Drawing from experience: exploring identity with individuals healing from brain injury

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Note on participant artwork
Copyright for all artwork produced by participants in this report is retained by the respective artist who created the piece. Permission was granted to share artwork for this report.

Abstract

Acquired brain injury often leaves an individual with long-term physical, cognitive and emotional impairments which can greatly impact their sense of self and relationships with others. Much of rehabilitation literature is focused on what is needed for the individual to return to a pre-injury 'normal', however that notion is rooted in a medical model of disability which puts most of the responsibility of recovery on the individual. This compounds the burden the patient and their caregivers have to carry. This study seeks to investigate the journey of recovery through a social model of disability to understand what a healing and supportive environment might look like to meet an individual where they are. Ten participants across Ontario living with brain injury were recruited from brain injury support groups and word of mouth. Qualitative art-based methods were used to deeper investigate the phenomenology of brain injury and its relationship with identity. Individual interviews and drawings produced rich data on the complex and diverse lived experience, building on previous arts-based studies with brain injury survivors.

Study findings offer further exploration into the lived experience of people living with brain injury through the challenges to their sense of self and coping mechanisms and solutions. Discussion centres around what shifts are needed in society to accommodate people with brain injury. Findings can inform approaches for healthcare professionals and service providers who work with brain injury. The research design intends to make a contribution to arts-based and participatory approaches in the current COVID-19 context, and to inform future researchers who intend to conduct research with remote participants who may often be excluded from in-person studies. Future work involves presenting the findings to family, friends, caregivers and professionals who work with brain injury through an arts-based knowledge transfer piece.

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Dedication

I want to thank dedicate this project to my participants who are living with a brain injury. I can't name you in this report but you know who you are. You were all so generous with your time and energy and I hope this work is an adequate reflection of all the things we have talked about.

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Introduction

In September 2017, I was in a serious accident while riding my bicycle in downtown Toronto. My last memory of that event was making a right turn onto Dundas St. from Spadina. I lost consciousness so I have no recollection of what caused my fall, but I remember fuzzy vignettes of the ambulance and emergency room. I had five stitches put on my head and a subarachnoid hemorrhage (minor brain bleed) which cleared up overnight. I was sent home within hours of arriving at the hospital. I was in the midst of starting a new job and moving houses at the same time. Everything had returned to normal pretty quickly, and life went on.

More than a year later in December 2018, I had a particularly hard fall while snowboarding with my family north of Toronto–I immediately felt confused and tired after. I had increasingly worsening pain, migraines, and panic attacks in the following weeks and was diagnosed with post-concussive syndrome. I was on and off work for a year from my design job as I had intense headaches from screens and being around others. I became incredibly isolated this time and questioned what lay ahead for me with my health, my career, and relationships. I didn't know how to explain what was going on during the time because it was difficult to grasp myself.

I begin this report with my own fragmented narrative of acquired brain injury as Shankar (2011) did in their auto-ethnography in an effort to humanize being a patient of this injury. Acquired brain injury (ABI) is common in sports (Langlois et al., 2006) but can also be caused by a brain tumour, stroke, or blow to the head. No matter the cause, ABI can be a traumatic event and have a drastic impact on an individual's life, potentially affecting their cognition, sensory processing, communication, social behaviour, and overall social, mental and physical wellbeing (Chamberlain, 2006). Normal recovery is expected to be less than one year, but due to the brain's complexity it can extend to long-term impairments and secondary illnesses. Many people with ABI often report ongoing difficulties in areas such as decision making, socializing, and self-awareness (Konrad et al., 2011) well after a year post-injury and need ongoing supports for many years (Kendall et al., 2001; Mirza et al., 2008). The often invisible nature of their impairments coupled with a lack of understanding from the general public further isolate the individual from meaningful dialogue and connections (Hagger, 2019; Mahar & Fraser, 2012). As such, a person living with ABI can become doubly isolated by their chronic physical and social challenges. Due to these often long-term and life-altering changes, a person's consistent sense of identity can be threatened after ABI. Many individuals can experience a loss of after the brain injury on top of everything else.

I came to this research project as my own way to reshape my identity after brain injury. After a few years of recovery I am in no way back to before but I am not limited by my impairments either. Where does this leave me? How can I process what I went through to move forward? Through the lense of the Inclusive Design program I came to realize that although I had impairments, much of the internal struggle I had experienced was due to society's inability to accommodate. I had always felt like I needed to fully recover or return to my previous self in order for life to continue. Why do I have to adjust to fit my environment, instead of the other way around? It is prudent that disability is not only dealt with by the individual, but by all levels of the system. This is not to discount the importance of medical research to innovate on treatments to improve quality of life for people, but our shared meaning around disability and identity need to be challenged as our society is shifting to embrace diverse human ability.

To push this further, disabled people themselves should bring the ideas for change. In the words heralded by disability activists: “nothing about us without us”. In this study I am seeking to centre the lived experience or phenomenology of identity and acquired brain injury as inspired by my own experience. Phenomenological inquiry seeks to understand “the truth of the event, as an abstract entity, is subjective and knowable only through embodied perception” (Starks & Trinidad, 2008). The heart of phenomenology lies in this embodied perception rather than the expert knowledge of a situation. I personally straddle a careful line between researcher and subject in this study. Ultimately, I am a single person with a single experience and chose to gather the lived experience of many others. Through this, I hope to uncover more complexities of living with a brain injury and contribute to the work that previous researchers have already established in this area.

In the following literature review I will summarize how brain injury researchers see identity and loss of self after ABI, why a more social must be applied in this research and how arts-based methods can help us get there.

Literature Review

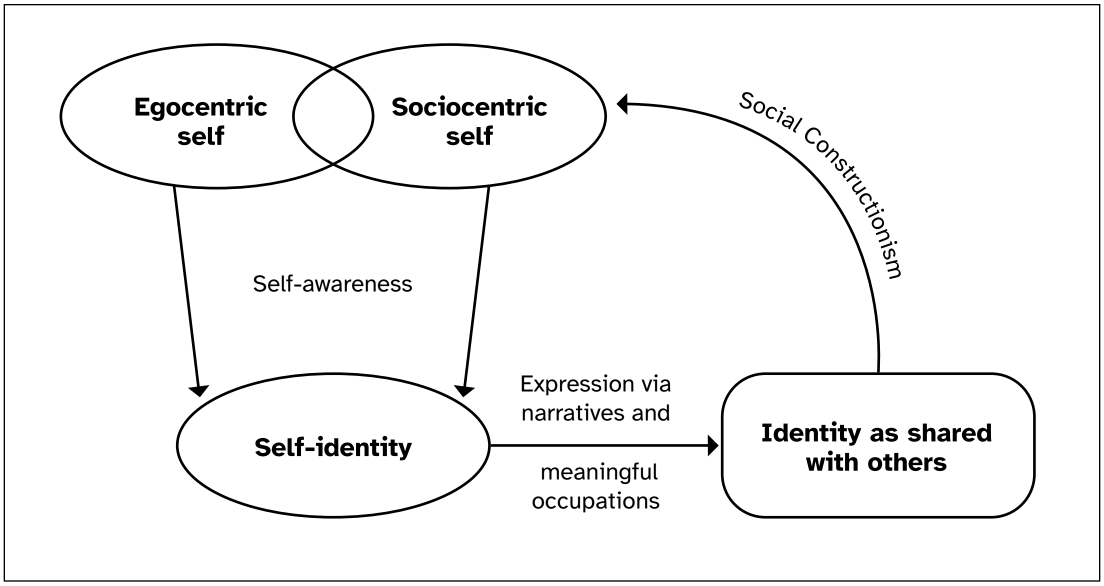
Identity and brain injury

The basis of identity in this study stems from Thomas et al.'s concept analysis of the phenomenon in brain injury research (2014). In qualitative reports of the lived experience of brain injury, many individuals report a great loss or experiencing "death of self and being reborn" (Muenchberger et al., 2008) while others report some sense of continuity in aspects of their identity (Rosigno & Van Liew, 2008). Thomas et al. found that researchers use a variety of theories to interpret these experiences that they call a change in sense of self. A clear shared definition of the change in sense of self after ABI was lacking among the literature, but from the analysis they came to generally describe it as "a change in one's inner subjective experience as a result of changes in egocentric/sociocentric aspects of self, or in the relationship with one's identity as shared with others" (2014).

In this definition, the egocentric self is the internal processes of an individual: their uniqueness, coherence, self-knowledge, predictability, agency, ownership, continuity which theorists have applied the lens of self-reflective meaning-making onto. This focuses on helping the individual reshift their purpose and goals in life. While this is a positive approach towards more holistic brain injury rehabilitation, it relies heavily on individual transformation and fails to address the larger social environmental impact on the person's sense of self or lack of it. In Thomas et al.'s definition sociocentric self is about who the person is amongst others: family, friends, hobbies, vocation, group membership, personhood, stigma and labels, all of which can also contribute to the change in sense of self. An added layer to this is identity as shared with others, or group identity. See Figure 1 for Thomas et al.'s concept diagram of the relationship between these components. Thomas et al. (2014) suggests these three are all interdependent and must be addressed simultaneously.

Social identity theorists in brain injury research posit that identity cannot be formed without the interactions we have with others (Nochi, 1998). They are "socially constructed in everyday interactions that are shaped and constrained by social systems, institutions, and macro social structures" (Muldoon et al., 2018). I call for the layered investigation with the social model of disability coined by disability activist Michael Oliver (1983). In this he champions for the shifting of systems, institutions and social structures to accommodate the individual. The social model of disability sees impairments as the limitations that a person has to contend with, but disability is a construct created by our shared beliefs. The hope is not to replace much needed rehabilitation for people with ABI, but rebalancing the focus of work and transformation from the individual to society. In order to understand what changes are necessary, we must consult with the people who are most directly affected.

Figure 1. Components and processes of self-identity threatened by ABI (Thomas et al., 2014)



Rehabilitation professionals have long been advocating for an insider or patient voice on living with a disability (Prigatano, 2000). To perceive a phenomenon that is so intangible, arts-based methodologies can be appropriate. According to Gerber et al. (2012), art has always been able to “convey truths, self-knowledge and other multiple ways of knowing”. This translates well to health research as art has the ability to make the ‘invisible’ visible, honour different epistemologies and methods of communication, and give the participant more control of their narrative than they would answering a traditional questionnaire. As arts-based methods are open-ended and flexible, they allow the participant to express their experiences of phenomena in their own way and can uncover a broad range of insights that researchers may not have considered. The current landscape of health and rehabilitation research specifically sees this method emerging as an accepted means for knowledge production and transfer approaches in the past two decades (Gonzalez de Armas et al., 2017).

Arts-based research and brain injury

Although researchers in other fields have been employing arts-based methods for some time (Eisner, 1981), the methodology is fairly new to the field of healthcare. Arts in health has become increasingly popular in the past 20 years as a therapeutic intervention, especially where patients experience conditions that threaten or alter their lives (Fraser & al Sayah, 2011). It has shown to be especially effective in group therapy environments for people living with ABI (Briks et al., 2020; Carbonneau et al., 2013; D'Cruz et al., 2020; Guay, 2019). Patients have participated in drawing, storytelling, theatre and dance workshops specifically designed for brain injury. These workshops provide a space for patients to talk about similar experiences and process trauma without the pressure of having to eloquently describe their experiences in words, especially when cognition and communication can be a challenge.

For knowledge production in research, an arts-based method is used to collect data from the participants. Common mediums for knowledge production in brain injury studies are songwriting (Baker et al., 2018, Roddy et al., 2020), photovoice (Lorenz, 2010) and drawing (Jones et al., 2016; Mah et al., 2019). Individuals are usually given an open-ended prompt pertaining to the research topic and asked to create artworks in response to the prompt within a predetermined time period. In doing so the research becomes more participatory as individuals are able to co-create their narratives with the researchers. The arts-based method acts as a supplement to other qualitative methods to probe further into themes of discussion. The act of creating the art piece and revisiting it upon the data analysis phase can create a site of further self-reflection, reframing, and meaning making for the participants (Baker et al., 2018).

Knowledge transfer in research focuses on synthesizing the findings from work created by participants and presenting them to other stakeholders (family, friends, healthcare workers, and the general public) often to spark a larger dialogue, challenge stigma and to inform policy changes on the intended issue. Art has the ability to speak to larger audiences and create a platform for shared understanding therefore it can be an effective knowledge translation tool. This approach may be especially useful in bridging the communication divide between healthcare professionals and their patients: "Such qualities [of arts-based methods] are likely to elicit a variety of feelings and perceptions in those who are affected by these health conditions, which may be difficult for them to articulate. Health professionals and caregivers may also encounter difficulties when attempting to comprehend such experiences, which in turn would affect the quality and individualised nature of their care" (Gonzalez de Armas et al., 2017).

Common mediums for knowledge transfer are theatre (Colantonio et al., 2008) and gallery exhibits (Lorenz, 2010). In the former project, a research-based theatre piece titled *After the Crash* was co-created with brain injury survivors, their circle of care, and theatre professionals. The final dramatic production was presented as an educational piece for healthcare workers to gain deeper insight into the lived experience of ABI. Feedback from focus groups after experiencing the play expressed that the emotional impact deepened their learning and understanding: "I enjoyed the play very much and feel like I will remember this knowledge more readily than if I had read the same thing in a book" (Colantonio et al., 2008). The creative knowledge transfer piece also produces an artifact sparking further dialogue that might otherwise have been difficult to broach. Health care research often focuses on heavy subjects such as ageing, death, disability and illness that are not a part of everyday conversation, thus producing a knowledge transfer piece is an opportunity for those viewing it to continue a deeper reflection.

Researchers from the literature review on ABI arts-based research call for further work in integrating these methods into inquiry and practice as it provides a lens into patient experiences and tacit knowledge that might otherwise be hard to articulate or find through quantitative methods. In my master's research project I sought to make a contribution to this research methodology given the current COVID-19 context in which we are required to physically be apart and conduct research remotely.

Research questions

What is the lived experience of identity in acquired brain injury?

- How might this be examined through the social model of disability?
- Are arts-based methods an accessible and supportive knowledge production approach for participants who have a brain injury?

Methodology

The specific knowledge production approach in this study is based on Guillemin's adaptation (2004) of critical visual methodology (Rose, 2001) in which drawing is used as a means for producing data. Out of all arts-based methods, drawing was selected as the most suitable for this study. Drawing was a familiar technique for participants who do not consider themselves to be artists, and the materials required were affordable, easy to send through mail, or readily available in their homes. Guillemin argues that drawing is an effective tool to gain further insight into a participant's view of the world, however it must be used in adjunct with other qualitative research methods (2004). Thus in this study, drawing is paired with one-on-one semi-structured interviews with the participants at the onset of the study.

Participant recruitment

The study gathered data from a total of 10 adult participants. Participants were recruited by word of mouth and from local brain injury support groups. Recruitment posters were sent through social media and email newsletters and individuals who were interested were sent an online screening form to determine eligibility. The requirements for eligibility to participate is being above the age of 18, living in Ontario, and being able to complete basic tasks independently (see Appendix A for a list of the screening questions). Since the focus of this study is on lived experience of patients, no formal diagnosis of brain injury was needed in order to participate and participants were asked to self-identify or disclose their health status. To establish rapport, I recorded a video greeting which was sent to all eligible participants (see Appendix B). All ten individuals who participated were female-identifying and their ages ranged from 18–68.

Table 1. Participant demographic information

Participant	Age	Occupation	Race or Ethnicity
1	40	student & landlord	Caucasian
2	18	not disclosed	Caucasian
3	39	post-secondary instructor	Chinese
4	38	researcher, educator, entrepreneur	Caucasian
5	38	not disclosed	Asian
6	not disclosed	not disclosed	not disclosed
7	68	artist, educator	White, person with disabilities
8	not disclosed	student	not disclosed
9	not disclosed	not disclosed	not disclosed
10	27	elementary school teacher	Caucasian

Data collection

Initial interviews

Initial semi-structured interviews ranging from 30 minutes to an hour in length were conducted with each participant over Zoom or phone focusing on the participant's emotional and social experience of healing from brain injury. As sharing personal health issues and recalling traumatic events can be very sensitive topics for participants, many steps based on guidelines by Dempsey et al. (2016) were taken in order to establish trust and rapport between the researcher and participant. An interview guide (see Appendix C) was prepared and sent to participants in advance to act as a general guide and to give time for preparation, but it remained open-ended for personal expression and interpretation. Interviews were audio-recorded then transcribed with an automated transcription service which the participant and I validated. I continued to keep in contact with each participant after the interviews through emails and voice messages to keep them updated on the study, get their feedback, fill in remaining gaps, and build further rapport.

Drawing activity

Following the interviews, postcard kits were then mailed to participants which included four paper postcards and a pack of pencil crayons if requested. The kits functioned as a probe on interesting and emerging topics from our interviews. The materials were designed to be supportive of vision recovery in brain injury (Powell et al., 2014). Therefore the kit was material instead of on-screen, designed to reduce cognitive and visual load, and participants were given a longer time period (one month) to finish their postcards at a time most suitable to them. The postcard had a prompt on one side and the other side was blank for the participant to draw an answer to the prompt.

Drawing is shown to incite a process of self exploration and development of a self narrative, especially through the collaborative approaches to data creation, analysis and presentation. Briks et al. (2020) studied brain injury survivors who participated in a group art therapy program and answered prompts about themselves with drawing. The study found that participants moved towards more personal expression, self-discovery, and social inclusion. Similar to the Briks study, it was explained to participants that it is the content of the drawing that matters more than the artistic skill. As Guillemin elaborates on drawing, it is "simultaneously a visual product and a record of the process of production...the word drawing is both a noun and a verb; it is both a product and a process" (Guillemin, 2004). The materials, colours, shapes reveal as much as the subject of the drawings. Thus, it is crucial that drawings are supported by verbal or written explanation to understand the artist’s choices. Guillemin highlights the importance of asking the participant on their choices for the drawing as an essential part of the method:

> It elicits from the participant the nature of the drawing, why she chose to draw that particular image, and the reasons for choice of colour and spatial organization of the images. Moreover, for participants to describe their drawing necessitates reflection not only on the drawing but also on the relationship of what they have drawn to their particular illness condition and the significance of what they have drawn to their previous statements made during the interview (2004).

As such, participants were asked to complete the postcards with a drawing on the front, followed by a written caption on the back describing what they have drawn and why (see Appendix D & E for instructions video and a photo of the kit). Each postcard had a different prompt:

1. How am I today?
2. How would I like to be?
3. How do I get there?
4. Extra postcard for anything they wish

Participants were asked to mail back their postcards with prepaid postage and were analyzed along with the transcripts from initial interviews. A form was included with the kit that collected permission to use the artwork and asked if the participant wanted to be credited with their name.

Analysis

In Guillemin’s proposed adaptation of critical visual methodology (2004), grounded theory is the method of analysis applied to the drawings. The analysis phase of phenomenology is very similar to that of grounded theory (Starks & Trinidad, 2008) in that common themes are derived from the data. Thus thematic analysis was conducted on the interview transcript and postcards through coding and grouping of common themes compared back to the social identity approach literature. Analysis was conducted on drawings with questions posed by Guillemin (see Appendix F).

The initial themes from interviews and postcards were presented to the participants through a pre-recorded video explanation with accompanying quotes and images (see Appendix G). Participants were encouraged to share their feedback within 2 weeks time through written feedback or audio recordings. They were asked to reflect on the presented themes, add anything they believed to be missing from the data and who they might want to share the findings with.

Findings

Continuing on Thomas et al.'s (2014) work suggesting that the ways in which identity researchers see the 'self' are interdependent and must be examined together, I wanted the findings from this study to break out of the egocentric and sociocentric dichotomy. Instead I chose to present themes from the data weaved together as 1) challenges to sense of self and 2) coping mechanisms and solutions. Processes that researchers see as egocentric and sociocentric selves are blended together in the two categories. According to Starks & Trinidad, phenomenologies are often written as thematic stories, "drawing on elements reported from different narrators to create a blended story. Such accounts allow the reader to get a feel for what it is like to have the experience" (2018). As such, data collected from our interviews, postcard drawings & captions, and personal communications are brought together in this format to create a blended story of brain injury and identity.

Challenges to sense of self

Adjustment to change

Similar to previous studies, most participants saw the brain injury as an event that disrupted their consistent life narrative. One participant talks about how they had to take a leave from school and sports due to their multiple brain injuries:

> That was my whole life...and I couldn't do either of those things. I was locked in my room with lights, no technology, it was really hard. Especially for someone who was is– a very social person: I like to go out, see my friends, go to the movies, do fun stuff, but I couldn't do any of that.

Due to the impacts of brain injury the very activities, hobbies, and commitments that once defined a person might be hard to keep up with. This was reflected in many of my participants and they saw themselves as 'present' self and 'pre-injury' self, often as drastically different people. One participant succinctly puts it as such:

> Some people have incremental change, so you kind of are always with yourself.

> But this was just like a really quick, I don't know, I just uploaded a different being. And now I'm like, who dis?

This person had a brain injury while abroad and had returned home to recover. They had had an ABI before but did not experience such substantial change in personality and behaviour as they did with this one. They compared the change in personality to feeling like they uploaded a completely new "operating system". There is a conflict at the present with adjusting to the new identity.

However others experienced a change that was not as drastic. One participant in particular had their brain injuries while growing up as a child, so the changes may have been more embedded in their personality:

> You can ask my parents, but I've always been a more shy, cautious child. I do think because of my early diagnosis, I was even more so. I don't think my personality changed too much since I was so young when it happened. But it definitely changed. Like how aware I am of certain medical things right now around COVID.

Changes to the mind, body, and behaviour can make one feel alienated from society as it involves recalibrating one's role and purpose in life. One participant spoke in depth about feeling out of sync with society's 'norms' and expectations after their most recent brain injury:

> It felt like everything that was a construct fell down…the standard way of being is something I remember, but it's just almost like I can't fit anymore. It's almost like being naked.

This participant compared their experience to being 'naked' several times, explaining she felt exposed and vulnerable with their drastic change in behaviour and emotional regulation. Meanwhile others without brain injury are able to hide their vulnerabilities.

Overwhelm

Stronger emotions are known to be quite common with a brain injury. As a result of this many participants noted feeling a sense of 'overwhelm'. Through the interviews and drawings, a complex emotional interaction was present for many participants on an individual and group level. They expressed feelings of grief, loss, sadness, and hopelessness, but also hopefulness, acceptance, pride, curiosity, and humour at the same time. In their postcard responding to the prompt “How are you today?”, one participant drew and wrote about the mix of emotions they felt in the span of one day:

Figure 2. Participant drawing, ‘Whelmed’

> *Caption:* Today I’m feeling all of the things.. I’m overwhelmed, uncertain, anxious, physically uncomfortable (thankfully not in acute pain today), exhausted and sensory overloaded. Yet I’m hopeful because today I’ve done more than I can sometimes manage in a half a week.

These emotions were often held at the same time for the participants, often regarding their limitations and how they saw themselves. It is then no surprise that the recovery process can feel like a rollercoaster for the individual. These mixed emotions can affect how a person might process the situation and choose to talk about it with others– is this a good thing or bad thing that has happened to me? Should I make light of it or hold space for grief? As John Wright writes in his introduction to *Health and healing after traumatic brain injury:*

> I will never recover from the deep sadness that engulfs me every time I think about what might have been had I not been injured. No silver lining can ever remove this

> sadness–intense sadness and happiness always coexist in a poignant and perpetual emotional interaction" (Muenchberger et al., 2013).

Lack of understanding

Many participants brought up being met with a lack of understanding of their brain injury from others. One participant who returned home from abroad remembers their closest friend's reaction to their changed behaviour:

> I came home and my best friend told me at one point, you've forgotten who you are, you're being desperate and pathetic. It was really harsh, it hurt a lot because people just, *I* still didn't understand. I just knew that everything felt different.

It was difficult for participants to put their brain injuries into words. This inability to put the experience into words poses a challenge for others who are trying to understand. Brain injury is often an invisible disability in that its effects are not obviously manifested on the physical body. A participant explains when I had asked them to describe their brain injury in words:

> I can't, that's the thing! There is that difficulty that this is something that's beyond the describable. And there's an attempt, I think, in medicine, to attempt to kind of label things, you know, like, I can say, Oh, I have intermittent headaches, I have problems with balance, I have dizziness. I have difficulty putting ideas together, which is really difficult for an academic... So those are things that I can talk around it, but it's still incomplete.

Although ABI can have a significant impact on individuals, it can be invisible to outside observers. It was found that there is a common understanding others that it should not take too long to recover from brain injury. One participant describes being met with frustration from their friends after not fully recovering for years:

> Others were like, you're fine now. You can walk. And they just kind of lacked empathy at that point, and just be like, get over it...nobody in my friend group really understood at all why I was still having problems and why it wasn't over yet.

Four younger participants noted that others assumed because they were young, their bodies should function normally. One participant in particular mentioned attending a seniors fitness class as the movements would be easier on their recovering body. She describes being met with a lack of understanding from the other class attendees:

> I tried to go to the YMCA for a while…people would look at you weird like, you're young, you're fit. Why are you struggling with stuff like this?

Finally, many participants discussed the disregard they experienced from some healthcare professionals and service providers they worked with. They emphasized the amount of time and self-advocacy it took to be believed or heard by professionals such as doctors or insurance providers. One participant shares their feelings when she was met with skepticism and inaction when she asked for accommodations:

> There's so many parts of the system that make you out to be a liar when you're looking for accessibility and accommodation or just understanding.

Facing many aspects of society that question an individual's truth can start to degrade their sense of self. This can feed back into the person's struggle to accept themselves and adjust to their changes.

Situating oneself in society

A few participants felt confused about where they should be in their lives with their relationships, school, and career to name a few. Due to brain injury-related impairments they might have to reconsider their priorities in life. In their postcard drawing in response to the first prompt – how are you today? – a participant shares their challenges:

Figure 3. Participant drawing

> *Caption:* I am doing alright today. I am feeling a bit all over the place. In some ways I feel right on track with my life (I have a great job, awesome supportive family and have lots of great opportunities/ experiences). But I also feel the stress of not being where I feel like I SHOULD be (some sort of long-term relationship, own place, children).

In their postcard drawing, they seem to be making an important choice between what she wants to do and what society expects of them. A long-term disability such as ABI can be seen as a setback in terms of advancing in life. It is especially apparent with my participants who are in the young adult age range (20s–40s) that they are in a period where everyone around them seems to be making progress, and a few years of setbacks can be a great challenge to their self identity.

Coping mechanisms and solutions

Handling change

Becoming a part of a support network relating to ABI was noted to be a major antidote to feeling less alone in the adjustment. These networks can be set up by local non-profit organizations such as Brain Injury Society of Toronto or Brain Tumour Foundation of Canada for people with brain injury to gather with a common purpose and to provide peer support. One participant who needed frequent hospital visits growing up noted that she often felt alone amongst their peers until she joined an online support group:

> Growing up as a kid, I felt like I was the only one who dealt with medical stuff. I thought I was the only weird one and I know now that it's a lot more common than everyone thinks, I just went to a small school.

During the pandemic, individuals with brain injury were able to find a wider network of friendship and support through virtual groups that have the same legitimacy as face-to-face groups. Many participants stressed the importance of these non-profit organizations in providing information and education around their brain injury and connecting them to further resources for support. One participant brought up the strength of virtual groups as it connected them with people all over the world:

> Connecting with these people, I got so good at typing with my eyes closed because I couldn't look at the screen most of the time. Just being able to have a motive to talk to people, it helps me get better at slowly gaining tolerance again… my friends, they are my closest friends but I've never met them in real life.

As they also noted, the support network can also provide a motive and method for the individual to rebuild from their loss. Non-profits also put on programming such as yoga classes and paint nights, which were noted to be incredibly helpful by several participants. These programs are specifically tailored to people with ABI and are mindful of limitations that they have. For example, the LoveYourBrain yoga program was a favourite of several participants as it provided accommodations such as modifications for specific yoga poses. Interestingly, LoveYourBrain was founded by someone who also had an ABI. A participant talks about her experience with the program and practicing yoga after her brain injury:

> I was having trouble leaving the house to do anything. And there's no way I could have done a normal yoga class. To have someone do something that was accessible and built for people who were experiencing brain injury. It was just like, oh my gosh, I can do stuff. And it's just like, kind of incredible for me because like since then I'm actually now a certified yoga instructor.

Having accommodations in place for brain injury limitations made this person feel a sense of accomplishment and gave them membership into a wider community of yoga practitioners, something they may not have been able to achieve in a traditional yoga program. Similarly, being surrounded by a community who understands the impacts and experience of brain injury helps the individuals feel less alone.

Dealing with overwhelm

Most participants mentioned areas of self improvement to cope with overwhelm, mainly focusing on becoming more accepting of themselves and being more intentional with their time and energy. A participant in their drawing responded to the prompt: 'How do I get there?' focused on wanting to become more accepting of their different and changing emotions:

Figure 4. Participant drawing

Caption: I (want to) feel more comfortable expressing positive feelings like happiness or excitement, I think moving little by little expressing different emotions like anger or sadness will come with time. I think it also comes from being accepting of each emotion, as well as being controlling of what I can control, and accepting of what I can't.

Sometimes participants just want to express their pain, as this person did in their postcard in response to the prompt–how are you today?

Figure 5. Participant drawing

> ONGOING skull pressure Relentless woofling, hoof pounding, HORN poking, BISON OVERWHELMING I metaphorically SHAKE my head Sleet/SNOW slapping inside my skull PRESSURE as my forehead folds.

While other times participants shared the humour they found in their experience:

> I've laughed about it with people online who have gone through this. We'll be there for each other, I have to laugh about this stuff. I have to, I don't know how to get through it otherwise.

One participant talked about managing their limited energy with activities and viewing it through the spoon theory:

Figure 6. Participant drawing

> Rest, physical activity, conserving my spoons (ie: energy) and using them intentionally To get to how I want to be, I need to be very intentional about how I spend my time and energy. Ideally I will focus on things that give me energy and capacity as opposed to activities that drain me. Consistent and sufficient rest is very important, so are gentle and meditative physical activities like walking and swimming.

Being intentional often means choosing to prioritize one thing and deprioritizing others to limited energy and resources. In our one-on-one conversation, the same participant shared that they chose to prioritize the activities that gave them energy over returning to work, which helped them have a better quality of life:

> Sure, I could probably try really hard to go back to half days online. But if I'm not going to have the energy to go for a walk to maintain my health or to go for a kayak ride to work on my stroke rehab, why would I give up all of my wellness activities that make me feel better and are going to help me have a better life just so I can appease insurance by working half a day?

The labelled self

A possible remedy to communicate one's experience to gain more understanding from others is the use of labels. Nochi (1998) calls this the 'labelled self'. The use of labels in self-identification was quite varied and personal in my participant group. In our conversations, only one participant openly introduced themself as a person with disabilities. For many others, there was a struggle to come to terms with identifying as disabled. One participant talked about how it took them a long time to become comfortable with the label:

> I definitely now identify as disabled. But I think that's once I started using an assistive device. And when I started having actual in-person confrontations with people where I felt like, Hey, this is totally not okay...it's been years of getting to be okay with that label.

Other participants do not identify with being disabled. Other terms they use include: 'brain drunk', 'differently abled', 'acquired neuro-divergent', and 'functionally impaired'. One participant refers to their brain injury as a neck injury instead. They mention it is much simpler for themself and for others to understand their needs:

> It's hard to explain...people understand broken bones. They don't understand damaged brains...So I always use neck injury because people get it.

Overall there was no consistent label that all participants seemed to identify with. The shared identity of 'brain injury survivor' was not something that resonated strongly with any of my participants. Ultimately, the choice of label was a highly personal decision made as the person rebuilt their identity and reflected on what they wanted to communicate with it.

Shifting our shared understanding

As mentioned earlier, the disruption to activities, hobbies and commitments can greatly challenge a person's identity. Many participants had to leave or reconsider their school or work, forcing them to find other ways to define themselves. One participant in particular noted this near the end of our conversation:

> For most of us, I find that we're more inclined to talk about our education or jobs...I think it's so important that we find new ways to define identity.

Discussion

I will discuss the findings of the study against the original research questions I sought to investigate: first by analyzing the lived experience of brain injury through a social model of disability lens, then discussing the use of drawing as a methodology.

Lived experience of brain injury

There is still a large process of internal struggle after an ABI which is unavoidable. There is a liminal time for the individual to understand what has changed, adjust to their new abilities, impairments, and needs. It can also involve choosing what and how much of that information they want to share with others. Many participants want to work on becoming more mindful and intentional through this process. This can bring back autonomy and control of their story. Self-narrative and identification through the use of labels is a highly personal choice. There is no one common term that my group of participants use to identify to others. This could signify a lack of group identity, but also point to the idea that no two experiences are alike. Often people with disabilities can be seen as a monolith. As Thomas et al. (2014) explain in their work, “it is a heterogeneous experience and needs to be interpreted within an individualistic context”.

What individuals have less control over is how others perceive them and how they might fit into society. It is apparent from seeing what participants choose to focus on that we as a society still place a lot of value in what our education and jobs are. Who are we without those things? That is something a lot of my participants had to contend with.

Participants noted that without the access to appropriate social support and information they would be facing their challenges alone. Further funding and investment of resources into nonprofits and social support for people with brain injury can help address some gaps. Currently the programming varies in terms of accessibility and availability. Many participants educate others about brain injury in their own lives through online platforms and advocacy in spaces that are inaccessible.
It should not be expected for a person with a disability to become an advocate, but currently that the case out of necessity. Systems and institutions especially those in healthcare, education, and the workplace need to be more informed about the lived experience to better support those living with brain injury.

There simply isn’t a one-size-fits-all solution to address all individuals affected by brain injury. This can be seen as a conflict to the point I made earlier about needing a societal shift. How can we push for change when there isn't a consensus? This perspective is exactly where Inclusive Design challenges. Inclusive design is about embracing human uniqueness and variability as well as understanding that we are always in a complex and adaptive system (Treviranus, 2018). There is no one easy and efficient answer on how to move forward, rather it is an ongoing process or constant conversation with those who are excluded.

Drawing as methodology

As evident in the drawings shared in the report, the postcards yielded a rich pool of data and acted as a good supplement for probing into emerging themes from interviews. Participants found drawing to be an accessible method as most were familiar with it and had pencil crayons at home. Some were happy to take a break from the screen and found it cathartic and therapeutic to share their experiences in this manner. Drawings elicited a further exploration into the lived experience of participants by providing a multi-modal representation. As Guillemin says,

> The drawing as a visual product is a visual record of how the drawer understands his or her condition at that particular place and time. In this way, drawings, like other representations, can be used as ways of understanding how people see their world (2004).

What resonated the strongest among participants was the use of visual metaphors, for example one participant's comparison of their brain injury to bison in their head, and another participant's intentional use of different colours and shapes. Unfortunately, there was not enough time for a second round of interviews in which the participants would be asked to reflect on their drawings, providing an opportunity for additional meaning-making.

Limitations

The study's biggest limitation was time and resources. With only one researcher and a limited amount of time to conduct the project, the scope was limited. This was compounded by the effects of the COVID-19 pandemic: illness, fatigue, burnout, lower levels of motivation, and connecting virtually all pose a large challenge to both researcher and participants. In terms of participants, there was a smaller recruitment sample which can impact generalizability. Although basic participant demographic information was asked for, it was optional and other socioeconomic factors such as race, age, income, gender identity & sexuality were not factored in and those can greatly contribute to a person's access to resources. Furthermore, no one who identified as male participated in the study. Statistically more men have acquired brain injury (Mollayeva, 2019) so this may not reflect the true population living with brain injury.

The medium of physical mail and postcards was novel but also posed a barrier to some. A few packages became delayed or lost in the system due to human error which slowed down the project. One participant felt pressure from the limited amount and size of the postcards. Others initially mentioned that they did not feel confident in their artistic skills. These were rectified but are important to note for planning of future work.

Finally, in trying to be inclusive of different modes of communication, more work was put on the researcher to accommodate for participants to meet at varying times and creating multimodal content. More assistance and planning is needed in these areas for the future.

Conclusion

Identity with ABI is personal and varied. For some, the injury is inextricably linked to their identity. For others, it is something they wish to separate. Not everyone with ABI will undergo this process, and the hope for the future is that there is a supportive environment where this is not a major challenge. It is important that it is not only communities and people close to those with disabilities who know how to make accommodations. This can create a fissure between the disabled and non-disabled communities and create two separate tracks of society. Public education is needed around disability and chronic illness so that everyone is more knowledgeable on accommodations and stigma on people with ABI can be lessened. People living with brain injury want to participate in everyday life– we want and can be yoga instructors, drive a car, get our Masters degree. At the present, the systems and structures in place do not allow us to achieve those things as easily as others.

Future work

These findings may inform healthcare and service providers on the lived experience of people with ABI. They can also serve as inspiration for creative knowledge translation pieces for public education purposes.

The study would benefit from another round of one-on-one interviews after the postcard drawings were finished to open another opportunity for meaning-making and discussion with participants. It would also be interesting to see a group discussion as everyone had participated in the study individually and only had one-on-one communication with the researcher.

Finally, further conversation is needed with caregivers, healthcare providers and the general public on these topics as identity is created with others. For example, we can present these challenges and solutions to the brain injury group to confirm, then bring to caregivers and HC professionals as another focus group for discussion on these themes and how we might bridge these gaps. Ultimately, this is the first step in a longer conversation.

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Appendices

Appendix A: Screening questions

- Are you currently recovering from a mild or moderate acquired brain injury (from a concussion, brain tumour, stroke, etc.)? (YES/NO)
- Are you currently in an in-patient program or living in a care setting for your brain injury?
- Are you above the age of 18? (YES/NO)
- Will you be living in Ontario from January to May 2022? (YES/NO)
- Do you need any accommodations in order to participate in online or arts activities? (eg. needing verbal/written instructions, having a phone call instead of a video call, etc.). Don't worry if you don't know at the moment, the researcher will ask you again during your one-on-one welcome meeting. (OPEN-ENDED)

Appendix B: Welcome video

Figure 7. Thumbnail of welcome video

Watch the video here: https://www.youtube.com/watch?v=S8prcyFVDCg

Appendix C: One-on-one interview themes

- Tell me about yourself and your current journey with your brain injury.
- How is your life different from your pre-injury days?
- What kind of emotional/social support did you receive while recovering, and is there anything you think was missing?
- What would you like others to know about your brain injury, or about brain injury in general? How do you talk about it with others?

For the Postcard Activity:

- I'll talk to you about the designs I'm currently working on and get your feedback.
- Are you comfortable with drawing?
- Do you have pencil crayons to complete the drawings? (If not I can provide)
- Time for any questions participants may have

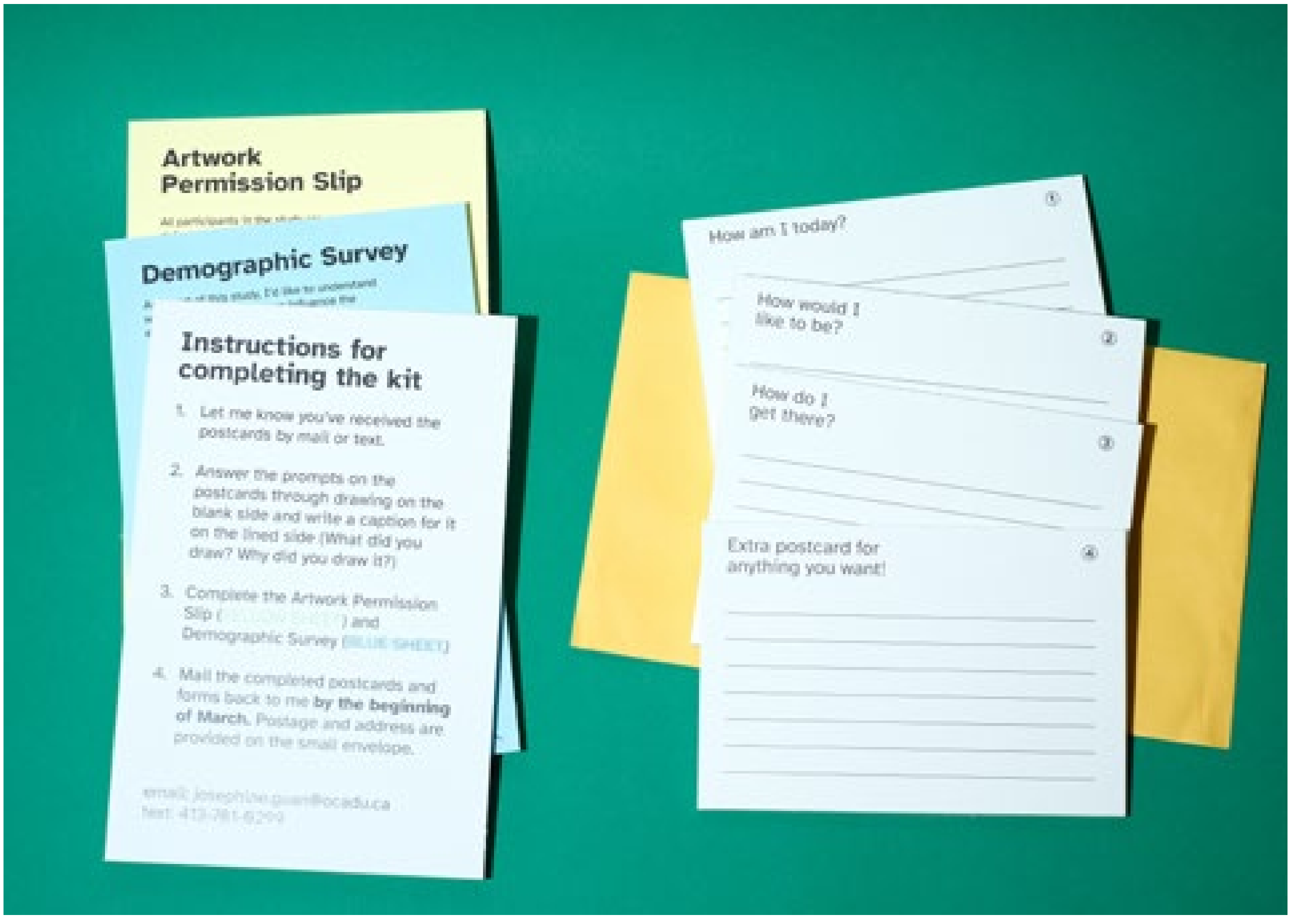
Appendix D: Postcard mail kit instructions

Figure 8. Thumbnail of instructions video

Watch the video here: https://www.youtube.com/watch?v=tYBD6MqamY0

Appendix E: Postcard kit

Figure 9. Photo of postcard kit



Instructions for completing the kit

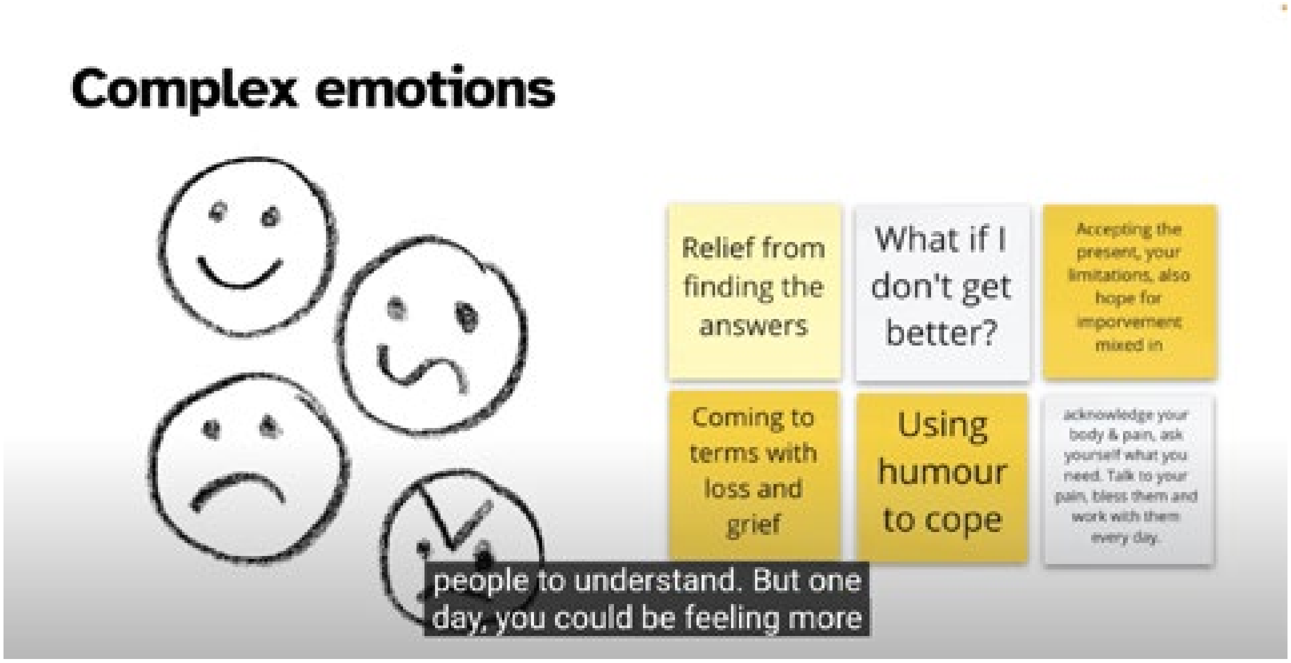
1. Let me know you've received the postcards by mail or text.
2. Answer the prompts on the postcards through drawing on the blank side and write a caption for it on the lined side (What did you draw? Why did you draw it?)
3. Complete the Artwork Permission Slip ([illegible]) and Demographic Survey (BLUE SHEET)
4. Mail the completed postcards and forms back to me **by the beginning of March.** Postage and address are provided on the small envelope.

Appendix F: Guillemin (2004) critical visual analysis of drawings

- What is being shown? What are the components of the image? How are they arranged?
- What relationships are established between the components of the image?
- What use is made of colour? What colours are used? What is the significance to the drawer of the colours used?
- What do the different components of the image signify? What is being represented?
- What knowledges are being deployed?
- Whose knowledges are excluded from this representation? and
- Is this a contradictory image? (to other data collected, for example, in interviews)

Appendix G: Initial findings video

Figure 10. Thumbnail of initial findings video



Complex emotions

Relief from finding the answers

What if I don't get better?

Accepting the present, your limitations, also hope for imporvement mixed in

Coming to terms with loss and grief

Using humour to cope

acknowledge your body & pain, ask yourself what you need. Talk to your pain, bless them and work with them every day.

people to understand. But one day, you could be feeling more

Watch the video here: https://www.youtube.com/watch?v=yVLqqcay3A0