still here and I tell my son every day I'm on this side of the dirt. Life is good. That's the way that I can look at it and continue. I got to live, I got things to live for. I've got my son to live for, I got me to live for.” **Angela**

In the section below Angela, Sophie, and Erika discussed aspects of before and now and coming to a level of acceptance and gaining insight through their experiences.

> **“**It was the hardest thing for me to...to get to know myself cause when I was growing up, I wasn't allowed to do that. This is the way you're supposed to be and if you're not this way then something wrong with you and you know you have to make a change. Well...no I don't need to change. You know, accept me for who I am because I accept me for who I am” **Angela**

> “Yeah, I think this experience, has been a chance to get to know myself more. Before I got sick I was kind of just (drum roll sound) getting through all these goals and then all of it was good but this experience has forced me to go inward because I couldn't do a lot of that for a while and for me now continuing on this personal journey, I'm trying to connect with my culture that I have been disconnected from and I feel like I've never really connected with spirituality on like anything more than surface level maybe doing that will I don't know, it’s not closure I don't think that’s the right word but just peace with life's curveballs you know?” **Sophie**

> **“**I think the challenges that I face the most have to do with how my behaviours affect others, and especially my family and you know like taking on this, Yes, like knowing what I need and listening a little bit more works sometimes. But that doesn't change that sometimes I'm still explosive or say things or act in ways that I like who's that person or I just generally I don't exist in the world how I want to right? And that still is the challenge.” **Erika**

Angela reminds us in her quote below that this is a daily process of working on acceptance and that it fluctuates from day to day.

> “I'm quite at peace with myself. Oh, yesterday I wasn't very much at peace with myself. Last week I wasn't. So, it's definitely a changing kind of thing, like a wave but yeah, my overall goal is to feel as peace, as peaceful with myself as I possibly can in that day in that moment...It's kind of the goal but it's not I don't think it's something that you can get there and say okay this is it I'm done! No, it's an ever-changing thing and that's okay!” **Angela**

Family

Another subtheme that stood out was family. Specifically, this included the types and qualities of relationships involved with family members including non-human companions. Within the subtheme of family were narratives around having purpose, bonding and connection, learning from one another, memories, care and nurturing. The notion of family and the types and quality of relationship play a key role in the development of our identity or sense of self.

Sara shares in her photo below the silhouette of her two boys and her thoughts of what is most important to her. Having a family, being a wife and most importantly being a mom have remained constant and given her purpose.

Figure 13. The most important role I see myself having is being a mom (Source: Sara, 2019).

> “I think it's one of the few things I've retained before and after and being a sister or a daughter and wife, but this is probably most important to me that I can still relate to them and still have memories of them growing up and they don't care... and they don't care if I'm in a wheelchair or can't walk or do other things that moms normally do. This is just one part of my life. I'm very thankful for it, that stayed the same because I'm very glad that I don't have any further cognitive impairments than I had before, so I still help them with their homework and all that stuff and the memories of them growing up are so important to me. So, this is one part I'm very thankful for, that I'm home for them. Yeah, and that's what I want my identity to be is their mom and but it's probably more important to me than what I consider my identity. If I didn't have them, I wouldn't have had a purpose, I think to get through this.” **Sara**

Erika shared a story about Halloween shopping with her daughter in the photo below. Her narrative speaks to the dynamics of being a parent but also how she bonds and relates with her daughter.

Figure 14. The Halloween shop (Source: Erika, 2019).

> “This was taken this week because we *had* to go Halloween costume shopping (second week of September 2019). That’s my daughter and she insisted that we go buy our Halloween costumes a month and a half in advance because she's very organized and she wants me to be organized and I'm not very organized, I'm creative. I’m like "let's make your costume let's find things around the house and be very fluid with it and she's like NO! we're gonna go to Value Village were going to buy it and so then she puts on this hamburger, and this would be so good for you and mommy and then she came around the corner wearing that mask. Yeah, it's totally terrifying. I think what the photo kind of says to me it's like there are these moments where my adorable beautiful, amazing little child sometimes just feels like the devil. Like it's all the amazing sides to being a parent right. Yeah, I think we actually had a lot of fun you know doing this Halloween shop.” **Erika**

Erika also discussed the challenges that arise with her daughter being more organized and pushing her to be organized. Sometimes it creates a narrative around identity in relation to her concussions as she shares that she does have a hard time with decision making…is it her or the concussion. For Erika, her relationship with her daughter highlights the tension in navigating “identity; is it me or is it the concussion (BI)” when struggling with decision making.

> "Like, were going on vacation in a month and she's got her bag packed. She even says to me "mom you need to pack your bag! You *need* to like you need to do this and you need to do that… I mean I think it does challenge me because I have such hard time with decisions …That's always my question is it me or is it the concussion right so? Like the executive function and decision making and organizing, those are truly the things that challenge me the most. And so, she definitely is that reflection of what I am not…" **Erika**

Angela is also a parent and shares how she spends time with her son. One of the ways she spends time with her son is through food as she discusses below. Her narrative also speaks to the relationship she has with her son and how she communicates what she needs such as not being able to do certain things because of her pain level.

Figure 15. My son (Source: Angela, 2019).

> **"**This is my son (all laughing). He likes to eat (Angela's son is 14 years old). Every time he comes over all he wants me to make is fried chicken because his mother doesn't make fried chicken. And I say well.... if that's what you want then that's what you want. But yeah, that's something I've been making since I was probably about seven or eight years old and something I'll make to the day I die probably. So, I'm trying to teach my son how to fry chicken, how to do some of the things that he likes that I do." **Angela**

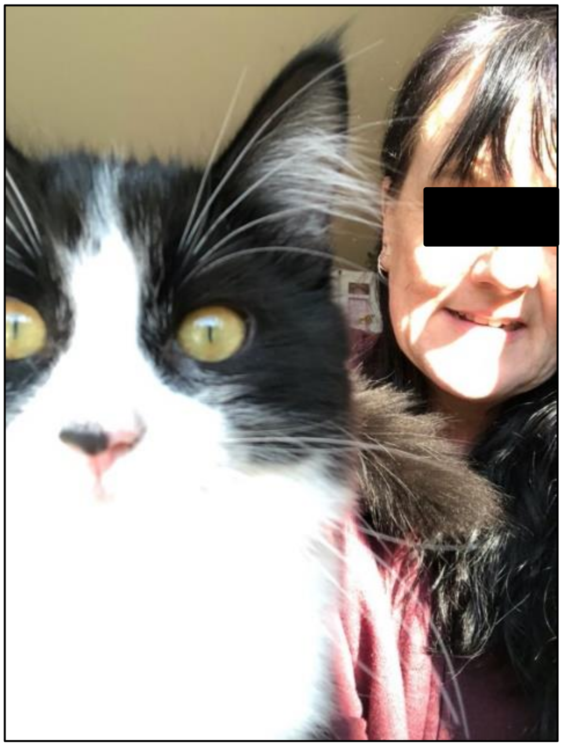
Angela also mentions that she also wants her son to be able to communicate, to ask for what he needs to and she’s trying to do that through sharing food and cooking.

> “You know and that's one of the things that I've been trying to teach him is that you've got to be able to open your mouth and say what you need to say… Talk and if you can tell me what you want to eat then that's a start. But food is very important in my life too, caring and just everything. Food is a big thing in my life, always has been.” **Angela**

During this conversation Erika asked that if Angela’s son was four when she had her stroke. Angela discusses how her son has grown up knowing her after her BI.

> *“*Yeah. yup, So I mean this is pretty much all he's known, for me anyway. He's pretty good about it, he has an issue every once in a while, but for the most part he's good. He understands, he doesn't like it, but he understands. And he knows that sometimes “Dude, I can't do it. I can't go today. I can't do it” and he'll say, "that's alright" and he does have an issue every once in a while, because I can see it in his face, but he never says anything. And I'll ask him “Are you okay? Or is there something else that we can do or something that I can do? "Oh no we can sit here, we can play PS4" alright, so we'll you know sit there and play baseball or hockey or whatever he wants to play, he's really good.” **Angela**

Diane’s photo speaks to the important relationships with non-human companions that are also family, her cat. In the narrative below she discusses how she feels safe to be herself around her cat and the reciprocal relationship in which she feels safe and understood while simultaneously having someone to care for, providing a sense of purpose and responsibility.



[redacted]

Figure 16. I am me when I am at home with my cat (Source: Diane, 2019).

“I am me when I am at home with my cat because I don't have to pretend, and I don't have to be different. She only knows me as me. We have a relationship and we both know each other's routines and she can she understands me…and that's where I feel most comfortable. she's not going to be judging me… it's the perfect situation. That's where I feel most comfortable is with animals and especially having one in my home. Something that I can focus on, that I can love and cherish. I don't have my kids all the time. So, this was my other kid.” **Diane**

I Feel Like I'm Part of…

Relationships within the community or to peers were also highlighted within interview and focus group discussions. Having relationships within the community brought feelings of acceptance and belonging or wanting to give back to the community. Sometimes it also brought up both a sense of belonging and of difference. While this can be challenging it also provides deep insight. In the photo below, Sara shared her positive experiences in community, specifically with horseback riding therapy, feeling accepted by the staff, volunteers, and the other participants. She has been going for the last six or seven years.

Figure 17. Horseback riding (Source: Sara, 2019).

"I go horseback riding every Wednesday. I feel very comfortable with the people there. I feel like I present as "normal" sitting in the saddle. I like not being hindered by my lack of speed. I think being by myself, is where I would feel most comfortable. I think the other place is the horseback riding because honestly, I feel that I sit on that horse and I look like everyone else, so no one could know I can't walk**.** The people there are so awesome that I feel totally accepted. I think that the other people there are invaluable, and they are not there to judge you...They're

> there because they believe in horseback therapy and they are used to seeing people with disabilities, I don’t have to explain myself or have people feel uncomfortable. They are voluntarily there to participate or to learn or help so I don't feel self-conscious. To have a horse take me where I want to go is so powerful and quick and people have their own struggles there too so their coming from a place of more understanding.” **Sara**

Part of accepting where we are at, either aspects or all of ourselves, is through the sense of belonging and acceptance within a community outside of ourselves. Sara also discussed the importance of having community and support in life. In the quote below she shares how a friend reminded her of who she is, the importance of those interdependent relationships that offer consistency and love, especially after life changing events.

> “People stand by you and I think that makes the biggest difference and I think going back to your identity I think that kind of helps because they know who you are and that it is helpful and kind of the aftermath where you have the mirror (people supporting you, remind you of who you are) I had a friend come visit me once and we were talking for a while and she goes "as soon as you said something with sarcasm I knew it was still you" ...I think that's really important to have that, like the friends who know who you are so they can help you find your way again and same with family.” **Sara**

Pearl’s narrative discussed the tension in duality. Feeling a sense of community and belonging while simultaneously feeling different and not quite fitting in with her peers.

Figure 18. The odd leaf (Source: Pearl, 2019).

> **“**I took the picture and then I zoomed in and then I started kind of thinking this is actually like my environment a little a bit. I feel like I'm part of a very strong community of beautiful people around me and I'm part of you know I'm on this branch and they're strong roots underneath and so much to be grateful for and everybody to hold me up. But at the end of the day, I still feel very different.” **Pearl**

Pearl also shared an image that described how she views the world through the lens of a body with vestibular issues (e.g., balance) and in navigating this change she notes that it’s hard to relate to others in the same way.

*Figure 19***.** How I see the world (Source: Pearl, 2019).

> **“**It actually makes a lot of sense in my world because I have a lot of vestibular issues and so this is how I perceive the world and I'm moving forward, there’s a lot in my life but a lot of times like after things are over it's kind of like how I remember them. Kind of vague so that is just kind of symbolic of how I see my world. Just trying to go to work and go to the grocery store, and driving you know. Your exhausted cause your bodies trying to equal itself out, it’s just kind of hard relating to people sometimes…” **Pearl**

Having a Safe Space

A dominant subtheme in participant narratives centered around their relationship and the importance of having a safe space to take refuge in and that provided them a sense of peace, safety and security. Participants shared narratives around connections to the land or having their own living space/home that offered safety, comfort and protection. Many participant narratives discussed the aspects of what a particular environment offered them such as feeling comfortable to be themselves and not having to worry about being judged, giving a sense of a time out, a space in nature that felt like home or the safety and comfort of having their own living space. In the photo below, Sara discusses the place she feels most comfortable, her garden, and being by herself. In her narrative she points out the freedom it offers her in not having to worry about her movements and that her *audience* offers her a non-judgemental environment.

Figure 20. I love to be in my garden. The plants don't judge me. (Source: Sara, 2019).

> "I think when I paint or when I write, then yes (talking about being comfortable in a creative environment or activity). Kind of like the garden photo is, um, any like the things that I enjoy is so solitary that it doesn't matter if I'm shaking when I move something or if I have to kneel down to get something, or if I have to like crawl to my mobility scooter. The plants don't care! And it's so nice not to have an audience for that because then I feel self-conscious but with a garden and with art, no one's there, no one cares." **Sara**

Erika also shared a photo from her garden. In her narrative below she discussed the importance of having a place of refuge, beauty, and hope. This photo represents her process of being adaptable and going with the flow and the strawberries signify aspects of hope when she discussed the process of planting seeds and remaining hopeful for things to grow and yet also hold space for possible disappointments.

Figure 21. Hope (Source: Erika, 2019).

> "I went out to my garden, and I see all these beautiful ripe strawberries and so this represents a lot for me. It represents my garden which is my place of refuge and my home and nourishment and beauty and hope. I remember reading a quote once that "anyone who plants seeds has belief that there is tomorrow". So, I think in the hope of planting the seeds I also have to be kind of chill about it and be ready for disappointments, there's some things you can control and some things you can't...And some things you can grow immediately, and some don't…" **Erika**

Participants also discussed the importance of having relationships to land and nature beyond their physical home environment as well as taking care of the environment. For instance, Erika's photo below describes the importance of having a timeout from the busy-ness of her life and the push to be constantly productive and the feeling of being in nature.

Figure 22. Morning walk (Source: Erika, 2019).

> "For me this photo really represents tranquility, but it also represents where we live. It represents our home, our environment…I guess for me it just represents my connection to nature and just taking time by myself specifically which seems important. One thing I think I want more of in my life is gratitude and so there's something when I look at this and then I remember that experience of feeling good and being out in nature, just the sense of time out." **Erika**

Angela also shared of photo which she described as "her happy spot". In her narrative she also discussed the importance of this specific spot and the sense of connection she feels when she visits.

> "That is my happiness, that's my happy spot. Anytime that I feel down, lonely, sad. I go to Esquimalt lagoon. Once I get there, I step off the bus and I feel like I'm.... I don't know a foot taller and about 15 pounds lighter. I just feel that is my spot, where I go and get in touch with myself again. This is it. This is home and right there in that spot. yep!" "When I do that when I go there. I don't have to worry about my money problems, to worry about where I'm going to get my next meal and not to worry about where I'm going to live. I'm just there and everything. It feels like everything just comes in and it just it just calms me. I don't know what it is, but I don't have those worries when I'm there. It's really opened my eyes to the things that I need to be responsible for and not just me! but things

> around me. And that was never important to me. But it's becoming more and more important to me now." **Angela**

Figure 23. My happy spot (Source: Angela, 2019).

Angela's sharing of her connection to this place sparked a discussion around relating to nature and the land that offers a sense of acceptance, belonging and non-judgement, something that humans can learn and be humbled from.

> "I think I like being around like plants and the ocean and stuff like because they seem like they're alive but they're not people. For me it's OK you're not being judged and like there's no comparisons and I'm just enjoying this." **Sophie**

> "I can be who I need to be. Yeah. And there's no one there telling me "Oh you can't do that. You can't do this." **Angela**

> "There's that extra mystery with Ocean to I remember one time I went like down to Dallas Road and I was just like I needed to talk to get something out of my head, but I didn't want to talk to anyone. So, I can talk to the ocean. And it was just like you know watching the waves go in and out. It's like there's acceptance and there's humbling and belonging you know." **Sophie**

> "Well, it's kind of like what we as human beings need to be. You know there's so many different types and we all need to live together and intermingle and grow together and accept you know and that's what the ocean does for me. It doesn't judge me, it's just there." **Angela**

Some participants shared narratives around having their own space, a place of refuge that offered safety and support. In Diane's photo below, she shares how she feels safer inside then outside around other people. During my first interview with Diane, she shared that she had been homeless for a few months and then experienced several months of transitional housing until she was able to acquire a two-bedroom suite in the program. In our discussion she emphasized she was happy to have her place. In the photo below, Diane discussed how she feels safer inside, at her home and feeling safe from the outside world. More importantly, not having to navigate other people and be in survival mode.

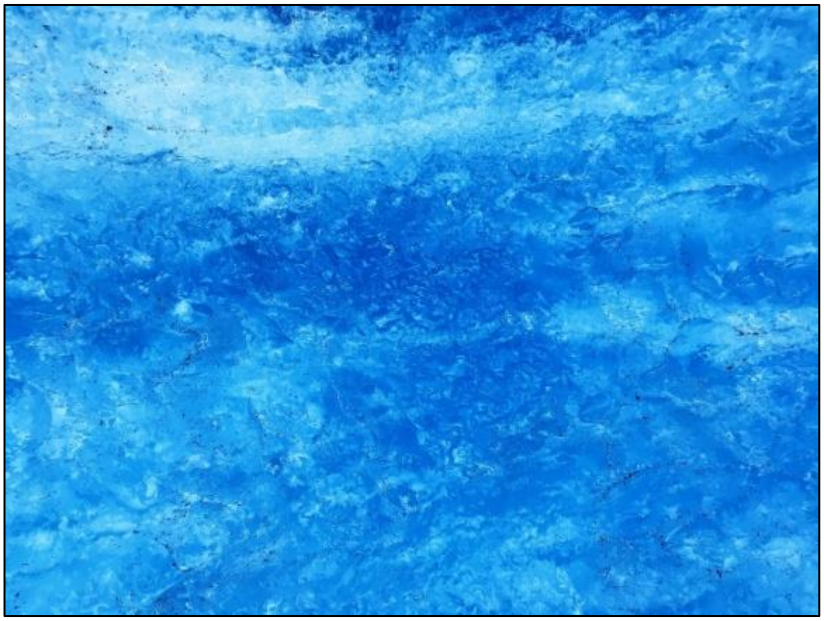


Figure 24. Ocean drops (Source: Diane, 2019).

> "My body just overreacts and goes "nah-nah, no. I gotta get out" it's too much right. So that's when I'm stepping out of my comfort zone. That's what I'm wearing. That's what I'm thinking. I'm just overwhelmed when I go outside. There are multiple factors in that like people… especially men because I have an issue with men right now like are they going to hurt me? So, you know, I'm constantly aware of that and the thoughts that go

> through my head. I just I can't. Like staying in here inside my place. I feel better. I'm safe” **Diane**

Sophie also shared a narrative that describes the importance of having a stable home base after her BI diagnosis. A place that she can make her own, that offers safety and comfort.


[redacted]

Figure 25. My space (Source: Sophie, 2019).

> “I just think of my whole body of like that, wanting to stay at home and rest has like amplified since my brain injury, like having this space, having my apartment, and making it like a sanctuary has been really helpful to my healing um, it was difficult for me not having a safe space after my brain injury. I feel like I can be myself here and this is, I think this is one of the few places that I can come and talk about my brain injury and not be judged and not worry about like being a burden.” **Sophie**

Chapter 5: Discussion

The purpose of this research was to explore the experiences of women who have survived a Brain Injury (BI), specifically focusing on the body concerning identity and environments. In addressing this inquiry, the literature reviewed examined research perspectives on BI, sex and gender, recovery, identity, embodiment, and the theoretical framework of Critical Feminist Disability (CFD). Semi-structured focus groups and interviews with six women with diverse experiences of BI provided images and narratives of their experiences of body, identities, and environments. This chapter discusses the significance of participants' perspectives, draws on current knowledge about women, BI and identity from the literature review and considers potential implications for professional practice. The limitations, strengths of this study, and possibilities for future research are also addressed.

Summary of Findings

Is it me or is it the BI? and Relationships were the two overarching themes that intersected in my research findings. Overall, participant narratives discussed aspects of identity that focused on loss, adapting, insight, and hopes. The themes that arose from participant narratives and discussions appeared to fit with the process of fluidity, diversity, and change when considering bodies, identities, and the role environments play. To fully explore participants' narratives about my research questions, subthemes within each overarching theme were identified. Subthemes generated within is it me or is it the BI? included: invisible/visible, disabled/not disabled, bodies marked by experience, and being/becoming. At the same time, subthemes distilled from relationships included: what my body is telling me, family, I feel like I'm part of…, and having a safe space.

In the following sections, I will specifically discuss relationships to body, the role of environments, identity and BI, loss of self, and roles and relating.

Relationships to Body

Embodiment was a core component of this research; this section discusses key elements shared about participants' body-self relationships. How this showed up in my findings was diverse and required a thorough examination of what was explicitly stated or implicitly implied. Throughout my data, I explored the continuum of being and becoming, which was informed by varying degrees of acceptance of self and body. Whether visible or invisible, this was a commonality that participants experienced in different ways. For example, it alluded to a level of acceptance by feeling comfortable and safe in their bodies and for some, it also included looking to the outside natural world for acceptance and understanding.

Elements of participants' relationship to their bodies have been explicit or implicit within their narratives of identity and relationship. When reflecting on their relationships to their body, participants discussed their unique understandings of their body, listening to it and striving towards varying levels of acceptance. Additionally, sometimes they straddled a spectrum of acceptance to disappointment depending on the moment. Participants' reflections on holding compassion for and acceptance of their bodies post injury aligned with research from Kling et al. (2018) on the process of developing an appreciation of their bodies and what they can do further supports a person's overall well-being and sense of identity versus placing the focus on a flaw, deficit or lack.

Participants also discussed having to navigate frustration, resentment, and disappointments about physical and functional changes which correlates with previous research findings from Kvigne and Kirkevold (2003) and Kitzmüller et al. (2013) who share similar findings of women’s experiences of BI. Additionally, participant narratives also pointed to having self-compassion and patience while trying to understand their bodies’ reactions and responses.

Participant narratives about their relationship and perceptions of their bodies appear to show varying levels of adaptation to changes in their bodies. Charmez (1995) describes the flow of adapting and acceptance when discussing experiences of chronic illness. For example, they describe adapting as acknowledging changes in the body and beginning with accommodating one’s personal and social life, moving through varying degrees of loss, and starting to shape into acceptance. These adaptations may be experienced at different times depending on their situations and may include ignoring, minimizing and resisting to regain an embodied sense of self after loss or change. This process of adapting and acceptance is evident in participant narratives around their relationship to their bodies and other subthemes that describe identity.

For BI survivors, living with an altered body, whether visible or invisible, requires a different approach to the world. A correlation with research from Charmez (1995) is the disruption or dis-embodiment caused by an illness or injury of a person's assumptions about the relationship between their body and self, or sense of self. All participants discussed how the injury had shifted their lives from changes to their bodies such as pain, fatigue, mobility and how they adapted to these changes. Charmez (1995) discusses taken for granted, assumptions about the body become the focus as one must re-learn how to move and communicate or adapt. In this case, adapting implies that the individual acknowledges the impairment and alters their life and self in social and personal acceptable ways. Thus, adapting occurs when aiming to accommodate and flow with the experience of injury.

The Role of Environments

In the overarching themes of is it me or is it the BI? and relationships, the influence physical and socio-cultural environments played in participants' narratives centered around non-judgmental attitudes, a sense of safety, acceptance, and connection. Participants reflected on which environments they felt most comfortable and at ease with their bodies. Specifically, when talking about environments, participants spoke about physical environments or spaces that were non-judgmental; this included being in more natural areas such as the garden or by the ocean. Participants also discussed their connection to a particular space or environment that brought positive feelings of hope, a sense of peace, letting go of worries, and being present. Some participants discussed the importance of finding and securing safe and stable housing that provides safety and offers comfort or a place of retreat. These findings suggest that having access to safe and affordable housing and access to natural environments such as parks or gardens will support recovery and overall wellbeing.

Identity and BI

Villa et al.'s (2020) definition of BI and self-identity encompasses our knowledge and understanding of ourselves, relationships, social roles, and self-perceptions. My findings correlated with social environments and connections, highlighting the importance of social roles and a sense of purpose. Specifically, four participants discussed their roles as parents and included narratives around bonding and spending time with their children, cooking or working on communication, learning from their children, and feeling a sense of purpose. Another participant discussed feeling a similar sense of purpose in taking care of her animal companion and that her cat was someone with whom she could be herself. In comparison, other participants discussed a sense of belonging and connection with peers in the community and in natural environments.

Loss of Self

Another correlation with previous BI literature and identity is a loss of self or grief and loss with aspects related to self-identity. Gelech and Desjardins (2011) discuss losses post injury that include functional performance, roles, status, relationships, and employment. All participants described several of these losses. This included the loss of physical functional abilities, previous career identity and employment, relationship status and possibility due to limitations. One participant discussed the loss of being able to hold her partner's hand due to her physical losses. Two participants discussed the loss of going back to previous career roles or altering them based on their specific needs. Another participant described feelings of grief and loss when thinking of her life before BI and changes in her relationship status, home, career, and the possibility of having children. Participant narratives also correlated with research from Carroll and Coetzer (2011) when examining the experience of loss and the awareness of loss post BI both tangible (employment, housing, physical health and ambiguous, such as the perception of control over one's life. While participants discussed aspects of loss in relation to their lives pre-injury, they also shared the insights they had gained in seeking to understand themselves post-injury.

Roles and Relating

Something that stood out in my findings was four out of six participants discussed their children and the role of being a parent (being a mother). Another participant expressed wanting to be a mom and the desire to have a child with the added pressure of age, recovery, and self-care. This finding piqued my curiosity as I searched for literature on mothers who survived a BI and parenting. I could only locate one article by McKinlay et al. (2014) discussing the possible threat of mothers physically harming their children. The language in the title of this article paints a negative image of mothers who survive BI's and that while aggression can be a component in post injury BI behaviour it is often contextual, or not true nor permanent for every survivor. Participants in this research spoke fondly of their children, time spent with them, aspects of parenting, and the purpose and focus their children gave them post injury. Additionally, research narratives on families navigating BI recovery are often hetero-normative, white, two parent families which is not realistic and does not capture the myriad of ways of what *family* entails.

Critical Feminist Disability and BI

CFD aims to reimagine disability while contesting dominant assumptions about disabled or impaired bodies and lives. It seeks to focus on often dismissed or silenced voices and challenge misrepresented or misunderstood experiences (Garland-Thomson, 2005a). It also conceptualizes the body and identity as dynamic and fluid and as something that is always in the process of becoming (Rice et al., 2021).

When thinking about identity and body, all participant narratives suggested they were in a process of being and becoming depending on their individual experiences. For many, it was not about fixing something about themselves that was broken or needing to be cured. To function in their daily lives required a level of acceptance of who they are in the moment. This also included finding meaning and purpose in their lives and a sense of connection and peace with themselves.

Purpose and meaning suggested by participant themes included being a mom, or a caregiver, having a job or profession that they enjoyed, a sense of community, and a place where they could go to feel safety and comfort. Furthermore, participants also spoke about certain levels of acceptance of themselves and who they were and that this came through spending time with themselves and having a chance to really understand who they are at that moment. Another layer that is connected to the concept of being and becoming, yet intricately linked with body and identity is the social and material world.

A specific focus of CFD is feminist material disability theory, centering on embodied experience in relation to the social and material world. Garland-Thomson (2011) uses the concepts of fitting and misfitting to explain certain bodies who *fit* or *misfit* in certain environments and discourses to explain the obstacles of appearing visibly different from what might be expected in society. This concept is a helpful way to critically reflect on the lived identity and experience of disability as it is situated in a place and time. A *fit* occurs when a harmonious interaction occurs between a particularly shaped and functioning body and an environment that sustains that body. A *misfit* occurs when the environment does not sustain the shape and function of the body that enters it. I also interpreted this concept when thinking about participants narratives as belonging; to belong was a fit and feelings, thoughts or actions that implied not belonging was a misfit.

There are several points illustrated in participants' narratives when applying the concept of fit or misfit. Participants in the research, while having diverse experiences, had some commonalities across themes. The terms misfitting and fitting can be applied when considering participants' narratives and themes centered around the body, identity and environment.

Misfitting in certain environments emerged in several occurrences across participant narratives. For example, two participants discussed being stared at and receiving unwanted attention for not visibly fitting in with what might be considered *normal* in social environments. Garland-Thomson (2005b) describes staring as an embodied act of non-verbal human communication, a way of expressing something such as a response to others that holds complex cultural and historical meanings. This misfit also not only includes physical differences, but also behaviours and or sharing parts of their identities that are often stigmatized (i.e., disability, brain injury, head injury) which implies attitudinal barriers in certain social environments. Misfitting in this case also includes the ways that we are socialized and hegemonic discourses on how women ought to look to be perceived as normal, including performing certain behaviours and roles.

Some participants spoke of certain environments that created barriers or a misfit, such as the medical system either letting them down for not recognizing their diagnosis or not taking them seriously and having to prove that something is wrong or a concern. Wendell (1996) has described this as the cognitive and social authority of Western medicine experience of our bodies, which means that this authority describes how our bodies affect how we experience our bodies. Further, it refers to how society describes our experiences and validates or invalidates them, and what can be known about the human body. This authority of Western medicine can delegitimize our experiences of our bodies as sources of knowledge and expertise about them and affect the relationship to the patient and the quality of medical care received. Similarly, research from Alston et al. (2012) states that due to the bias of sex and gender, women post BI often navigate their health concerns from subordinate social positions which undermines their own self-advocacy and credibility.

Participants also spoke about environments where they felt like they *fit*. This included socio-cultural environments such as: community, family and friends, and natural and built environments. The qualities these environments held included attitudes of compassion, understanding, non-judgment and empathy, as well as stability and safety. This suggests that participants want to be free from stigma and feel like they belong in social and material environments and there are certain qualities about these environments that convey belonging or connection, in which they fit.

Research and Practice Implications

This study highlighted the diverse experiences of participants and did not lend itself to generalizing findings to a larger population; however, its implications still call for research and practice considerations. There is much to be learned from the unique experiences explored and the process of inquiry. The following section focuses on implications and future research suggestions for allied health practitioners and educators in the helping fields such as Child and Youth Care (CYC), families and communities.

The qualitative findings of this study can inform future research on women who have survived a BI and their individual and collective experiences. There is the potential to impact BI service quality and accessibility and contribute knowledge to the allied helping professions. Additionally, this research may also contribute to a better understanding of the value that rehabilitative and therapeutic programs that address the body and identity can have and what physical and socio-cultural environments may support these programs.

In recent years, research practices have been shifting to include differentiating sex and gender in health and social science research (Mollayeva & Colantonio, 2017). This is important to ensure services are accessible and survivor centered. As noted in chapter four, research from Hamberg (2008) shows that women and girls tend to receive a diagnosis of anxiety when their symptoms are not recognized or easily recognizable. Additionally, there is still a lack of knowledge in many helping sectors about intimate partner violence (IPV) BI and screening. This may come from many factors. First, there is a disconnect between the most up-to-date research in the field of BI and knowledge translation reaching medical practices. While BI has been noted as a concerning issue globally, there is still a lack of funding for this knowledge translation and training to gain complete access, such as in rural and remote communities.

In the area of CYC, there are multiple areas of research on children with disabilities and families, yet it is hard to find articles or research areas that depict the role of mothers caring for children after a surviving BI. It should be noted that this is also true for fathers and that BI literature emphasizes rehabilitation and identity in returning to work but not their roles as parents and caregivers. This is particularly important when thinking about the intersections of BI, family, community and where CYC practitioners and other helping professionals may be involved such as hospitals, schools, shelters, child protection services, counselling and community programs.

Practice implications for CYC practitioners working alongside BI survivors should include engaging a trauma informed and anti-oppressive practice. Practitioners should also have an awareness and knowledge of BI and how it may affect survivors beyond individual symptoms such as relationships, occupations or school, parenting, housing, finances. Consideration of symptoms or behaviours that might not be so obvious is needed, such as awareness of neuro fatigue which impacts short term memory, decision making, organization, timing, balance, focus, vision and nervous system function. Having patience and compassion, using visual cues such as written reminders and creative ways to include repetition can go a long way in supporting survivors achieve their goals.

Recommendations for Practice and Future Research

Previous literature on BI survivors has emphasized the need to ask survivors what they recommend regarding research and practice. During my final interviews and focus groups, I asked participants what advice or recommendations they could share for survivors and helping professionals. For survivors of BI, participants spoke of having patience, self-compassion and being your own advocate during recovery and onward. As for helping professions and services, participants suggested that more knowledge translation and advocacy work be done within hospitals and rehabilitation centres. Additionally, clearly communicating to survivors what to expect during short-and longer-term recovery periods, providing written communication (an actual list) of advocacy and community resources and funding. Finally, creating more programs in community that also include family members and other support networks.

Conducting research studies with larger sample sizes of individuals and in different geographical locations may allow for more specified results in relation to the area and available resources. This should also include longitudinal research that would allow for the investigation over longer durations of time. Additionally, research focused on the lived experiences and needs of women whose voices are often missing in BI research is needed, including Indigenous, Black and women of colour, immigrant and refugee, and transgender women to understand and develop supportive, culturally safe and appropriate therapeutic services unique to their needs and communities for successful well-being and recovery.

Limitations

This research explores and reflects the experiences of these six participants residing in greater Victoria, B.C., within this moment in time. It is very specific, localized, and the sample size is small. While participant size does not reflect research rigor, it is essential to emphasize that the findings are not generalizable to the experiences of all women who have survived a BI. Another limitation noted is the researcher's beginning knowledge in qualitative research and analysis experience. Additionally, a critique of CFD research is that while it includes race in its framing it is often not centered within the analysis. Schalk and Kim's (2020) *Integrating race, transforming feminist disability studies* discusses the necessity of thinking beyond representation and identity framing disability studies to analyze the intersecting systems of ableism, heteropatriarchy, white supremacy, colonization and capitalist violence, particularly as they assign value or lack thereof to certain bodies. While participants were diverse in this study, I was not explicitly focused on other aspects of identity (race, religion, language, non-binary) which as noted in the literature review is imperative to consider for future research to understand the lived experience of BI alongside other intersecting identities, especially when thinking about long-term therapeutic programs, recovery, and community programs for survivors.

Strengths and Final Thoughts

This research offers several strengths. For instance, since I was already working in the community with BI survivors, I had insider/outsider status that supported rapport building and trust among myself and participants. I was also able to meet with them on three occasions over the course of a month during data collection. Additionally, incorporating an embodied visual arts-based activity might have provided a sense of autonomy over expressing personal narratives and guiding questions to offer a semi-structured framework for their stories. This offered participants the choice to focus on how they wanted their narratives to unfold and be told. Visual elements can sometimes help when discussing specific experiences that may be harder to articulate or express through narrative alone.

This research provides detailed and rich descriptions of the experiences of women who have survived a BI through their narratives and photographs. Specifically, it aimed to focus on the body and environment’s role in identity post injury and how this may provide insight and contribute to short- and long-term rehabilitative programs in community and future research aims. Thinking about survivors and the diversity of BI, invisible or visible, there needs to be a greater understanding and considerations about the contextual factors of how and where BI occurs, and the aftermath and impacts of an injury. More importantly, the idea that this is not the end of someone's story is critical, and for practitioners, families and community members coming in with a lens of compassion and understanding beyond anything else.

References

Alston, M., Jones, J., & Curtin, M. (2012). Women and traumatic brain injury: "It's not visible damage." *Australian Social Work*, *65*(1), 39–53. https://doi.org/10.1080/0312407X.2011.594898

Bach, H. (2012). Composing a visual narrative inquiry. In D. J. Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology* (pp. 280–307). Sage.

Baumann, R. M., Hamilton-Wright, S., Riley, D. L., Brown, K., Hunt, C., Michalak, A., & Matheson, F. I. (2019). Experiences of violence and head injury among women and transgender women sex workers. *Sexuality Research and Social Policy*, *16*(3), 278-288.

Berg, B. L., & Lune, H. (2017). *Qualitative research methods for the social sciences* (9th ed.). Pearson.

Berthold Lindstedt, M., Johansson, J., Ygge, J., & Borg, K. (2019). Vision-related symptoms after acquired brain injury and the association with mental fatigue, anxiety and depression. *Journal of Rehabilitation Medicine*, *51*(7), 499–505. https://doi.org/10.2340/16501977-2570

Boss, P. (2010). The trauma and complicated grief of ambiguous loss. *Pastoral Psychology*, *59*(2), 137–145. https://doi.org/10.1007/s11089-009-0264-0

Boss, P. (2016). The context and process of theory development: The story of ambiguous loss. *Journal of Family Theory and Review*, *8*(3), 269–286.

Brain Injury Association of Canada. (n.d.). Brain injury statistics. Retrieved from: https://www.braininjurycanada.ca/en/statistics-brain-injury. Accessed on November 22, 2021.

Brain Institute. OHSU. (n.d.). Retrieved November 21, 2021, from https://www.ohsu.edu/brain-institute/autoimmune-encephalitis.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Butler-Kisber, L. (2010). *Qualitative inquiry: Thematic, narrative and arts-informed perspectives*. Sage.

Campbell, J. C., Anderson, J. C., McFadgion, A., Gill, J., Zink, E., Patch, M., ... & Campbell, D. (2018). The effects of intimate partner violence and probable traumatic brain injury on central nervous system symptoms. *Journal of Women's Health*, *27*(6), 761–767.

Carroll, E., & Coetzer, R. (2011). Identity, grief and self-awareness after traumatic brain injury. *Neuropsychological Rehabilitation*, *21*(3), 289–305. https://doi.org/10.1080/09602011.2011.555972

Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *Sociological Quarterly, 36*(4), 657–680. https://doi.org/10.1111/j.1533-8525.1995.tb00459.x

Chrisler, J. C., & Johnston-Robledo, I. (2018). *Woman's embodied self: Feminist perspectives on identity and image*. American Psychological Association. https://doi.org/10.1037/0000047-001

Clandinin, D. J. (2007). *Handbook of narrative inquiry: Mapping a methodology*. Sage.

Colantonio, A., Harris, J. E., Ratcliff, G., Chase, S., & Ellis, K. (2010). Gender differences in self-reported long-term outcomes following moderate to severe traumatic brain injury. *BMC Neurology*, *10*(1), 102. https://doi.org/10.1186/1471-2377-10-102

Colantonio, A. (2015). Science fact or science fiction: Traumatic brain injury: Does gender matter? *CIHR Institute of Gender and Health, 4*, 4–5. http://www.cihr-irsc.gc.ca/e/documents/igh_mythbuster_january_2015_en.pdf

Colantonio, A. (2016). Sex, gender, and traumatic brain injury: A commentary. *Archives of Physical Medicine and Rehabilitation*, *97*(2), S1–S4. https://doi.org/10.1016/j.apmr.2015.12.002

Colantonio, A. (2020). Beyond football: Intimate partner violence and concussion/brain injury. *Canadian Psychology/Psychologie Canadienne, 61*(2), 163.

Dassah, E., Aldersey, H. M., & Norman, K. E. (2017). Photovoice and persons with physical disabilities: A scoping review of the literature. *Qualitative Health Research, 27*(9), 1412–1422. https://doi.org/10.1177/1049732316687731

Davis, A. N. (2005). Invisible disability. *Ethics, 116*, 153–213.

Dewey, J. (1958). *Experience and nature* (Vol. 471). Courier Corporation.

Dudley, J. R. (2011). *Research methods for Social Work: Being producers and consumers of research* (2nd ed.). Pearson Education.

Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, *8*(1), 54–63.

Erikson, E.H. (1968). *Identity: youth and crisis.* Norton & Co.

Fabricius, A. M., D'Souza, A., Amodio, V., Colantonio, A., & Mollayeva, T. (2020). Women's gendered experiences of traumatic brain injury. *Qualitative Health Research*, *30*(7), 1033–1044. https://doi.org/10.1177/1049732319900163

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, *5*(1), 80–92. https://doi.org/10.1177/160940690600500107

Garland-Thomson, R. (1997). *Extraordinary bodies: Figuring physical disability in American culture and literature.* Columbia University Press. https://hdl-handle-net.ezproxy.library.uvic.ca/2027/heb.02826

Garland-Thomson, R. (2001). Re-shaping, re-thinking, re-defining: Feminist disability studies. *Center for Women Policy Studies*.

Garland-Thomson, R. (2002). Integrating disability, transforming feminist theory. *Feminist Disability Studies*, *14*(3), 1–32. https://www.jstor.org/stable/4316922

Garland-Thomson, R. (2005a). Feminist disability studies. *Signs: Journal of women in Culture and Society*, *30*(2), 1557-1587.

Garland-Thomson, R. (2005b). Staring at the Other. *Disability Studies Quarterly*, *25*(4).

Garland-Thomson, R. (2011). Misfits: A feminist materialist disability concept. *Hypatia*, *26*(3), 591-609. doi:10.1111/j.1527-2001.2011.01206.x

Gelech, J. M., & Desjardins, M. (2011). I am many: The reconstruction of self, following acquired brain injury. *Qualitative Health Research*, *21*(1), 62-74. https://doi.org/10.1177/1049732310377454

Given, L. M. (2008). *The SAGE encyclopedia of qualitative research methods*. Sage.

Goldberg, G. (2011). Medical phenomenology and stroke rehabilitation: An introduction. *Topics in Stroke Rehabilitation*, *18*(1), 1–5. https://doi.org/10.1310/tsr1801-1

Haag, H., Caringal, M., Sokoloff, S., Kontos, P., Yoshida, K., & Colantonio, A. (2016). Being a woman with acquired brain injury: Challenges and implications for practice. *Archives of Physical Medicine and Rehabilitation*, *97*(2), S64–S70. https://doi.org/10.1016/j.apmr.2014.12.018

Haag, H., Jones, D., Joseph, T., & Colantonio, A. (2019). Battered and brain injured: Traumatic brain injury among women survivors of intimate partner violence-A scoping review. *Trauma, Violence, and Abuse*, 1–18. https://doi.org/10.1177/1524838019850623

Haag, H.L., Biscardi, M., Smith, N. N., MacGregor, N., & Colantonio, A. (2019). Traumatic brain injury and intimate partner violence: Addressing knowledge and service gaps among Indigenous populations in Canada. *Brain Impairment*, *20*(2), 197-210.

Hamberg, K. (2008). Gender bias in medicine. *Women's Health*, *4*(3), 237–243. https://doi.org/10.2217/17455057.4.3.237

Harrison, J., Macgibbon, L., & Morton, M. (2001). Regimes of trustworthiness in qualitative research: The rigors of reciprocity. *Qualitative Inquiry*, *7*(3), 323–345. https://doi.org/10.1177/107780040100700305

Hartney, E. (2020, November 20). *What is dissociation*. Retrieved December 4, 2021, from http://www.verywellmind.com/what-is-dissociation-22201.

Heart & Stroke. (2018). Lives disrupted: The impact of stroke on women. https://heartstrokeprod.azureedge.net/-/media/pdf-files/canada/stroke-report/strokereport2018.ashx?la=en&rev=8491d9c349f7404491f36be67f649c0b

Howes, H., Benton, D., & Edwards, S. (2005a). Female body image following acquired brain injury. *Brain Injury*, *19*(6), 403–415. https://doi.org/10.1080/02699050400025158

Howes, H., Benton, D., & Edwards, S. (2005b). Women's experience of brain injury: An interpretative phenomenological analysis. *Psychology & Health*, *20*(1), 129–142. https://doi.org/10.1080/0887044042000272903

Hunter, L. (2017). If you see what I mean? Visual narratives – stories told through, with and by visual images. In R. Dwyer, I. Davis, & E. Emerald (Eds.), *Narrative research in practice: Stories from the field.* (pp. 89–116). Springer. https://doi.org/10.1007/978-981-10-1579-3

International Brain Injury Association, IBIA, (n.d.) Brain injury facts. Retrieved from: https://www.internationalbrain.org/resources/brain-injury-facts. Accessed November 22, 2021.

Kennelly, J., Ledger, A., & Flynn, L. (2017). Critical junctures in narrative research: Collaborative reflections on methodological issues. In R. Dyer, I. Davis, & E. Emerald (Eds.), *Narrative research in practice: Stories from the field.* (pp. 67–88). Springer. https://doi.org/10.1007/978-981-10-1579-3_4

Kirby, S. L., Greaves, L., & Reid, C. (2006). *Experience research social change: Methods beyond the mainstream.* University of Toronto Press.

Kitzmüller, G., Häggström, T., & Asplund, K. (2013). Living in an unfamiliar body: The significance of the long-term influence of bodily changes on the perception of self after stroke. *Medicine, Health Care and Philosophy*, *16*(1), 19–29. https://doi.org/10.1007/s11019-012-9403-y

Kling, J., Wängqvist, M., & Frisén, A. (2018). “This body is me” Discovering the ways in which the body is salient in people’s identities. *Body Image*, *24*, 102–110. https://doi.org/10.1016/j.bodyim.2017.12.009

Kolakowsky-Hayner, S. A., & Goldin, Y. (2020). Sex and gender issues for individuals with acquired brain injury during COVID-19: A commentary. *Archives of Physical Medicine and Rehabilitation*, *101*(12), 2253–2255). https://doi.org/10.1016/j.apmr.2020.08.004

Kreutzer, J. S., Mills, A., & Marwitz, J. H. (2016). Ambiguous loss and emotional recovery after traumatic brain injury. *Journal of Family Theory and Review*, *8*(3), 386–397. https://doi.org/10.1111/jftr.12150

Kuntz, A. M. (2010). Representing representation. *International Journal of Qualitative Studies in Education*, *23*(4), 423–433. https://doi.org/10.1080/09518398.2010.492769

Kvigne, K., & Kirkevold, M. (2003). Living with bodily strangeness: Women’s experiences of their changing and unpredictable body following a stroke. *Qualitative Health Research*, *13*(9), 1291–1310.

Kwako, L. E., Glass, N., Campbell, J., Melvin, K. C., Barr, T., & Gill, J. M. (2011). Traumatic brain injury in intimate partner violence: A critical review of outcomes and mechanisms. *Trauma, Violence, and Abuse, 12*(3), 115–126. https://doi.org/10.1177/1524838011404251

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage.

Lindsay, G. M., & Schwind, J. K. (2016). Narrative inquiry: Experience matters. *Research Methodology*, *48*(1), 14–20. https://doi.org/10.1177/0844562116652230

Lorenz, L. S. (2010). Visual metaphors of living with brain injury: Exploring and communicating lived experience with an invisible injury. *Visual Studies*, *25*(3), 210–223. https://doi.org/10.1080/1472586X.2010.523273

Masel, B. E., & DeWitt, D. S. (2010). Traumatic brain injury: A disease process, not an event. *Journal of Neurotrauma*, *27*(8), 1529–1540. https://doi.org/10.1089/neu.2010.1358

Mazzei, L., & Jackson, A. (2012). Complicating voice in a refusal to "let participants speak for themselves." *Qualitative Inquiry*, *18*(9), 745–751. https://doi.org/10.1177/1077800412453017

McIntyre, A., Rice, D., Janzen, S., Mehta, S., Harnett, A., Caughlin, S., Sequeira, K., & Teasell, R. (2020). Anxiety, depression, and quality of life among subgroups of individuals with acquired brain injury: The role of anxiety sensitivity and experiential avoidance. *NeuroRehabilitation*, *47*(1), 45–53. https://doi.org/10.3233/NRE-203080

McKinlay, A., Bishop, A., & McLellan, T. (2011). Public knowledge of "concussion" and the different terminology used to communicate about mild traumatic brain injury (MTBI). *Brain Injury*, *25*(7–8), 761–766. https://doi.org/10.3109/02699052.2011.579935

McKinlay, A., van Vliet-Ruissen, C., & Taylor, A. (2014). Traumatic brain injury among mothers identified as having a high risk of child maltreatment: A pilot study. *Journal of Family Violence*, *29*(4), 391-395.

Merleau-Ponty, M. (1962). *Phenomenology of perception*. Routledge.

Mollayeva, T., Kendzerska, T., Mollayeva, S., Shapiro, C., Colantonio, A., & Cassidy, D. (2013). Fatigue in adults with traumatic brain injury: Predictors and consequences. A systematic review of longitudinal study protocols. *Systematic Reviews*, *2*(1), 57. https://doi.org/10.1186/2046-4053-2-57

Mollayeva, T., & Colantonio, A. (2017). Gender, sex and traumatic brain injury: Transformative science to optimize patient outcomes. *Health Care Quarterly*, *20*(1), 6-9.

Mollayeva, T., Mollayeva, S., & Colantonio, A. (2018). Traumatic brain injury: Sex, gender and intersecting vulnerabilities. *Nature Reviews Neurology*, *14*(12), 711–722. https://doi.org/10.1038/s41582-018-0091-y

Mukherjee, D., Reis, J. P., & Heller, W. (2003). Women living with traumatic brain injury. *Women & Therapy*, *26*(1–2), 3–26. https://doi.org/10.1300/J015v26n01_01

O'Connor, H., & Gibson, N. (2003). A step-by-step guide to qualitative data analysis. *Pimatisiwin: A Journal of Indigenous and Aboriginal Community Health*, *1*(1), 63–90.

Omar, S., Nixon, S., & Colantonio, A. (2021). Integrated care pathways for Black persons with traumatic brain injury: A critical transdisciplinary scoping review of the clinical care journey. *Trauma, Violence, & Abuse*, 1-28. doi.org/10.1177/15248380211062221

Padgett, D. K. (2008). *Qualitative methods in social work research* (2nd edition). Sage.

Pallesen, H. (2014). Body, coping and self-identity. A qualitative 5-year follow-up study of stroke. *Disability and Rehabilitation*, *36*(3), 232–241. https://doi.org/10.3109/09638288.2013.788217

Pinnegar, C. S., & Daynes, J. G. (2007). Locating narrative inquiry historically: Thematics in the turn to narrative. In D. J. Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology*. (pp. 3-35). https://doi.org/10.4135/9781452226552

Polkinghorne, D. E. (2007). Validity issues in narrative research. *Qualitative Inquiry, 13*(4), 471–486. https://doi.org/10.1177/1077800406297670

Ralph, A., & Derbyshire, C. (2013). Survivors of brain injury through the eyes of the public: A systematic review. *Brain Injury, 27*(13–14), 1475–1491. https://doi.org/10.3109/02699052.2013.823653

Rice, C., Riley, S., LaMarre, A., & Bailey, K. A. (2021). What a body can do: Rethinking body functionality through a feminist materialist disability lens. *Body Image*, *38,* 95–105. https://doi.org/10.1016/j.bodyim.2021.03.014

Ryan, G. W., & Bernard, H. R. (2003). Techniques to identify themes. *Field Methods*, *15*(1), 85–109.

Schalk, S., & Kim, J. B. (2020). Integrating race, transforming feminist disability studies. *Signs: Journal of Women in Culture and Society*, *46*(1), 31-55.

Simmonds, S., Roux, C., & Avest, I. (2015). Blurring the boundaries between photovoice and narrative inquiry: A narrative photovoice methodology for gender-based research. *International Journal of Qualitative Methods, 14*(3), 33–49. https://doi.org/10.1177/160940691501400303

Slatman, J. (2014). Multiple dimensions of embodiment in medical practices. *Medicine, Health Care and Philosophy, 17*(4), 549–557. https://doi.org/10.1007/s11019-014-9544-2

Tasker, S. L. (2003). Acquired brain injury: Meaning making out of lived trauma. *Illness, Crisis & Loss, 11*(4), 337–349. https://doi.org/10.1177/1054137303256585

Thomas, E. J., Levack, W. M. M., & Taylor, W. J. (2014). Self-reflective meaning making in troubled times: Change in self-identity after traumatic brain injury. *Qualitative Health Research*, *24*(8), 1033–1047. https://doi.org/10.1177/1049732314542809

Timothy, E. (2015). *Some (body) else: Transitions in embodiment after stroke* (Doctoral dissertation, University of Otago).

Toccalino, D., Haag, H. L., Estrella, M. J., Cowle, S., Fuselli, P., Ellis, M. J., ... & COVID TBI-IPV Consortium. (2022). The intersection of intimate partner violence and traumatic brain injury: Findings from an emergency summit addressing system-level changes to better support women survivors. *Journal of Head Trauma Rehabilitation*, *37*(1), E20-E29.

Tuck, E., & McKenzie, M. (2015). Relational validity and the “where” of inquiry: Place and land in qualitative research. *Qualitative Inquiry*, *21*(7), 633–638. https://doi.org/10.1177/1077800414563809

Valera, E., & Kucyi, A. (2017). Brain injury in women experiencing intimate partner violence: Neural mechanistic evidence of an “invisible” trauma. *Brain Imaging and Behavior*, *11*(6), 1664–1677. https://doi.org/10.1007/s11682-016-9643-1

Valera, E., Joseph, A.L., Snedaker, K., Breiding, M., Robertson, C., Colantonio, A., …, & Bellgowan, P. (2021). Understanding traumatic brain injury in females: A state-of-the-art summary and future directions. *Journal of Head Trauma Rehabilitation*, *36*(1), E1–E17. https://doi.org/10.1097/HTR.0000000000000652

Villa, D., Causer, H., & Riley, G. (2020). Experiences that challenge self-identity following traumatic brain injury: A meta-synthesis of qualitative research. In *Disability and Rehabilitation* (pp. 1–17). Taylor and Francis. https://doi.org/10.1080/09638288.2020.1743773

Weiss, G. (2015). The normal, the natural, and the normative: A Merleau-Pontian legacy to feminist theory, critical race theory, and disability studies. *Continental Philosophy Review*, *48*(1), 77–93. https://doi.org/10.1007/s11007-014-9316-y

Wendell, S. (1989). Toward a feminist theory of disability. *Hypatia*, *4*(2), 104–124. http://www.jstor.org/stable/3809809

Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. Disability (1st ed.). Routledge. https://doi.org/10.4324/9780203724149

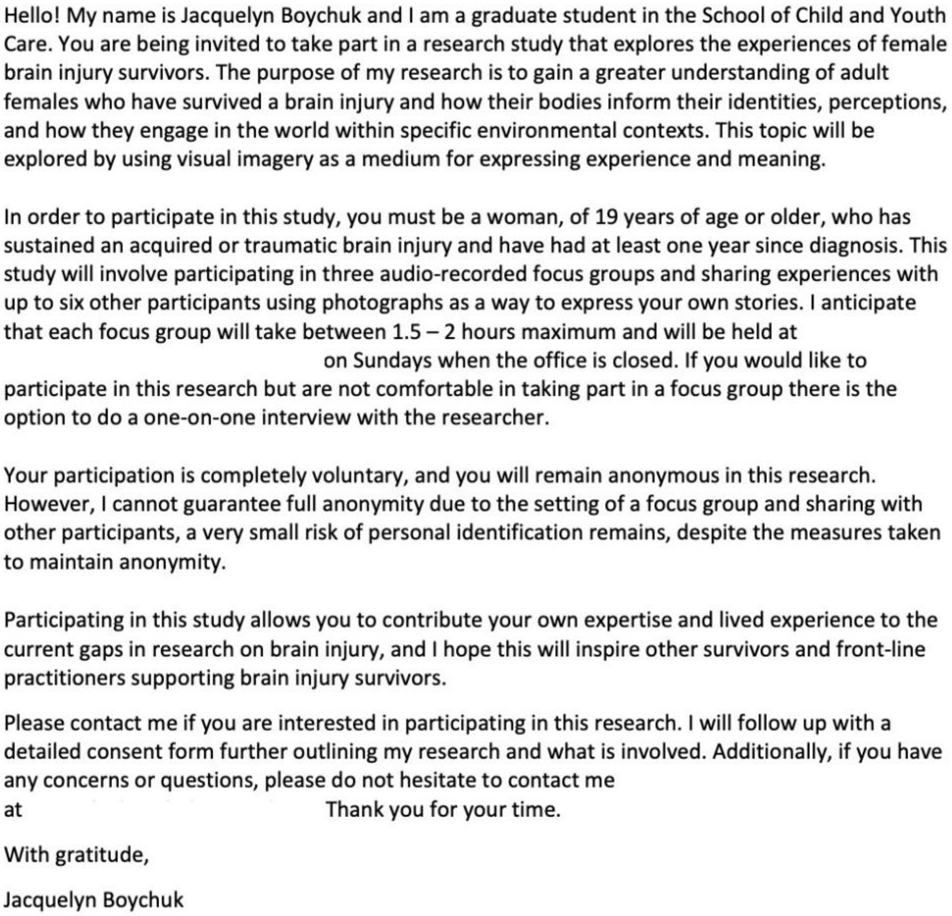
World Health Organization. (March 2021). Violence against women. Retrieved from: https://www.who.int/news-room/fact-sheets/detail/violence-against-women. Accessed November 22, 2021.

Ylvisaker, M., McPherson, K., Kayes, N., & Pellett, E. (2008). Metaphoric identity mapping: Facilitating goal setting and engagement in rehabilitation after traumatic brain injury. *Neuropsychological Rehabilitation*, *18*(5–6), 713–741. https://doi.org/10.1080/09602010802201832

Zitzelsberger, H. (2005). (In)visibility: Accounts of embodiment of women with physical disabilities and differences. *Disability & Society*, *20*(4), 389–403. https://doi.org/10.1080/09687590500086492

Appendix

Appendix A: Research email invitation



Hello! My name is Jacquelyn Boychuk and I am a graduate student in the School of Child and Youth Care. You are being invited to take part in a research study that explores the experiences of female brain injury survivors. The purpose of my research is to gain a greater understanding of adult females who have survived a brain injury and how their bodies inform their identities, perceptions, and how they engage in the world within specific environmental contexts. This topic will be explored by using visual imagery as a medium for expressing experience and meaning.

In order to participate in this study, you must be a woman, of 19 years of age or older, who has sustained an acquired or traumatic brain injury and have had at least one year since diagnosis. This study will involve participating in three audio-recorded focus groups and sharing experiences with up to six other participants using photographs as a way to express your own stories. I anticipate that each focus group will take between 1.5 – 2 hours maximum and will be held at on Sundays when the office is closed. If you would like to participate in this research but are not comfortable in taking part in a focus group there is the option to do a one-on-one interview with the researcher.

Your participation is completely voluntary, and you will remain anonymous in this research. However, I cannot guarantee full anonymity due to the setting of a focus group and sharing with other participants, a very small risk of personal identification remains, despite the measures taken to maintain anonymity.

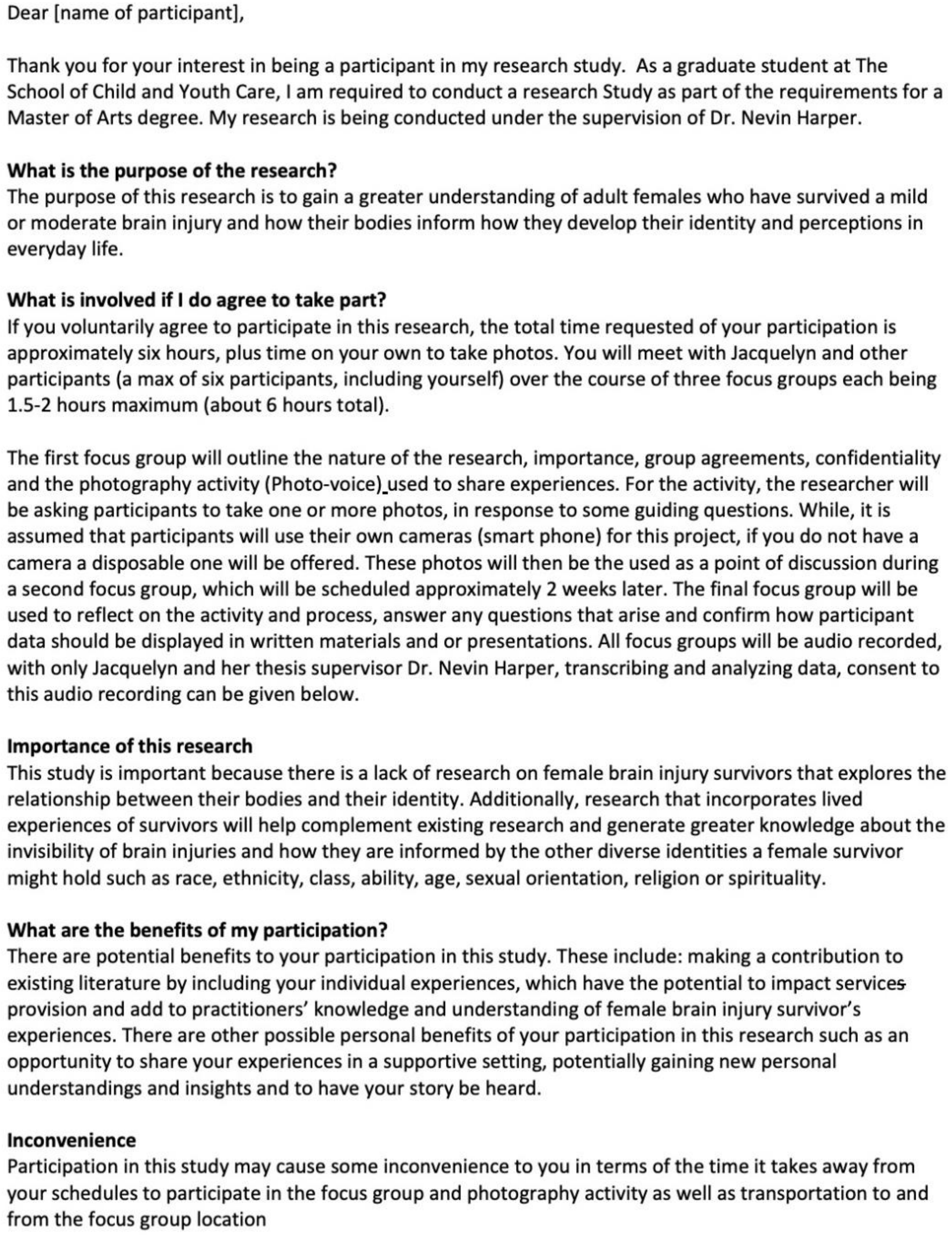
Participating in this study allows you to contribute your own expertise and lived experience to the current gaps in research on brain injury, and I hope this will inspire other survivors and front-line practitioners supporting brain injury survivors.

Please contact me if you are interested in participating in this research. I will follow up with a detailed consent form further outlining my research and what is involved. Additionally, if you have any concerns or questions, please do not hesitate to contact me at Thank you for your time.

With gratitude,

Jacquelyn Boychuk

Appendix B: Voluntary Consent Form Focus Group



Dear [name of participant],

Thank you for your interest in being a participant in my research study. As a graduate student at The School of Child and Youth Care, I am required to conduct a research Study as part of the requirements for a Master of Arts degree. My research is being conducted under the supervision of Dr. Nevin Harper.

What is the purpose of the research?

The purpose of this research is to gain a greater understanding of adult females who have survived a mild or moderate brain injury and how their bodies inform how they develop their identity and perceptions in everyday life.

What is involved if I do agree to take part?

If you voluntarily agree to participate in this research, the total time requested of your participation is approximately six hours, plus time on your own to take photos. You will meet with Jacquelyn and other participants (a max of six participants, including yourself) over the course of three focus groups each being 1.5-2 hours maximum (about 6 hours total).

The first focus group will outline the nature of the research, importance, group agreements, confidentiality and the photography activity (Photo-voice) used to share experiences. For the activity, the researcher will be asking participants to take one or more photos, in response to some guiding questions. While, it is assumed that participants will use their own cameras (smart phone) for this project, if you do not have a camera a disposable one will be offered. These photos will then be the used as a point of discussion during a second focus group, which will be scheduled approximately 2 weeks later. The final focus group will be used to reflect on the activity and process, answer any questions that arise and confirm how participant data should be displayed in written materials and or presentations. All focus groups will be audio recorded, with only Jacquelyn and her thesis supervisor Dr. Nevin Harper, transcribing and analyzing data, consent to this audio recording can be given below.

Importance of this research

This study is important because there is a lack of research on female brain injury survivors that explores the relationship between their bodies and their identity. Additionally, research that incorporates lived experiences of survivors will help complement existing research and generate greater knowledge about the invisibility of brain injuries and how they are informed by the other diverse identities a female survivor might hold such as race, ethnicity, class, ability, age, sexual orientation, religion or spirituality.

What are the benefits of my participation?

There are potential benefits to your participation in this study. These include: making a contribution to existing literature by including your individual experiences, which have the potential to impact service~~s~~ provision and add to practitioners' knowledge and understanding of female brain injury survivor's experiences. There are other possible personal benefits of your participation in this research such as an opportunity to share your experiences in a supportive setting, potentially gaining new personal understandings and insights and to have your story be heard.

Inconvenience

Participation in this study may cause some inconvenience to you in terms of the time it takes away from your schedules to participate in the focus group and photography activity as well as transportation to and from the focus group location

Are there any risks associated with participating?
If you choose to participate in this study, you may experience some emotional discomfort or fatigue by sharing personal information in front of other participants. In order to minimize any discomfort, Jacquelyn will create a safe and supportive environment, offer breaks and be available to debrief after group sessions. In the event you would like to debrief with a counsellor or support worker outside of the focus groups, Jacquelyn will provide you with contact information through .

Researcher's relationship with participants
It is possible that Jacquelyn could have a prior relationship with potential participants as past or present clients. Jacquelyn will not acknowledge any prior relationship as support worker-client, if one existed, in the research setting as that would breach a prior confidentiality agreement and violate ethical protocols. Additionally, whether you choose to participate fully or partially in this research will not affect your ability to access support or services from or any relationship with Jacquelyn outside this study.

Is my participation in this study voluntary?
Your participation in this research must be completely voluntary. If you do decide to participate, you may leave the study at any time without explanation or consequence. Nothing you say will be in any way identifiable as having come from you as all information that is gathered will be anonymous. If you do withdraw from the study, you may request that the anonymous data that you have contributed should be deleted from the collected materials and this request will be immediately carried out. After the focus groups are over, it will not be possible to remove your individual data, as none of the data will in any way be identifiable to you specifically. No names or personal identifiers or information will be collected during the focus groups and no recorded remarks or suggestions will be attributable to who shared what in the group, so it will be impossible to remove your individual contributions after the focus group is over.

How will you make sure I still want to participate?
It is important to check with you that you give your permission to take part throughout the entire study. To make sure that you continue to consent to participate in this research, Jacquelyn will verbally ask for your continued consent before each focus group.

Will you be able to know which responses were mine?
Your anonymity will be protected before, during, and after your participation in this study. If you choose to not participate at any time, your anonymity will still be protected. This will be done by removing all identity information from the focus group transcripts and photographs, and referring to participants by pseudonyms when analyzing transcripts, and reporting findings. This will help minimize the risk that anyone will be able to associate your data (interview transcripts and photography) with you. However, due to the small number of women with traumatic or acquired brain injury in the greater Victoria are, a very small risk of personal identification remains, despite the measures taken to maintain anonymity.

Will my responses be kept confidential?
As you will be in a group discussion, other participants in the group will know what you have shared inside the group. Your confidentiality and the confidentiality of the data will be protected by not using any identifying information in the data. The consent forms and focus group transcripts will be kept separately from each other (i.e. not attached to one another). Hard copies of the interview transcripts will be kept in a locked filing cabinet. Digital recordings, visual images and accompanying analysis will be kept on a password protected laptop, only the researcher (Jacquelyn Boychuk) will have access to this information.

Will I be able to read the results of the study?

It is anticipated that the results of this study will be publicly shared with others in the following ways: Thesis and class presentation, presentations to scholarly meetings, published article or chapter; and a summary of findings directly to the participants if they desire. Additionally, the results will be posted on the University of Victoria's Library Website "UVic-Space."

Will you keep my responses forever?

The information you've shared during the study will be destroyed once the research has been completed, or up to seven (7) years from now. All digital data including; photos/images, audio recordings, and transcriptions will be stored in password protected laptop. All printed data and photographs will be kept in a locked filing cabinet in a locked room. Digital data stored on researcher's laptop will be permanently deleted, any printed data will be shredded.

Who else can I contact for information?

Individuals that may be contacted regarding this study include: Jacquelyn Boychuk or Dr. Nevin Harper . 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 at: or ethics@uvic.ca.

Consent

I understand the information above presented about the study. I have had the opportunity to discuss this study and my questions have been answered to my satisfaction. I consent to take part in the study and to participate in three Focus groups between 1.5 to 2 hours each with the understanding that I may withdraw at any time without penalty. I can also refuse to answer any questions at any time without penalty. I understand that my participation in the focus groups are entirely voluntary. I have received a signed copy of this consent form. I voluntarily consent to participate in this study.

I voluntarily consent to participate in the focus groups

☐**Yes** ☐**No**

Participant's Name (Please Print) Participant's Signature Date

I voluntarily consent to being audio recorded for all focus groups

☐**Yes** ☐**No**

Participant's Name (Please Print) Participant's Signature Date

I voluntarily consent to the use of the photos I take for this research study to be used for analysis

☐**Yes** ☐**No**

Participant's Name (Please Print) Participant's Signature Date

I confirm that I have explained the nature and purpose of the study to the subject named above. I have answered all questions to the participant's satisfaction.

Name of person obtaining consent (Please Print) Signature Date

Appendix C: Voluntary Consent Form Interviews

Dear [name of participant],

Thank you for your interest in being a participant in my research study. As a graduate student at The School of Child and Youth Care, I am required to conduct a research Study as part of the requirements for a Master of Arts degree. My research is being conducted under the supervision of Dr. Nevin Harper.

What is the purpose of the research?
The purpose of this research is to gain a greater understanding of adult females who have survived a mild or moderate brain injury and how their bodies inform how they develop their identity and perceptions in everyday life.

What is involved if I do agree to take part?
If you voluntarily agree to participate in this research, the total time requested of your participation is approximately four hours, plus time on your own to take photos. You will meet with Jacquelyn at at time that is outside of programming and convenient for you over the course of three interviews. The first interview will be one hour, the second being 1.5 hours and the final wrap up interview being 1 hour (approximately 3.5 hours total).

The first interview will outline the nature of the research, importance, confidentiality and the photography activity (Photo-voice) used to share experiences. The researcher will be asking participants to take one or more photos, in response to some guiding questions. While, it is assumed that participants will use their own cameras (smart phone) for this project, if you do not have a camera a disposable one will be offered. These photos will then be the used as a point of discussion during the second interview, which will be scheduled approximately 2 weeks later. The final interview will be used to reflect on the activity and process, answer any questions that may arise and confirm how participant data should be displayed in written materials and or presentations. All interviews will be audio recorded, with only Jacquelyn and her thesis supervisor Dr. Nevin Harper, transcribing and analyzing data, consent to this audio recording can be given below.

Importance of this Research
This study is important because there is a lack of research on female brain injury survivors that explores the relationship between their bodies and their identity. Additionally, research that incorporates lived experiences of survivors will help complement existing research and generate greater knowledge about the invisibility of brain injuries and how they are informed by the other diverse identities a female survivor might hold such as race, ethnicity, class, ability, age, sexual orientation, religion or spirituality.

What are the benefits of my participation?
There are potential benefits to your participation in this study. These include: making a contribution to existing literature by including your individual experiences, which have the potential to impact service provision and add to practitioners' knowledge and understanding of female brain injury survivors experiences. There are other possible personal benefits of your participation in this research such as an opportunity to share your experiences in a supportive setting, potentially gaining new personal understandings and insights and to have your story be heard.

Inconvenience

Participation in this study may cause some inconvenience to you in terms of the time it takes away from your schedules to participate in the interviews and art-based activity. Additionally, transportation to and from the interview site,

Are there any risks associated with participating?

If you choose to participate in this study, you may experience some emotional discomfort or fatigue by sharing personal information. In order to minimize any discomfort, Jacquelyn will create a safe and supportive environment, offer breaks and be available to debrief after interview sessions. In the event you would like to debrief with a counsellor or support worker outside of the interviews, Jacquelyn will provide you with contact information through There will be no pressure to continue in the research and you can decide to withdraw at any time without an explanation.

Researcher's Relationship with Participants

It is possible that Jacquelyn could have a prior relationship with potential participants as past or present clients. Jacquelyn will not acknowledge any prior relationship as support worker-client, if one existed, in the research setting as that would breach a prior confidentiality agreement and violate ethical protocols. Additionally, whether you choose to participate fully or partially in this research will not affect your ability to access support or services from or any relationship with Jacquelyn outside this study.

Is my participation in this study voluntary?

Your participation in this research must be completely voluntary. If you do decide to participate, you may leave the study at any time without explanation or consequence. Your participation in this research must be completely voluntary. If you do decide to participate, you may leave the study at any time without explanation or consequence. Nothing you say will be in any way identifiable as having come from you as all information that is gathered will be anonymous. If you do withdraw from the study, you may request that the anonymous data that you have contributed should be deleted from the collected materials and this request will be immediately carried out.

<u>To be communicated to Jacquelyn in the event you decide to withdraw from the study:</u>

Yes, please include my data (audio recordings, transcripts, photographs) in the study even if I withdraw part way through______________________

No, please destroy the data(audio recordings, transcripts, photographs) if withdraw________________________

How will you make sure I still want to participate?

It is important to check with you that you give your permission to take part throughout the entire study. To make sure that you continue to consent to participate in this research, Jacquelyn will verbally ask for your continued consent before each interview.

Will you be able to know which responses were mine?

Your anonymity will be protected before, during, and after your participation in this study. If you choose to not participate at any time, your anonymity will still be protected. This will be done by removing all identity information from the focus group transcripts and photographs, and referring to participants by pseudonyms when analyzing transcripts, and reporting findings. This will help minimize the risk that anyone will be able to associate your data (interview transcripts and photography) with you. However, due to the small number of women with traumatic or acquired brain injury in the greater Victoria are, a very small risk of personal identification remains, despite the measures taken to maintain anonymity.

Will my responses be kept confidential?
Your confidentiality and the confidentiality of the data will be protected by not using any identifying information in the data. The consent forms and interview transcripts will be kept separately from each other (i.e. not attached to one another). Hard copies of the interview transcripts will be kept in a locked filing cabinet. Digital recordings, visual images and accompanying analysis will be kept on a password protected laptop, only the researcher (Jacquelyn Boychuk) will have access to this information.

Will I be able to read the results of the study?
It is anticipated that the results of this study will be publicly shared with others in the following ways: Thesis and class presentation, presentations to scholarly meetings, published article or chapter; and a summary of findings directly to the participants if they desire. Additionally, the results will be posted on the University of Victoria's Library Website "UVic-Space."

Will you keep my responses forever?
The information you've shared during the study will be destroyed once the research has been completed, or up to seven (7) years from now. All digital data including; photos/images, audio recordings, and transcriptions will be stored in password protected laptop. All printed data and photographs will be kept in a locked filing cabinet in a locked room. Digital data stored on researcher's laptop will be permanently deleted, any printed data will be shredded.

Who else can I contact for information?
Individuals that may be contacted regarding this study include: Jacquelyn Boychuk or Dr. Nevin Harper 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 at: or ethics@uvic.ca.

Consent
I understand the information above presented about the study. I have had the opportunity to discuss this study and my questions have been answered to my satisfaction. I consent to take part in the study and to participate in three interviews between 1 to 1.5 hours each with the understanding that I may withdraw at any time without penalty. I can also refuse to answer any questions at any time without penalty. I understand that my participation in the interviews are entirely voluntary. I have received a signed copy of this consent form. I voluntarily consent to participate in this study.

I voluntarily consent to participate in the one-on-one interviews

☐**Yes** ☐**No**

Participant's Name (Please Print)	Participant's Signature	Date

I voluntarily consent to being audio recorded for all interviews

☐**Yes** ☐**No**

Participant's Name (Please Print)	Participant's Signature	Date

I voluntarily consent to the use of the photos I take for this research study to be used for analysis

☐**Yes** ☐**No**

Participant's Name (Please Print)	Participant's Signature	Date

I confirm that I have explained the nature and purpose of the study to the participant named above and have answered all questions to the participant's satisfaction.

Name of person obtaining consent (Please Print)	Signature	Date

Appendix D: Photo Release Form

Image Release Form for subjects of photos taken by research participants

I give my permission to ____________________________ (name of research participant) to:

1. Photograph my likeness for use in the Exploring Women's Visual Narratives of Brain Injury project.

I give my permission to Women's Visual Narratives of Brain Injury project (University of Victoria), and all persons authorized by or claiming through or under it to:

1 Make copies of my image in photographs for the sole purposes of the research project; and,

2. Publish, exhibit, and otherwise use my image, photographs, and any copies so made, or any part therefore, and,

I understand that the photographs will become property of the Project and the research participant should the participant wish to retain copies.

____

Date _______________________________
Name (print) ______________________________ Phone number: ________________
Address _____________________________________ Signature
____

Postal code: ________________

This information has been collected, and will be used and maintained, in accordance with the policies and procedures of the Human Research Ethics Committee of the University of Victoria. Should you have any questions about the above, please contact Jacquelyn Boychuk:

You may also contact the research Supervisors, Dr. Nevin Harper:

Appendix E: Semi-structured Guiding Questions

Guiding questions for photo-voice

This project emphasizes using images of objects in everyday life, nature, animals…as a way to answer some or all of the following questions. These images may help to express and interpret your own experiences. You will choose to use photos based on your own interpretations.

All pictures taken belong to you and can be left on your smart phone or printed if you choose to use a disposable camera. I will use my copies to learn about your experience and may describe them in my study based on your interpretations. I will not print copies of the pictures or share with anyone else without your permission (as indicated on the consent form).

The following questions are meant as a guide for your images. Please keep in mind that these questions are based from how your body plays a role in your identity and in different environments.

Who are you?

How do you see yourself (your identity and relationship with your body)?

How do your body and abilities inform who you are?

How do you think other people "see you" (your identity)?

Does your perception of yourself change depending on the environment you are in? Can you provide an example?

In what places do you feel that you can be "you"?

Where do you feel a sense of community?

In what environment(s) or communities do you feel the most comfortable in your own body?

In what environment(s)/community do you feel you thrive in?

What places/environments reinforce your sense of self?

In what environment(s) do you feel uncomfortable?

In what environment(s) do you feel you cannot be yourself or have to be less visible?