

“YOU OWE IT TO YOURSELF”: DISCOURSES OF HOPE AND WORK IN BRAIN
INJURED INDIVIDUALS' EXPERIENCES OF BRAIN TRAINING GAMES

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Abstract

Brain training is a multi-million dollar market, with products that boast claims to enhance cognitive functions through the power of neuroplasticity. In this MA research I explore the experiences of individuals with an Acquired Brain Injury (ABI) who use brain training in an attempt to regain past identities or to create new and improved ones. The concept of neuroplasticity embedded in brain training programs represented hope to brain injured individuals: hope that they could regain skills that they have lost because of their injury. Brain training programs are also part of a larger theme of self-rehabilitation, in which individuals who were either neglected by the healthcare system or who wanted additional care turned to at-home treatments and programs. Finally, I argue that brain training fits with the dominant cultural imperative of health in North American society in which individuals must work to exercise self control and better themselves and their health in order to contribute to society.

Keywords: Acquired Brain Injury, brain training, neuroplasticity, hope

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Chapter 1: Introduction

Brain Training has become a multi-million dollar market in the past 10 years, with new programs and companies cashing in on this growing industry every day. With the hype of these programs comes a lot of criticism and uncertainty about their effectiveness. Do these products actually do what they claim? I became interested in the world of brain training programs when my mother, a brain injury survivor, started playing these games on the recommendation of her occupational therapist. I began to see that brain training was not just marketed to the everyday person to boost their intelligence and cognitive skills, but also to individuals who have cognitive impairments. The claim made by brain training programs and select neuroscientists is that the brain is able to regain lost skills through the power of neuroplasticity, and these games will help it do so. Neuroplasticity is the brain's ability to rewire itself through the formation and integration (or destruction) of new neural connections, which can occur through new behaviours, environmental changes, injuries and/or mental stimulation (George and Whitehouse 2011, Rubin 2009). Brain training games claim to promote the growth of synapses, create neural connections and improve overall cognitive health through their repetitive use, which is supposed to challenge one's cognitive abilities. I wanted to see if these programs did indeed benefit people with cognitive impairments, not from a clinical standpoint, but from the perspective of brain injured individuals themselves. Whether or not these products *actually* worked was not as much of a concern to me, but rather how brain injured individuals experienced the programs, and what the programs meant to them.

I pursued these questions by first experiencing these games for myself, and then by interacting with brain-injured survivors who use these programs. I asked survivors why they played brain training games, if they thought that they worked or did what they claimed, and how they understood the concept of neuroplasticity. What I discovered was that these brain-training programs were more than just computer games for these individuals. Neuroplasticity and brain training programs represented hope and motivation to brain injured individuals, hope that they may regain skills that they have lost because of their injury and hope to one day return to their pre-injured selves. Brain injured individuals commonly experience a change or loss in their core identities after injury, and brain training is used in attempt to regain past identities or to create new and improved ones (Hoogerdijk et al. 2011). Brain training programs were used by my participants as a replacement for traditional cognitive rehabilitation that they were unable to receive due to lack of funds or insurance coverage. Brain training programs are also part of a larger theme of self-rehabilitation, in which individuals who were either neglected by the healthcare system or who wanted additional care turned to at-home treatments and programs. Finally, I argue that brain training is used to fulfill a neoliberal attitude of health and the body in which individuals must work to exercise self control and better themselves in regards to their own health and well-being in order to contribute to society, specifically the ill or injured individuals who are stigmatized and pose a threat to the social order.

Acquired Brain Injury (ABI)

One fact about Acquired Brain Injuries (ABI) that makes studying them so

difficult is that the outcomes can differ greatly depending on the person. No individual brain injury is the same as another. The factors that differentiate brain injuries include what area(s) of the brain were injured, including the frontal lobe, parietal lobe, temporal lobe, occipital lobe or the cerebellum. Even injuries in the same area of the brain can cause different problems and affect different functions from one person to another. Another factor is how severe the injury is, which usually affects the level of recovery possible and the quality of life that person will have post-injury. Typically brain injuries are separated into three categories: mild, moderate and severe, and this is measured by the Glasgow Coma scale which determines the initial severity of a brain injury. There are other factors that affect one's injury including if the individual was in a coma, if there was any other physical damage to the individual, or if the head injury was penetrating or closed. A brain injury is commonly referred to as the 'silent epidemic' in the scientific community because while many brain-injured individuals may look physically healthy, they are actually suffering a myriad of cognitive, social, and emotional problems that outsiders cannot see. Brain injuries can cause a variety of impairments such as communication problems, physical disabilities, behavioural and emotional problems, and finally cognitive and intellectual problems (Barnes 1999). Another common feature of brain injuries is the loss or alteration of identity, which is brought on by the changes in one's daily routines, occupations, and habits, which structure and form individual's lives (Hoogerdijk et al. 2011).

My research participants fell into two groups of brain injuries: traumatic brain injury and stroke. A traumatic brain injury is an acquired brain injury that occurs when some form of trauma causes damage to the brain, such as a motor vehicle accident or a

fall. A stroke occurs when either a blood vessel bursts in the brain or when the blood supply in a part of the brain is cut off¹. Within these two categories are a large number of subcategories, including type of stroke or area and severity of trauma to the brain, but these subcategories will not be discussed in detail in my research. My project will explore a variety of brain injury patients and their experiences with brain training programs. Due to time constraints and access to participants, I will not be focusing on one particular type of brain injury, but that may be something to consider for future research for a more specific type of information.

ABI Rehabilitation

The key to recovering from a brain injury is proper rehabilitation, which begins almost immediately after the injury occurs. The process of rehabilitation, for brain injuries must “go beyond the confines of physical disease and must deal with the psychological consequences of physical disability and with the social milieu in which the disabled person has to operate” (Barnes 1999). Rehabilitation focuses on the functionality of illnesses, which places emphasis on the disability more than the impairment. Brain injury rehabilitation is used to reduce areas of disability and to increase skills in dealing with new disabilities both physically and socially (Barnes 1999). Some of the main rehabilitation methods used for brain injuries and used by my participants are speech therapy, physiotherapy, occupational therapy, cognitive therapy, and often times neuropsychology or psychiatry for any emotional stress or mood disorders caused by their injury. These rehabilitative strategies are practiced while in the hospital after the

¹ www.ninds.nih.gov/disorders/stroke/stroke/htm.

initial injury, at a rehab center, as outpatient therapy or even at-home services. Assistive technologies may also be provided during rehabilitation such as communication aids, driving devices, and other at-home assistive equipment, which can help reduce disability and increase levels of independence for injured individuals (Barnes 1999). Access to rehabilitation is varied and depends on the severity of one's injury. Specialists will examine the need for various rehabilitations, and depending on the availability of these services as well as the cost or coverage of these services, one will gain access.

The first three months after injury is the most crucial period for the rehabilitation of head injuries and is when the most improvement occurs, yet long-term rehabilitation is important in order to sustain the short-term gains. According to Barnes (1999), often times the psychological and cognitive impairments take the longest to recover from, and also cause the most stress to both the injured individual and their families. Some studies have even demonstrated that successful rehabilitation after a brain injury results in overall costs savings per year for brain injured individuals and society as a whole, compared to individuals who did not undergo or receive enough rehabilitation (Barnes 1999 and Humphreys et al. 2013). The reason for this is that the initial costs that come with ABI rehabilitation are typically offset by the savings in costs for care and support that would be needed in the long-term for someone who did not undergo rehabilitation (Humphreys et al. 2013). Another reason is that individuals who undergo successful rehabilitation are typically able to return to work quicker than non-rehabilitated patients, which benefits the health insurer in terms of cost savings, and the individual, both financially and in terms of independence and self-worth (Barnes 1999).

Along with traditional forms of clinical rehab that I have described above, brain injured individuals are recommended to employ their own means of community or self-rehabilitation. This can include joining various support groups that deal with the issues that they face, both online and in person, as well as other group activities. Many of my participants were part of various support groups as both members and even leaders, and described the meetings as helpful not only for information and support, but also as a form of interaction and sociality. George and Whitehouse (2011) discuss not only the cognitive benefits, but also the emotional well-being and meaningful relationships that can be formed through community and group activities. The more personal side of self-rehabilitation can include practicing healthy nutrition, introducing exercise into one's lifestyle, stimulating the mind with books and puzzles, and even includes the use of brain training programs. Self-rehabilitation can at times provide an alternative to regular clinical therapies, and has benefits to traditional therapy such as cost-savings, unlimited independent practice, and increased accessibility- but the effectiveness of self-rehabilitation has not yet been adequately explored and should not necessarily replace traditional rehabilitation (Zickerfoose et al. 2013).

The Plastic Brain

Neuroplasticity is the theory that the brain is plastic and malleable and therefore can be rewired and trained to improve. According to this theory, injured brains can regain lost functionality (Rose and Abi-Rached 2013). This way of thinking was not always accepted by the scientific community, with many studies and papers on neuroplasticity being dismissed and disregarded. Resistance to the theory of neuroplasticity in adult

humans was due to the fact that it would have to eliminate a long held and valued belief of the unchanging adult brain in favour of a brain that has the ability to change structurally and functionally during all phases of life. According to Rubin (2009), the stable un-changing brain was part of an old “thought collective”-a term described as a particular way of understanding and acting while rejecting all other beliefs- that insisted on maintaining their particular thought style by means of concealing or discrediting novel evidence against it. In 1998, an international study by Fred Gage provided ample evidence of ongoing neurogenesis² in the adult brain, which proved structural plasticity was present in all species. This study changed the dominant thought collective of the time, and also opened up endless possibilities for therapeutic interventions for brain injuries and neurodegenerative diseases (Rubin 2009).

With the advent of the plastic brain came the scientific community’s willingness to exploit the potential of neuroplasticity with therapeutic interventions such as pharmaceuticals, therapies, and new tools such as brain training. Many social scientists argue that Neuroscience has the tendency to be reductionist, that is, it tends to isolate the brain and its components to explain neural processes while ignoring the fact that brains are embodied organs in a larger more complex body of flesh and blood (Abi-Rached and Rose 2013). Neuroscience also further reduces the brain itself, localizing different areas of the brain that affect different parts of one’s cognitive functioning (Dumit 2004). The reductionist mentality has made drugs and technology such as brain training seem like a quick fix, without considering the many other issues that affect the health of the brain such as diet, stress, and exercise (George and Whitehouse 2011). This notion of the

² Neurogenesis is the growth and development of neurons in the brain (<http://www.jneurosci.org/content/22/3/612.full.pdf>)

plastic brain, malleable and capable of change, fits neatly with a strong cultural tendency in North America towards making each person responsible for being their best selves, always striving to attain a healthy mind and body (Abi-Rached and Rose 2013).

The brain has played an important role in the social sciences for many years, specifically with it being the centre of the mind and brain debate. The mind/brain debate, also known as monism and dualism, is the argument surrounding whether the mind is a physical or non-physical substance, and therefore if it is located in the brain or not. Cartesian Dualism is the belief that the mind and body are separate entities but are correlated and influence one another, whereas monism is the belief that the mind is physical, and thus located in the brain (Berecz 1976). The mind/brain debate is important because it suggests certain things about the mind and the self. The cultural importance of the brain is significant for my research because of its supposed connection to the self, which informs the decisions of brain injured individuals. Brain injured individuals typically experience a change in their sense of self, which they may attribute to the changes in their brain due to damage. The same logic can then be applied to re-training the brain in order to regain that sense of self.

Brain Training Programs

Neuroplasticity: the discovery that made brain training possible

Research has found that certain types of activities may impact the brain more than others (Mechelli et al., 2004; Gaser and Schlaug, 2003; Draganski et al., 2006).

It's believed that as an activity is repeated, the brain tends to fall back on the same set of existing neural pathways. To continue changing, the brain must be exposed to novel, adaptive experiences that challenge it to work in new ways.



Figure 1: Description of neuroplasticity on the Lumosity website (www.Lumosity.com)

When the theory of neuroplasticity became accepted in mainstream neuroscience, it opened the door for a new market of brain training programs to be developed by companies that could make scientific claims for their products. I discovered the important role of neuroplasticity in brain training while navigating the various brain training websites. Pictured above in Figure 1 is an excerpt found on the Brain Training website Lumosity, which claims that brain training was made possible by the discovery of neuroplasticity. The excerpt includes references from various research articles in order to add validity to the statement, as well as a brief explanation on how neuroplasticity works. The term neuroplasticity can be found in almost every brain training program, and is used as a major feature for legibility of the products and for advertising purposes. Brain Training programs come in many shapes and forms, and each program focuses on different aspects of cognition. Almost all brain training programs require the use of technology to function, be it a computer, cell phone, television or video game console. The programs are typically a series of games, brain teasers, and/or puzzles that are said to enhance your memory, attention, spatial and visual skills, concentration, recall and other

cognitive functions (George and Whitehouse 2011). The games and activities are designed to be fun and interactive in order to keep users entertained and wanting to continue playing.

As part of my research, I decided to play some of the popular brain training games in order to have a better understanding of them and in order to relate to my research participants who use them. I decided to focus on the most popular brain games as well as the most easily accessible games, so I made a free trial account on Lumosity, and downloaded the free online app Brain Wars for my cell phone. I even tried other games that are not marketed as brain training games but that promote learning and brain stimulation, such as the language learning app Duolingo and online quiz websites Sporcle and JetPunk. I did not pay for any of the games, I only played the free games or used the free trials that are available for the paid games. The games available on the various brain training programs were all fairly similar in style. There were a variety of similar games such as memory games that show images or patterns and then make you recreate the pattern, as well as math games, games that test your speed and agility, and problem solving.

Lumosity

Lumosity is probably one of the most popular and well-known brain training programs out in the market, although it requires a monthly paid subscription to access. They do offer a free trial during which you can try out the games, but it restricts you from full access to all of the games and it does not track your progress or compare your scores to other members as it would in the paid version. In the free trial they test your current

cognitive performance by playing a few games, and ask you which aspects of cognitive training you would like to improve: speed, memory, attention, flexibility or problem solving. They then propose a training plan for you, and promote their full paid membership program in order to get the best results. Although I only signed up for a free trial myself, my mother has a paid subscription to Lumosity so I was still able to observe the extended features of the paid subscription. Some of the games include: 'Memory Matrix' which tests your memory and spatial recall by trying to recreate a pattern on a grid, 'Lost in Migration' which tests your selective attention by pressing the arrow key on your keyboard in accordance to the direction of the birds, and 'Raindrops' (seen in Figure 2 below) which is a math game that tests your problem solving skills by quickly solving math problems in rain drops before they disappear. I found the games to be entertaining, but without a paid subscription you are denied access to a lot of the features of Lumosity, and are restricted from continuing the games as you would if you paid.

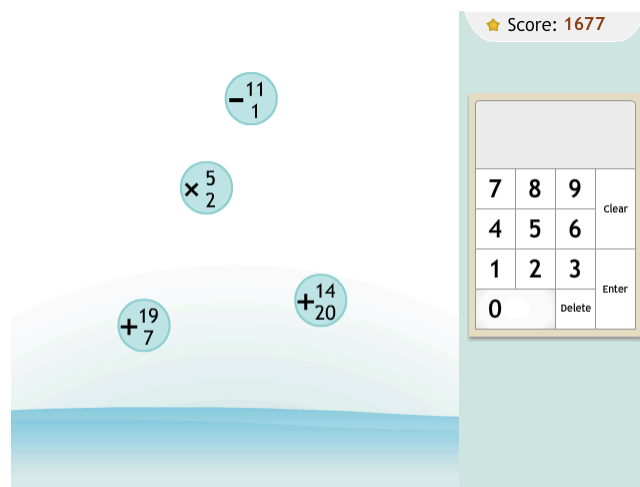


Figure 2: Lumosity Game 'Raindrops'

Brain Wars

The free app Brain Wars is a unique program because the brain games are

interactive and involve playing brain games against other users, whether they be strangers or your friends. The app can be easily downloaded on your cellphone or tablet, and is free which makes it highly accessible for anyone with a smartphone to play, and can be played anywhere you have an internet network connection. The app divides its games into the following categories: speed, memory, observation, accuracy, calculation and judgment. It includes the same style of games you would play in other brain training apps, but instead of playing independently to improve your score you are also facing other players and earning points based on your wins and losses (see Figure 3 below). You can also play the games individually to practice under the ‘training’ section. This added a more competitive edge to the games, but could also be intimidating to new users.

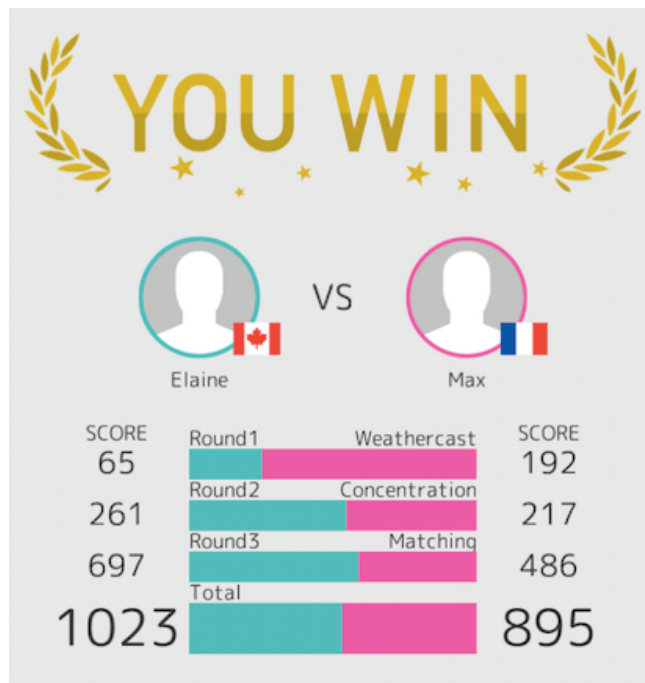


Figure 3: Game of BrainWars that I played against a fellow competitor in France

“Activate A Better You”

Besides Lumosity and Brain Wars- games that are marketed as brain training- I

also tried a few other games and apps that my participants had used, specifically Duolingo, Sporcle, and JetPunk. Duolingo is a language learning app you can use on your phone or computer and is designed to teach users new languages. The website offers free courses in 21 different languages and focuses on various aspects of a language such as Basics, Conjunctions, Food, Adjectives, and Directions, among others. The more you play, the higher level you achieve as well as percentage of fluency. The websites Sporcle and JetPunk are very similar websites that offer quizzes in a variety of topics such as History, Geography, Science and Television. The quizzes are timed and often involve graphics, charts or lists that you must fill out before time runs out. You can make accounts on both of the sites that track your progress and how well you do on the quizzes. JetPunk has a level system, and the more you play and improve the higher level you achieve. It also shows your stats in the games you have played and compares it to the average scores. Sporcle on the other hand does not have levels, but does include your statistics, and also has Badges that one can earn if they play a series of quizzes of one topic, or play a certain amount of quizzes in one month, etc. Sporcle also has a feature where you can add your friends or other members and challenge them in different quizzes.

The advertising and claims made for these programs are what I found most interesting, as they provide insight into what the games are trying to promote and sell to consumers, as well as what they claim the products can do. Figures 4 and 5 (below) are actual Lumosity advertisements found online and in popular media. Figure 4 features a digital picture of a brain, and claims that Lumosity games are scientifically proven to improve memory, focus, and relieve stress, which will therefore “activate a better you.”

What is interesting to note is the image of the brain has highlighted areas which I believe represents the brain being stimulated and 'activated' by using Lumosity. Figure 5 is an advertisement featuring popular basketball player LeBron James, which claims that LeBron uses Lumosity to improve his vision for playing basketball, and that you too can "train like the pros". Not only is Lumosity using scientific claims to sell their products, they are also using the claims of celebrities to make the product more appealing to consumers. Celebrities and pro athletes are valued in our society and seen as 'better' than the average person, thus they are used in advertisements as a way to promote that their product can make you better, just like the celebrities. Other brain training programs use similar advertising techniques as Lumosity, such as Brain Wars which describes itself as "Competitive Brain Training" that claims to "increase your brain power...through repetition and adaptation." Although Brain Wars does not boast scientific evidence that their games work, they still make strong claims that their product will improve brain function through games that they describe as "simple and intuitive brain training."



Figure 4- Lumosity Advertisement "Activate a Better You"



Figure 5- Lumosity Advertisement with LeBron James

The Brain Training programs, such as the ones I've described above, are often marketed towards individuals with cognitive issues such as mild cognitive impairment, cancers, and cognitive decline. Whether or not brain training programs actually do increase cognitive functioning for these individuals is still yet to be determined, although many clinical trails of brain training programs have been done, which will be discussed in Chapter 2. While individuals with brain injuries may have many different types of impairments, the use of brain training programs focuses on the improvement of mainly cognitive skills. This can suggest that cognitive abilities and intellect are one of the features that people with and without brain injuries are most invested in improving.

The brain training industry is a multi-million dollar endeavour that strategically feeds on the cultural importance of self-improvement and uses language that fetishizes the brain as an "object of alterity and veneration...a separate privileged entity that healthy individuals must constantly stimulate, rewire, rebuild, nurture and attend to"

(George and Whitehouse 2011). Neuroplasticity has made the brain a site of intervention, able to change and improve, which can begin as early as child rearing from parents to raise good citizens in our society (Abi-Rached and Rose 2013). The brain as an organ is given superiority over other organs as a separate entity that represents the individual, thus a healthy brain reflects a healthy mind and soul of an individual (George and Whitehouse 2011). The plastic brain also represents hope, both for people who have cognitive impairments and people wanting to slow down the process of cognitive decline. Brain training programs play on this hope in the advertising of their products, claiming that their programs are created based on the concept of neuroplasticity that can change your brain if you put the work in. They also strategically design the games to be visually appealing, fun, and to have levels that track your progress and compare it to others in order to keep you interested and wanting to play more.

My Research

Besides the many physical, cognitive and behavioural issues individuals face after suffering an ABI, it is important to note the other areas of life that are affected by such an injury. Almost all of my participants were not working because of their ABI, and many could not drive. This is not uncommon, as a study showed that most survivors living 4 years post injury neither worked or attended school, and were living with their families (Humphreys et al. 2013). Money was a concern to many individuals as a result of unemployment, and although most were receiving compensation from their insurance provider, the government, or their work compensation board³, it usually was still not

³ The Worker's Compensation Board provides loss of earnings benefits and health care coverage to employees

enough. Traumatic brain injury is one of the biggest causes of long-term disability in industrialized and developing countries, and is predicted to be the most major cause of death and disability (Humphreys et al. 2013).

The monetary issues they faced usually affected the quality of rehabilitation they were receiving, with some not receiving any rehabilitation at all after their coverage ran out. As a result of the lack of rehabilitation coverage and limited income from disability or government assistance, many individuals could not pay out of pocket for traditional rehabilitation and thus resorted to other methods such as brain training programs. Yet even brain training is its own market and many of the most popular or highly reputable brain training programs require monthly payments for subscriptions, which cost up to \$15 a month. For most of my participants, this monthly subscription cost was too expensive for their budget, which was used for basic necessities such as food, rent, and transportation. For my participants, brain training was not deemed as important enough to justify paying for it, considering there were other free options that were available to them.

Emotional disorders were also fairly common among my participants, and can be attributed to various reasons such as the physical trauma to the brain, or the recovery from the injury itself. Injuring certain parts of the brain may change the way one reacts to things emotionally, as well as changes in general mood and emotions. Other factors can trigger emotional changes and depression such as physical, psychological, and social factors (Guillamondegui et al. 2011). Emotional disorders can arise in brain injured individuals from the loss of independence that may come from no longer being able to do activities one used to do, the physical and/or cognitive disabilities that one has to get accustomed to living with, and the overall act of recovering from trauma (Humphreys et

al. 2013). Many of my participants expressed having some sort of emotional distress after their injuries, and some were on anti-depressants. Depression and emotional impairment post-brain injury can occur directly after injury or can appear years later (Guillamondegui et al. 2011). There are many other features of life that are disrupted and changed for brain injury patients that will be explored more in the following chapters.

What I Hope to Contribute

A lot of research on brain training programs has been published, specifically in the past ten years as brain training has exploded in popularity. Yet, not much of this research focuses specifically on brain training for individuals with brain injuries, and the fragment of research that does is mainly quantitative. While there are many benefits to quantitative research when it comes to brain training and its effectiveness, I believe that qualitative research is important in exploring the social, cultural and personal experiences behind brain training programs, and how they are being consumed by individuals with acquired brain injury. My contributions to literature on both brain injuries and brain training will focus on the personal experiences of brain training, and how individuals with brain injuries consume these products. While much research has been done on what brain training does to the brain via controlled tests and visual imaging such as fMRI scans, these studies lack the individual experience of these games. I also think it is important to discuss the way these products are marketed to consumers, and how consumers use these products and create their own meanings from them in the domestic setting of the home.

Overview of Chapters

My thesis will be divided by the various themes that emerged from my research on brain training programs for ABI patients. Chapter 2 will discuss both scientific and social science literature on the design and effectiveness of brain training programs, as well as how they are marketed. I will also summarize the social science literature on the lives of people with ABI. Chapter 3 will detail my research methods including online research, participant observation and semi-structured interviews, as well as outlining the challenges and obstacles that I faced throughout the research process and how I overcame them. Chapter 3 concludes with a series of short profiles of five of my participants, giving a brief background of their injury, their lifestyles and their relationship with brain training programs. Chapter 4 will introduce the descriptive themes of my research findings, which include: the loss of identity, financial issues, mental illness, use of pharmaceuticals, and alternative coping mechanisms. Analysis of my research themes will be presented in Chapter 5, to explore why my results are meaningful, and explore their anthropological significance. My first theme involves the sense of hope that brain injured individuals have of returning to their former selves, whereas my second theme involves the desire of brain injured individuals to ‘work’ in order to become valuable citizens again, whether it be in traditional employment or other forms of improving themselves. My third and final theme, self-rehabilitation explores how my study participants try to achieve the first two desires of returning to one’s previous self and ‘working’, which is where brain training is introduced. Finally, my conclusion will provide a short summary of my research arguments and my findings, including any limitations that may have affected my research.

Chapter 2: Literature Review

In this chapter I will explore relevant literature in anthropology and neuroscience on brain injuries and brain training. These texts are valuable to understanding the experiences of brain injured individuals, the need or use for brain training tools, and the underlying significance of the brain in our society. The purpose of this chapter is to explore the current state of knowledge, both scientific and social scientific, about the brain and the self, and about brain training programs. I will begin with relevant literature on neuroplasticity and its importance in the marketing and consumption of brain training programs, and outline the various clinical studies that have been done on brain training programs and their efficacy. I will then discuss literature in medical anthropology to explain the significance of the brain and brain health in modern society, and the significance of the home in health care and the domestication of health. The overall goal of this chapter is to show how the scientific ideas of neuroplasticity and the brain as the location of the self connect with the cultural importance of being a healthy and productive citizen by ‘working’ on the self.

Neuroplasticity and The Plastic Brain

Neuroplasticity is an important concept in regards to the brain and the self. As I discussed in chapter 1, the theory of neuroplasticity was not always accepted in the scientific community nor was it a common term in Western culture. The introduction of evidence of production and integration of neurons in adult hippocampi opened up many possibilities for therapeutic interventions, such as the potential of the self-healing brain (Rubin 2010: 13-4). Neurobiologist Beatrix Rubin suggests that the plastic brain

represents a change not only in neuroscience and new therapeutic approaches, but also a change in thought styles. Whereas the previously accepted theory of the stable brain meant any negligence or damage to the brain would be irreversible, the new plastic brain represents hope for adult regeneration (Rubin 2010: 409). For brain injured individuals, this newfound hope promises a path to return to 'normal' functionality, or to an even a better state than before an injury (Beauregard 2012).

Psychologist and neuroscientist Elaine Fox (2012) extends the theory of neuroplasticity by arguing that even our affective mind- that is our emotions, moods, and personalities- can be altered by mental training, medication, or talking therapies. Fellow neuroscientist Dr. Mario Beauregard (2010) discusses the power of the brain to change itself, proving the plasticity of the brain and showing how practices such as meditation can alter the physical structure of your brain. He claims that not only acquired knowledge impacts plasticity, but also changes in thoughts and emotions. Philosopher Catherine Malabou (2012) offers a unique perspective on neuroplasticity, claiming that there are two types of plasticity: constructive and destructive. While constructive plasticity is seen as the good plasticity that forges bonds and multiplies relations, destructive plasticity is the opposite, destroying and undoing connections. She describes destructive plasticity as the ability to create identity through the loss of past identity, with no return to a previous state (Malabou 2012: 60). The neuroplasticity that is frequently referred to in neuroscience and in the marketing of brain training is constructive plasticity, while destructive plasticity is never mentioned. The concept of destructive plasticity could be used to relate to the loss of self that many brain injured survivors face, and the changes in

personality and identity that brain damage has been known to cause, and should not be dismissed.

Marketing Neuroplasticity

The marketing of brain training programs is worth exploring to see the social and political influences in the language being used to attract consumers. Advertisements for brain training programs and games can be found everywhere in online and traditional media, with slogans encouraging people to build better brains, and even including celebrities and popular athletes to promote their products. In these advertisements, the brain is separated from our other vital organs and is viewed as a privileged entity that requires stimulation, rebuilding, and constant work to remain healthy and fully functional. George and Whitehouse (2011) argue that within the language used in brain training programs, the brain is being fetishized, and a focus is placed on the Western values of cognition, rationality and memory. Marketing for brain training programs also invariably includes the mention of ‘neuroplasticity’, as well as terms such as ‘cognitive’ and ‘neural’, and almost always include that the products were created and/or tested by neuroscientists. This scientific language is there to convince consumers that these products are scientifically tested and effective, and that they can indeed alter one’s brain and cognition (George and Whitehouse 2011).

The fetishization of the brain in brain training marketing also enforces principles of liberalism, and that self-responsibility, individualism, and personal well being holds the most moral value in society. The individual is responsible for bettering themselves and participating as a consumer in the marketplace, which is a much different attitude

than the community centered pre-capitalist ideologies (George and Whitehouse 2011). The individual is the focus of brain training programs, and this is apparent in the lack of multi-player or interactive features of these products. Most games are made to be played alone on a personal device such as a laptop or cell-phone, and in the quiet privacy of one's home. The overall message to be taken from the marketing of brain training is that the brain is a "symbiotic source of selfhood for the atomized consumer", and these products, if used consistently, will improve the efficacy of the brain and prevent the process of neurodegeneration (George and Whitehouse 2011:3). One of the issues with brain training programs is that they tend to be reductionist, claiming that the use of their product alone could slow down the effects of brain aging and increase cognition in the brain. This idea disregards many important factors that attribute to the health of the brain such as diet, stress, exercise, interaction, etc. (George and Whitehouse 2011). If other factors of brain health were integrated with the use of brain training, the products may produce different results.

Marketing brain training was recently discussed in a CBC Marketplace segment titled "Mind Games" which explored the increased popularity of brain games, especially in relation to Alzheimer's disease and Dementia. The segment explored the growing fear of losing one's memory, and how the brain training market is building off of that fear with the introduction of brain games. The program claims that these products are selling hope in a world where there is no cure for memory loss or cognitive function, and people will try anything in order to stall memory loss or the onset of Alzheimer's. The segment criticizes Lumosity, which backs up its claims with studies proving its efficacy, yet no independent studies or scientific evidence has shown that their program will benefit

cognition in every day life. CBC partnered with neuroscientist Adrian Owen to conduct an assessment of 54 adults who used Lumosity for up to a month. They were assessed in memory, reasoning, concentration and planning, and the results found that there were no significant improvements in any of the tests. The segment concludes by claiming that regular exercise, good diet and the inclusion of games are your best bet for delaying the onset of Alzheimer's, rather than just relying on the effects of brain training alone.

Clinical Studies on Brain Training Programs

With the popularity of brain training programs comes the critique of the scientific community. Various studies have been done testing the effectiveness of the popular brain training games on the market. Most of these studies require the use of a brain-imaging tool such as an fMRI machine, which is used on the participants before, after, and sometimes during the brain training experiments. A control test to measure participants' cognitive ability is used before and after a period of using a brain training programs on a regular basis for a specified duration of time. Exact results of these studies differ depending on different variables and limitations, but a lot of these studies shared the common conclusion that brain training programs do not transfer the cognitive skills learned in the games to one's everyday lives, and there is little to no increase in overall intelligence.

One study by Zickerfoose et al. (2013) focused on the use of two brain training programs to remediate attention deficit post brain injury. While all of the participants progressed in levels and difficulty in the games, only half of the participants showed any signs of generalization, whereas the other half experienced no apparent generalized benefits. Zickerfoose et al. (2013) claims that the results can confirm the opinions of

many researchers that while there is ease in improving on specific intervention tasks, the challenge is transferring those gains into everyday living. The study claimed that benefits of the programs were their “low cost, wide-spread availability, provision of immediate and unbiased feedback and built-in entertainment” (Zickefoose et al. 2013: 714).

Similar results were found in a six-week online brain training study by Owen et al. (2010) that involved 11,430 participants. They found that whilst there were improvements observed in each of the cognitive tasks and games being practiced, there was no evidence to show that the improvements transferred their effects to untrained tasks, even when they were closely related cognitively. The study concludes that the results debunk the popular belief that regular use of brain training programs improves general cognitive function of healthy individuals. The study does claim that other approaches to brain training such as face to face cognitive training may be more valuable than what was practiced in the study, as well as the possibility that a longer period of practice of brain training may or may not alter the results (Owen et al. 2010).

A study on the effects of brain training for Alzheimer’s patients found that the improvement in scores reported by participants was restricted to games and did not transfer into the cognitive skills assessed by neuropsychological testing. The study did find some benefits of brain training, such as the reduction of general anxiety and increased measure of verbal fluency in Alzheimer patients (Branscombe-Caird 2011). Finally, another study conducted by Redick et al. (2013) focused on the claims made by brain training programs Lumosity that their games focused on computerized working memory (WM), which would eventually improve overall intelligence. They concluded that participants in their study who used accessible cognitive training programs improved

in their abilities in the games and activities over time, yet they found no evidence between a relationship between their improvement in their training practice and fluid intelligence gains. They did note that the “subjects believed that certain aspects of their cognition had been affected by the experiment, even though objectively none of the transfer measures reflected differences over and above practice effects”, therefore the activities may produce a placebo effect on participants (Redick et al. 2013: 376).

All of these scientific studies share similar results, in that while there may be benefits to brain training, the games that are marketed as increasing intelligence and cognitive performance do not do so. While there is no doubt that an individual’s score will increase after playing these games, the issue is the lack of acquired skills transferring into everyday cognitive tasks. Figuring out how to transfer the skills learned in brain training games into everyday life remains the biggest concern of both researchers studying brain training and the companies marketing brain-training programs today (Branscombe-Caird 2011). Yet as was seen in the Redick et al. (2013) study, participants often feel that these games are indeed improving their cognition even if they may not be, and most participants enjoy the games and experience improved moods after playing them. These studies also show that the marketing of these products remain a crucial motivator for individuals to use brain training, specifically with their claims to improve cognitive functioning, even if they may not actually do so. In the next section, I will discuss anthropological literature on the brain and the body, medicalization, and the unhealthy other, and how these theories relate with what I have discussed regarding neuroplasticity and the marketing of brain training.

The Mind vs. The Body

When studying cognition and the brain, it is important to note the philosophical history of the brain, mind and body. The mind/body debate is the argument surrounding whether the mind is a physical or non-physical substance, and thus if it is located in the brain or not. The two famous views on this topic are referred to as dualism and monism. Dualism refers to the idea of the separation of the body and mind, and was first introduced by French Philosopher Rene Descartes. The theory of the separation of the mind and body distanced the body from the human essence and sacred soul, giving the understanding of illness and disease as merely physical in nature. This meant that the soul was external from the body, and thus the body could become the object of scientific exploration through anatomical dissection, which led to the current realm of biomedicine that we have today (Samson 1999). Hacking (2007) argues that the Cartesian dualism distances us from our bodies which then become foreign entities, permitting the objectification and commodification of the body, allowing us to fix, replace, sell, and trade our bodies like commodities. Monism, on the other hand, is the belief that the mind is physical, located and controlled in the brain. This view rejects a separation of mind and body and “emphasizes man’s absolutely basic unity” (Berecz 1976: 280). A common form of monism is material monism, popular in the scientific community, which views mental and brain illnesses as completely physical, located in the brain, rather than in the conscious mind. While most neuroscientists are materialists and argue that one day, neuroscience will be able to prove the mind is located in the brain, other neuroscientists claim the exact opposite, that is it in fact impossible to prove (Damasio 1999, Beauregard 2012). Monism and dualism are important when looking at brain injuries, especially in

regards to the changes in self that brain injured individuals face. Scientists and philosophers argue the origins of the change in self that are experienced after an injury, and how this may prove the physicality of the mind.

Author and former brain injury case manager Michael Paul Mason (2009) explores the fragile state of the brain and how various injuries can affect the way it functions, as well as affecting a person's own identity. A study on the adaptation after traumatic brain injury finds that brain injury patients struggle to gain a new identity after trauma, and that their identities are threatened when they discover that they could not perform the same activities they previously could, or sustain important relationships (Hoogerdijk et al. 2011). It is also common that those with a brain injury are always comparing their present selves with their past selves, and that their present selves "are not desired selves" (Hoogerdijk et al. 2011). Humphreys et al. (2013) use the term neurobehavioral disability to describe the change in personality or character of an individual due to a range of disabilities. Changes in personality and emotional state are often seen as the greatest source of distress and burden to caregivers, as well as more socially debilitating for survivors than physical disabilities (Humphreys et al. 2013). Many survivors never gain their social independence back after their injury, which can pose risks to relationships and marriages, and cause psychological burdens on families who care for brain injured survivors. This can cause more distress to the survivor and the potential for increased social isolation, which explains the commonality of mood disorders in brain injured survivors (Humphreys et al. 2013: 281-2).

How individuals see their brains in connection with their bodies is important with the emergence of brain training, which relies on the idea that you can change the physical

structure of your brain through neuroplasticity, and thus changes your cognition and mind. Anthropologist Emily Martin (2010), in her study of bipolar disease in the United States, found that most individuals with a mental illness believe that their illness stems from a defect in their brain, and thus that their illness is physical rather than a defect in their mind. Physical illnesses are less stigmatized than mental illnesses in the Western world because it is believed that if an illness has a physical location it can be treated more easily through medication or therapy (Martin 2007, 2010). In regards to brain injuries, the physicality of the injury can be viewed through brain imaging technology such as fMRI's or PET scanners. Brain scans produced from these imaging technologies provide evidence of the physicality of the mind and become items of social significance to individuals with brain injuries. The individuals can then use these scans to defend the physicality of their injuries and its resulting cognitive damage (Dumit 2004, Cohn 2010).

It is apparent that material monism is preferred by brain injured individuals, and this can be explained by the theory of medicalization, which describes when a condition or behaviour is given a medical label, is described in medical terms, and thus uses medical interventions to treat it (Baer and Singer 2007). When something becomes medicalized, "there tends to be a reduction in the degree to which the disorder is stigmatized because other causes besides individual moral failings are ascribed, be they the consequence of pathogens or the effects of genetics" (Baer and Singer 2007: 109). Sociologists Conrad and Schneider (1992) use the phrase "from badness to sickness" to describe the process of medicalization of qualities that were once seen as deviant, such as mental illness or obesity. It is said that with medicalization comes the potential for intervention and control over individual's bodies and health, in the name of "individual

rights or desires” (Baer and Singer 2007: 109). When brain illnesses became medicalized, therapies, medications and commercial products such as brain training were created for individuals to improve the condition of their brains and their overall health, which illustrates how medicalization creates “the medical marketing of profit-making commodities” (Baer and Singer 2007: 109, Conrad and Schneider 1992).

The Unhealthy Other

Why is it important for people with ABI to defend the physicality of their injuries? Because material monism - the approach that the mind is a physical entity located in the structures of the brain - is less stigmatizing than the idea that their changed cognitive and emotional abilities are mental illnesses. We live in a society in which health is central to the modern identity, and the healthy body and its pursuit is valued, while the diseased and injured body threatens the individual and the social order (Crawford 1994, 2006). The healthy self is one who is in control and takes personal responsibility of their health and overall well being, while the unhealthy other does not take control of their health and therefore deserves the outcome (Crawford 2006). To avoid becoming the ‘unhealthy other’ individuals with brain illnesses must continue to work on themselves and their bodies and strive to become the healthy citizen in order to improve themselves.

Sociologist Nikolas Rose (2013) argues that corporations and the government get involved in the health of its citizens by promoting products and interventions that are made to improve one’s health and productivity, especially if it benefits the state. Institutions use the human body as an object and target of power in order to formulate

their subjectivities, and to normalize their subject positions (Foucault 1984; Rose 1996). Foucault (2003) claims that the strategies and programmes that regulate individuals try to shape the technologies of the self, the ways in which humans understand and relate to themselves as humans. An example of this is Nikolas Rose's concept that the plastic brain is a site of intervention by governments and corporations to both control and change individuals, as well as a site of improvement and personal responsibility for citizens (2013: 52).

Health Care at Home

The setting of the home plays an important role in the discussion of brain training programs and self-rehabilitation. For the most part, the home is the setting where these training programs are being used, and thus becomes a site for personal self-rehabilitation. Medical anthropologist and neurologist Daniel George and Peter Whitehouse (2011) claim that brain training programs have dictated that brain training activities should typically occur privately in one's home, rather than in public or in a group setting. They claim that they are marketed for individual consumption in the home, an idea that has been shaped by "the neoliberal ideologies of the marketplace" (George and Whitehouse 2011). The use of at-home brain training programs eliminates the clinical setting of traditional rehabilitation, as well as the trained biomedical clinician or therapist. In this day and age, health consumption is not limited to the clinical space, but rather is an everyday encounter that is increasingly taking place in private realms such as the home (Childerhose and MacDonald 2013).

The everyday practices and occurrences of the home are disrupted and transformed with the introduction of healthcare tools and practices (Angus et al. 2005). The changes within the home associated with injury and illness disrupt the “intimate, co-constitutive relationship between self and home” as new meanings are given to the spaces and the time spent within the home (Angus et al. 2005: 182). The home is also transformed when individuals consume biomedical tools and techniques at home without the need of a medical expert, an act that Childerhose and MacDonald call the domestication of health, and argue should be considered ‘work’ that consumers perform (2013:2). The domestication of health, specifically self-rehabilitation, will be discussed in further detail in chapter 5.

Chapter Summary

This chapter sought to illustrate the connection between the scientific discovery of neuroplasticity and the dominant cultural ideology of the healthy citizen who puts ‘work’ and effort to better themselves. The neuroplastic brain created an opportunity for the medicalization of brain diseases and injuries, allowing brain health to be commodified with the introduction of pharmaceuticals, therapies, and at-home treatments like brain training. It was the combined discoveries of the plastic brain that had the ability to be altered, along with the introduction of brain scanning tools that allowed physicians to physically see brain damage, that brain training was able to flourish. Brain injuries and neurodegenerative diseases were legitimized as physical illnesses rather than mental, and neuroplasticity opened up a space for therapeutic intervention of these illnesses. While the medicalization of brain illnesses got rid of the blame and stigma of a mental illness, it

also created a space for improvement due to neuroplasticity. It became the individuals' responsibility to try and improve their brains and health, because it was now possible, and brain training therapies and products flooded the market for consumption. The home transformed into a space for self-rehabilitation, self-improvement and the domestication of health. These scientific discoveries were occurring around the same time that the dominant neoliberal thoughts at the time were that of individualism and personal improvement, and where health was valued and strived for whereas the ill body was stigmatized.

Chapter 3: Methodology

The methods that I used for my research were three tiered and multi-sited. I initially used online research to gain preliminary data and used online public Acquired Brain Injury (ABI) forums to gather themes for my interviews. I then used participant observation at the ABI Conference in Toronto and at various brain injury support groups in the GTA to hear directly from brain injured individuals. Finally, I conducted semi-structured interviews with brain-injured individuals who have experience with brain training programs. In this chapter I will discuss each method that I used in detail and explain why each was important to my research. I will also outline the challenges that I faced while doing my research and how I overcame them, and finally I will include participant profiles that I have created to introduce the narratives of five of my interlocutors.

Online Data

To begin exploring brain training programs I looked to the internet, which has endless information and is where many of these programs are found and used by members. I browsed the websites of the popular brain training programs Lumosity, Duolingo, Brain Metrix, and Happy Neuron to investigate their claims and to see how they market their products to consumers. I also downloaded the brain training apps Lumosity, Brain Wars and language app Duolingo on my smartphone, and spent a few hours per week playing the games myself. I took field notes after playing the games to see how I felt, how the games compared to each other, and if I thought the games were at all doing what they claimed. This preliminary research was helpful for when I

interviewed individuals who used these games because I became familiar with the programs, how the games work, and how I felt before and after playing them. I was also curious to see if the games would have any affect on me. Would training my brain improve my memory, brain flexibility and attention? As my interviews progressed I discovered many other brain games and online websites that my interlocutors used- such as JetPunk, Word Storm, Mahjong, and Pogo.com- which I also explored and played to get a better grasp of the activities my participants were using. What I noticed from playing the games was that I quite enjoyed playing them, and did feel a sense of happiness when I got a high score or improved in a game. Although I improved in the games, I did not notice any significant cognitive differences in my everyday life, although I was not consistent with using the games, and I never paid for the full subscription services of some of the programs. With the online quiz games such as Sporcle and JetPunk, I also thoroughly enjoyed playing them and also felt that I learned a lot of information on various topics such as Geography, Science and Popular Media, but I do not think that it has made me necessarily any more intelligent.

Another way that I utilized the Internet for my research was by seeking out online forums for individuals with ABI- public communities that allowed individuals to share their struggles, thoughts, and to connect with other ABI survivors who are able to help each other and share helpful resources. Online forums are a great resource because they cater to specific groups of people who share common interests and experiences; in this case individuals who experienced a traumatic brain injury or family members and caregivers of survivors. To find these groups I used search terms such as ‘TBI forums’, “Traumatic Brain Injury discussion” and “Resources for Acquired/Traumatic Brain

Injury” on Google. I decided to focus on two brain injury forum websites that I felt provided sufficient information and topics that were helpful to my project. Although I only used a small sample of the content of online forums, I chose the top two public brain injury forums that also had the most members, and used search terms that individuals with brain injuries might use to find such resources. The two forums that I ended up using as resources were TBI Network (www.tbisn.org), and TBI Forum (www.traumaticbraininjuryforum.com). TBI Network is an online resource for TBI survivors, and the website contains event listings, various TBI Blogs, helpful videos, and a public forum. The forum is open for anyone to join, and the posts are open to the public to read, but one must become a member if they want to post a reply or to create a new forum topic. Currently there are over 500 forum discussions on TBI Network and over 2000 members. TBI Forum is similar to TBI Network but it only contains a forum for discussions and a chat room, no other resources or information is available on the site. TBI Forum is not only a forum for TBI survivors but also caregivers and family members. There are forum categories specifically for Parents of children with TBI, Spouses of TBI survivors, and Care Givers. Other category topics include TBI Stories, TBI Rehabilitation, Self Therapy, Support Groups, and Resource Websites.

After I discovered these sites, I visited them on a weekly basis to see if there were new posts or new discussion topics created by members. People used these forums as a space to share thoughts and feelings they could not necessarily share with others, and felt a sense of community because other individuals in the forum could relate to them. The forum topics that were of interest to me were “On Neuroplasticity”, “Have you tried Lumosity”, and “Accepting my new self.” Through observing the ABI forum websites I

was able to pick out various themes and topics that were important to ABI survivors, like gaining confidence after a brain injury, techniques and ways of dealing with your injury (such as tools, services or programs), and sharing one's brain injury story. I knew forums would be a place for people to share stories and tips, but I was not aware of how helpful and supportive members would be to one another. Navigating these websites helped me in creating questions for my semi-structured interviews. I picked out relevant concerns and discussion topics from the forums and used them as questions for my participants, such as "what does neuroplasticity mean to you?" and "what has helped you deal with your injury the most?" I have also used various responses and opinions from individuals in the forums throughout my paper. My online research was beneficial as it provided me with basic information and themes regarding brain training and gave me valuable data from individuals who have had a brain injury. No ethics clearance was necessary to obtain this online data because it was available in the public domain, and any names, usernames, or identifying information have been changed in my thesis for confidentiality (Social Sciences and Humanities Research Ethics Special Working Committee 2010).

Participant Observation

The second method I used to collect data for this research project was participant observation, which involves observing various events or groups of people. My participant observation included attending various brain injury support group meetings at the Brain Injury Association of the Greater Toronto Area. Anthropologist Paul Antze (1996) claims that support groups are a supplement to other forms of therapy where members can share and sometimes even solve the problems they face in their everyday lives (4). Support

groups can also provide social connections and support from members, while providing a safe community that is free from any stigma that may occur outside of the community (Crabtree et al. 2010).

The meetings were held once a month and I attended 7 meetings in total from 2014-2015. I was given permission by the support group coordinator to attend and observe the meetings under the condition that all names and identifying information be kept confidential. The meetings were valuable because I was able to observe how brain injured individuals interacted with one other, and what topics were important to them. The meetings I attended all had a different theme and invited guest speaker, including a nutritionist who discussed foods that are beneficial to brain health, a chiropractic neurologist, and a motivational speaker. I would take field notes during these meetings, which yielded some insights and themes that would be important in my paper. Issues that were commonly brought up were financial concerns or issues with insurance or disability claims, different techniques that were helpful for brain injured individuals in everyday life, and the various changes and alterations in life style that were faced by individuals and their families or friends. These support group meetings were valuable because I was able to meet different individuals who would eventually be participants for my interviews, as well as to observe a variety of individuals who had brain injuries and see how they interact with each other in a group setting. Interacting with brain injured individuals and hearing them voice their concerns helped to prepare me for the different physical, behavioural, and cognitive impairments that my participants would have.

I also attended the Acquired Brain Injury General Conference in Toronto, Ontario. The conference was two days long and was attended by physicians and

therapists, brain injury survivors, caregivers, and scholars. There were also vendors that provided information on their products and services such as naturopaths, personal law offices, new pharmaceutical drugs, and therapy techniques. The conference was helpful to my research because I was able to pick out the relevant themes and issues that are important in current brain injury research. Some of the major themes of the conference included mindfulness based stress reduction - a type of therapy that has gained popularity in the past decade-, mental illness following ABIs, financial management, therapies that may be helpful for brain injuries such as art therapy and mindfulness based cognitive therapy, social role return, and the loss of the 'self' experienced post brain injury. I was also able to network and communicate with brain injury researchers, therapists, and patients. My discussions with occupational therapists and neuroscientists regarding brain training gave me a unique perspective on these programs from a clinical standpoint, and their responses were interesting to compare to the responses of my brain injured participants who use the programs.

Semi-Structured Interviews

For my primary data, I interviewed individuals with acquired brain injuries who had specifically used brain-training programs as a form of rehabilitation or as a supplement to their regular rehabilitation. My interlocutors were all adults who had incurred a brain injury either by trauma or a stroke. I recruited three participants through the brain injury support group that I attended. I also designed a flyer to send to the support groups that I could not attend who then shared it with their members via social

media or during their monthly meetings (For flyer see Appendix A). I used images on the flyer that depicted a brain lifting weights, making a reference to ‘brain training’, as well as images of the popular brain training program Lumosity. I was hoping that individuals who were familiar with the program or who used it would be drawn to the flyer and would be willing to participate in my study. I recruited two participants through this method. I also used the snowball technique, where I recruited another participant through the help of a fellow participant who knew an individual that would be suitable for me to interview.

My interlocutors were asked a series of 16 questions during a semi-structured interview about their experiences with brain training programs and living with a brain injury (For the list of questions see Appendix B). All of their names have been changed into pseudonyms for confidentiality purposes, as well as any identifying information. All of my participants gave informed consent and agreed to have the interviews recorded on an audio-recording device. Proxy consent was not required for any of my participants. My interviews ranged from 40 minutes to 70 minutes long, and were held in various settings such as cafés, the homes of participants, and my university campus. My participants ranged in age but were all over the age of 40, and all had acquired brain injuries. Three of my participants suffered from traumatic brain injuries, and the other three had experienced one or more strokes. I interviewed four females and two males, all with various educational levels, ethnic backgrounds and class status.

Semi-structured interviews were valuable to my research goals because although the format had structure, my questions were fairly open-ended which allowed my participants to take the conversation in any direction they desired (Bernard 2011). I was

also able to hear the stories and narratives of different people who have an ABI, and how their experiences are both similar and different in many ways. The interviews were also helpful in that I was able to see a glimpse of the diversity of symptoms that brain injury survivors face, and that no brain injury is the same as another. Except for one participant whom I will call Barbara and the paralysis of her left arm, none of my participants had any visible injuries, and thus presented as completely healthy individuals, even if you were to interact with them. Yet once I began talking to these individuals and hearing their stories, it became apparent that brain injuries are more about what you can't see than what you can- the internal struggle that these survivors have to face every day.

Challenges

Meeting and interviewing individuals with ABI has slight challenges, and there proved to be a few obstacles that I had to work around. Most of my interlocutors were not employed at the time of the interview because of their injuries, which made it easier to find time to schedule a meeting. Yet although they were more available, it proved quite difficult to meet with individuals as most could not drive and thus had concerns with accessibility. Some of the complications that are associated with brain injuries were apparent in the interviews, such as issues with memory, fatigue, attention span, and behavioral interactions. A few instances I had to pause and take a break from the interview for the participant to rest or organize their thoughts. A few participants had auditory issues, thus I had to speak louder and slower for them to properly hear me. Some individuals had physical injuries that caused issues with accessibility such as taking the elevators rather than the stairs, or having to walk slower to keep up with their pace of

walking. Brain injuries typically affect one's memory, speech, and behaviour, which were a few things that I could pick out during the interviews. A few times my participants would say the wrong words or stop mid sentence, forgetting what they were about to say. Some participants had issues with slurring their words or stuttering. These issues throughout the interviews often caused frustration for the participants, so I had to ensure that I gave them time to organize their thoughts and to give them a break if needed.

Although these issues made the interview process slightly more challenging than they would be with a non brain-injured population, I did not find that it affected my interviews and it also provided me with more information and experience with various people with brain injuries. The fact that I have lived with a family member who has a brain injury and that I have spent time at brain injury support groups did help prepare me for the interviews because I knew how to react to certain struggles that brain injury patients face, and I knew how to point out the various symptoms that come with brain injuries. Although my experiences living with a brain injured family member helped me, every brain injury survivor is different and has different issues, so I never knew what to expect.

Another challenge that I faced throughout my research process was difficulty recruiting participants to interview. While I found a large group of brain injured individuals through support groups, only a small fraction of them fit my qualifications of mild-moderate brain injury survivors who have experience with brain training games. Some individuals had too severe of an injury to participate, whereas others have never played brain training games, or had no interest in participating. A few individuals who were interested in participating had asked to be compensated for their time. My research

was voluntary and thus I did not have any funds to put towards compensation for participants, so after informing them that I could not offer compensation, they were no longer interested.

After I conducted a few interviews and discovered the financial hardships that most of my participants were going through, it became clear why so many individuals wanted compensation. Many individuals who are no longer employed do not make much money from insurance or disability, and were forced to find other means of saving and making money. Some individuals would participate in various studies held by universities, health care companies or pharmaceutical companies where they were compensated for their time. They were able to participate and also get paid, something I was unable to provide. Because of the difficulty in accessing participants who fit my qualifications, I focused more on the narratives and overall experiences of five of my participants, as well as using a lot of the data that I have obtained online from public forums.

Participant Profiles

Marco

Marco was the first participant that I met with to interview. He greeted me with a hug and plenty of enthusiasm, and had brought along the Paralympic gold medals he won in 1992 for the 100, 200, and 400 meter run races to show me, and insisted that I take a photo with him while wearing one of the medals. While this introduction may seem unusual, I eventually discovered that brain injured individuals are not necessarily

predictable, yet all of my participants were very welcoming and open to talk about their experiences. Marco was a single male in his early 50's who had suffered a traumatic brain injury thirty years ago from a work accident, which left him in a coma for three weeks. He endured brain damage in his frontal lobe, which left him with impaired subconscious memory, attention deficit disorder, issues with mental processing, seizures from the scar tissue on his brain, sensory problems such as double vision and loss of sight, as well as changes in his behavior and social skills. He also faced physical injuries from his accident such as lower back pain, as well as damage to his face and eyes, which he had to undergo surgery to repair.

Marco expressed some of the frustrations and struggles of having a brain injury, specifically the issues that people cannot see physically. Even simple every day moments such as going to the grocery store can be frustrating because he usually needs more time and energy to find the items and to complete the transaction. Things that helped Marco get by in everyday life include a strict routine, especially when it comes to sleeping, taking his medication, and grocery shopping. He used tools such as his smartphone, a date book, and various multi-coloured highlighter pens to help him organize and remember various appointments and tasks. He claimed that after his injury he felt like an infant, having to learn even basic skills all over again. After his work accident he attended physiotherapy, speech therapy, occupational therapy, and chiropractic decompression to help with his injuries. He began using brain training games as self-rehabilitation when his compensation board stopped providing him with clinical therapy. Marco was unable to return to work after his brain injury, and was only provided a small monthly pension from his compensation board, which was not enough to pay for the

clinical rehabilitation he required out of pocket. He tried the free trial of Lumosity, which he found to be confusing and could not afford the paid subscription, so instead used online interactive games on Facebook and other websites where he was able to play with people from around the world. Although Marco used brain training games to help him recover from his brain injury, he knew that most people “want to be like how [they] were before the accident, and...most of the people will never be back where we were before because the injury is what it is”.

Timothy

Timothy was a 69-year-old single man who suffered a traumatic brain injury at birth, after a difficult three day labour and the forceps delivery of him and his twin brother. The brain injury caused by the forceps left him with ADHD⁴, auditory processing, and dyspraxia⁵ - a developmental coordination disorder. Although he had no physical attributes of injury, he did have slight weakness and hemiparesis⁶ on the left side of his body. He had tried many brain training programs including Lumosity, Bruno Furst: You can Remember Course, and the Evelyn Wood Speed Reading Course, and although they have had some benefits such as introducing doodling and providing educational descriptions of cognition, he did not think that they have helped him in any significant way. He had also tried other means of self-rehabilitation such as exercise, which did not help him, and learning how to play instruments such as the trumpet and piano, which he felt had helped him slightly. He had also tried popular ADHD medicines such as Ritalin,

⁴ ADHD (Attention Deficit Hyperactivity Disorder) is a neurodevelopmental psychiatric disorder. Symptoms include inattention, hyperactivity and impulsivity. (<http://www.nimh.nih.gov/health/attention-deficit-hyperactivity-disorder>)

⁵ Dyspraxia is a development coordination disorder affecting fine and/or gross motor coordination

⁶ Hemiparesis is a reduced muscular strength and weakness of the entire left or right side of the body

Adderall and Dexedrine, with no effects. The one thing that Timothy claimed had helped him and his symptoms the most was caffeine and caffeine compounds such as Tired and NoDoz, which he claimed temporarily improved his attention, alertness, working memory, consciousness and visualization.

Timothy knew a lot about neuroplasticity and brain training, and that was apparent throughout our conversation. He was frequently referring to books or articles he has read, as well as giving examples of the various brain training programs, medications, and rehabilitation methods he has tried. Timothy was also very present in the online brain injury support group forums, and frequently posted helpful information for other members, shared his experiences, and also ran a few of his own online groups that focused on ADHD and dyspraxia. Although Timothy's experience with brain training was negative, he expressed that since every brain injury is different, some people do benefit from brain training games; yet in his opinion, many do not. His opinion on neuroplasticity was that it was a false promise that is "oversold today, on purpose, as a way to get customers into consultants' offices to make money."

Nancy

My interlocutor Nancy was a 55-year-old woman, married with three kids, who experienced a traumatic brain injury at the age of 50 after being struck by a car. The accident caused trauma to the temporal lobe of her brain, and she suffered from a subdural hematoma⁷, and a broken clavicle. As result of her brain injury, Nancy dealt with word-finding issues, trouble with reading and writing comprehension, vertigo,

⁷ Subdural Hematoma is a collection of blood outside the brain, usually caused by severe head injuries

fatigue, seasonal depression, and issues with her short-term memory and attention span. Other issues she expressed were increased social anxiety and apprehension in social scenarios that she would have thrived in pre-injury. She was provided with occupational therapy, physiotherapy, speech therapy, and a psychologist for 4 years after her injury and was prescribed Ritalin to aid in her focus, and painkillers for her headaches and fatigue. At the time of our meeting she was only receiving occasional speech therapy sessions, which she paid out of pocket. Nancy focused on the help and support that she had from her family and friends as something she has always relied on and that has kept her motivated after her injury. Nancy was unable to work or return to school as she had planned to before her injury because of her lack of focus, attention, and memory issues caused by her brain injury. Other activities she participated in included gardening, walking, exercising, and socializing with her friends.

Nancy was one of my only participants who was currently using and paying for the brain training subscription service Lumosity. She expressed that it was worth the money (around \$15/month) for her in the long run, because of its convenience, complexity in games, and the fact that it tracks your progress and compares it to various demographics. It is important to note that Nancy did not express the same struggles with money and lack of coverage for rehabilitation that many of my other participants voiced, and she was also one of the only participants who was married and thus had the shared income of her partner to help with finances. She enjoyed playing Lumosity because not only were the games fun and addictive, she felt that she had improved a lot in most of the games and that it had helped her concentration, memory and spelling. While she had seen improvements, she didn't believe that it took the place of clinical rehabilitation, and

instead viewed brain training as a good addition to existing therapy. Nancy had accepted her injury and that she would have to live with it for the rest of her life, but she wouldn't "give up on trying to improve myself, even though I know I'm not going to get rid of my issues 100% ... at least they're not going to get worse." Although Nancy loved practicing brain training games and believed that they did help with neuroplasticity, she claimed that she took it with a grain of salt, and was not entirely sure if the results translated into her everyday life.

Hannah

Hannah was a highly educated and academically driven woman, and offered a unique experience of losing one's cognitive abilities post brain injury. Hannah had a Masters Degree and PhD in health related fields, and prior to her stroke was working at a Canadian health research company. She had experience with conducting and participating in research, and thus knew the procedures involving ethics and informed consent, which was very helpful for our interview. Hannah had a successful career in dental hygiene prior to her stroke but decided to go back to school in her 40's to get her PhD in health sciences. She had always loved school and learning new things, and expressed that it was a big part of her identity. Her stroke affected her cognitively, which was the most difficult factor for Hannah to accept, as she stated "it's a personal thing- I'm competitive academically, and if I can't compete, who am I?"

Hannah, now 52 years old, suffered from a stroke at the age of 49, and had a second stroke at the age of 51. Her stroke was located in her amygdala⁸, which is the part

⁸ Amygdala: The amygdala is a set of neurons located deep in the brain's medial temporal lobe. It is shown to play a key role in the processing of emotions. (<http://www.sciencedaily.com/terms/amygdala.htm>)

of the brain that allows one to feel and perceive emotions. This caused her to suffer from increased emotional responses to situations, specifically crying at things that wouldn't have made her cry pre-injury. Other symptoms she had post-stroke was aphasia, which is a communication disorder that affects one's ability to speak or understand words, paralysis on the right side of her body, detached retinas and loss of vision, and trouble with memory, stuttering and word recognition. She was not working at the time of our interview, and was receiving money through disability and government benefits, although she struggled with her finances. She did not receive long-term disability from her job, and used up all of her savings after her stroke. After her stroke she had only received one occupational therapy visit, a few speech therapy sessions as well as a few physiotherapy sessions. Her financial issues affected her ability to receive rehabilitation, as she had used up any therapy she had coverage for. In terms of brain training, she could not afford to pay for subscription services such as Lumosity, thus she used free online game sites such as JetPunk and WordStorm, and practiced several hours a day to stay on top of her brain training. She also read on average a book per day, played various puzzle games, and occasionally attended stroke and aphasia support groups. She claimed that the brain training programs she used had helped her more than the healthcare system and little clinical therapy that she did receive: "I feel like I've helped myself after my stroke. I didn't get help- the [healthcare] system failed me."

Barbara

I met Barbara in a bustling coffee shop on a rainy Tuesday morning. I later discovered that it was not the best choice of location as she was deaf in her left ear and

could scarcely hear my questions, forcing us to move to a different location. She was a sweet lady in her late fifties who was divorced with two kids, and who loved sharing stories about her life and experiences. Even after the interview was over we sat and talked for a while, as she told me stories about her children and her life growing up, and gave me advice for the future. Although Barbara stated that she has had no major cognitive issues, she was affected physically from a stroke she experienced 6 years ago, with the complete loss of use of her left arm and hand, as well as deafness in her left ear, dizziness and vertigo, and depression. She underwent physiotherapy for a short period of time after her stroke, but other than that was not provided any other rehabilitation, and would have had to pay out of pocket for additional therapy, which she felt was unnecessary. She previously worked in an office, but was unable to return to work after her stroke because of her physical disability. It took Barbara a while to accept her injury because she “went through a various sort of depression, or just getting acquainted with what had happened.”

Her experience with brain training programs, like Timothy, was more negative than most of my participants. She even admitted to me that she hesitated even meeting with me because of her negative experience with the games. She played them but found most tedious and boring, and did not believe that their results translated into her everyday life. She started playing them around a year after her stroke, and still played some puzzle games occasionally, mainly to work her brain and keep her occupied since she was no longer busy with work. A main issue she had with games such as Lumosity was that they were not accessible for individuals with physical disabilities such as herself, as well as the fact that you had to pay for a subscription to play which she could not afford, and the games she did play were not challenging for her. Outside of brain training, she

participated in other activities to keep her busy and stimulate her brain such as darts, wood burning, and attending and even running her own stroke support group.

Chapter 4: “I’m Not Myself Anymore”

During my interviews and online forum research, I discovered many similarities between my participants, even though they were all very diverse people in slightly different situations. While they all had an acquired brain injury, they were also injured in various different ways and in different parts of the brain. Thus, the symptoms they faced varied, from speech aphasia, to memory loss issues, attention deficit, fatigue, and other physical injuries. The shared descriptions of ABI patients provide a background of their use of brain training programs and why their participation in brain training is significant. The descriptions I want to focus on for this chapter include expressing a change in identity after injury, financial complications due to loss of work or lack of insurance coverage for their injury, mental illness or emotional issues post injury, the use of pharmaceuticals, and finally introducing a variety of coping mechanisms into their lives to help them deal with their injuries. Finally, I will begin to analyze how these themes inform the reasons why individuals use brain training programs. These shared descriptions all relate to the larger analytical themes of hope, work, and self-rehabilitation, which will be discussed in the subsequent chapter.

Changes in Self

An ABI can cause many drastic changes in people’s lives, including changes or the loss of one’s career, ability to drive, independence, and social life. In this particular section I will focus on the changes in identity and self that ABI survivors experience. Common reasons for change in identity for brain injured individuals include both changes in their health and the changes in their lifestyle. Common changes in health that affect

brain injured individual's identity include changes in physical health, as well as memory, speech, personality, and behaviour. Physical damage to one's brain can alter many traits about an individual, which can in turn result in a change in how one sees one's self as well as others. Changes in identity can be linked to the loss of change of occupational competence, loss of certain skills such as driving or physical labour, and a change in relationships, as well as the everyday routines and habits that give our lives structure and meaning (Klinger 2005; Hoogerdijk et al. 2011). Many mild to moderate ABI patients are unable to return to work after their injury due to their physical or cognitive injuries. Others are still able to work but cannot keep up with the physically or cognitively demanding jobs they previously had, and thus are forced to change career paths or lighten their workload. Crawford (1994) argues that the type of work that one does and how good they are at it is one of the most significant markers of identity, which can explain why many ill or injured individuals seem to lose their sense of self due to loss of employment. For many people, returning to everyday routines and schedules helps them regain their sense of self, such as returning to work, picking children up from school, or going to the gym. According to Jim and Shel Taylor (1997), self-identity is comprised of all things that provide validation and sense of self-worth in a person's life including activities, people, objects and experiences (36). If one is unable to do these activities or experiences, whether they are unable to return to work, can no longer drive, or perform physical activities like they used to, the act of returning to a pre-injury self becomes quite difficult. Brain injured individuals begin to compare their current situations with their past ones, and then have to learn to adapt to their new situations (Hoogerdijk et al. 2011).

The act of adapting to one's new life can be quite difficult for brain injury survivors, which became more apparent to me when I found a forum thread on TBI Forum Network titled "Accepting My New Self." The author of the thread claimed that she had a hard time accepting her new self after her injury, and that "parts of me are the old me and parts of me are this stranger living in my body, who I have to get to know eventually". Other forum members agreed with the author, such as John who stated that it was even more difficult to accept his new self when people would tell him that he 'looks fine' and believed that he was just overreacting, when in reality he was struggling. More than one member of the forum who commented on the post revealed that they wished they had died in the accident that caused their brain injury, rather than having to recover and deal with the consequences of their injury. Accepting a new self after brain injury can also be difficult for family members and friends, with some not fully understanding the effects of the injury, or not being able to accept that their friend, family member, or partner has changed. Many friendships and marriages can suffer from a major brain injury, such as TBI Forum member Martha, who divorced her first husband because of his "inability to accept the fact that I got tired".

While recovering from her stroke, my interlocutor Hannah discovered many things about herself that had become altered, thus changing her self-identity. Hannah had an impressive academic resume, having returned to school in her adult life and completing her Masters and PhD in health science. She was well-read and proud of her academic accomplishments in life, especially coming from blue-collared immigrant parents with no post-secondary education. She felt that what set her apart from so many people was her hard work ethic and academic intelligence. Prior to her stroke she was

working at a Health Research Centre, a job that she had worked hard to get. Her ABI left her with many cognitive issues including aphasia, speech impairments including slurring and stuttering, memory loss, changes in her emotional reactions, and issues with word recognition. Her injury affected the way she was able to communicate, her memory, and her overall health, which ultimately caused her to stop working, and wondering if she will ever be able to return to work. One of Hannah's biggest worries was that she was losing her cognitive abilities, which she claims "[is] a personal thing. I'm competitive academically, and if I can't compete, who am I?" Hannah attributes her identity to her intelligence and competitive drive, which after her injury had been affected. She had worked very hard to achieve her academic goals, and felt that she was losing all that she worked for because of her injury.

"I'm not myself anymore... I'm scared, I'm 52, I may not be employable. [Brain training games] is kind of all I have for cognitive stuff." Because of her fear of losing her cognitive abilities, Hannah practiced her brain training games several hours a day, every day. Out of all of my participants, she spent the most time using these programs, and would play the games several times over until she got a perfect score and then move on to another game. Although she felt she has changed after her stroke, her attitude towards brain training games reflects her pre-injury personality, as she was always striving to do better and achieve her goals, whether it be school or work. She was using that same mentality in regards to brain training in attempts to regain her former skills and sense of self. According to Hoogerdijk et al. (2011), for some brain injured individuals, their 'new' self is not fully accepted by them, thus their old self and old ways of doing things are still existent in their present self, just like Hannah's academic determination (125).

Her overall hope was to be able to return to work in the health sector, get back to her old routines and abilities, and thus return to her pre-brain injured self.

My other participant Barbara worked at an office doing computer work up until she had her stroke, but was unable to return mainly due to the non-use of her left hand and arm. She felt that she could perform well at her job cognitively, but without the use of her left arm her typing was much slower and thus her ability to complete work was hindered. In her situation, her physical disability created a barrier to complete tasks that she used to be able to do easily before her stroke, now making her unable to properly fulfill the requirements of her job. Barbara expressed some negative aspects of not being able to work anymore including a lot more spare time that she has to fill, and a decrease in cognitive abilities. She believed that after her stroke she became “a little bit slower, but sometimes I think that’s due to not working all the time...you don’t think as fast as what you could do”. Her loss of career and decrease in cognitive stimulation was a major reason that Barbara decided to begin using brain training programs, claiming that she “just wanted to try and work the brain more because I wasn’t going to work anymore.” Barbara’s stroke resulted in not only the loss of use of her arm, but also the loss of her job, which together resulted in a major change in her life and daily routines, leaving her with a lot of free time which she did not know how to fill. She also had to learn to adapt to doing things with only the use of her left arm. One of the most difficult things for her to deal with was not being able to drive immediately after her stroke. It took her 13 months to get her license back, which she said was extremely hard for her because she felt “that something was taken away from me and it shouldn’t have been, [and] until I could get my license and feel better, some people had to deal with me...I was not a nice

lady.” For Barbara, the inability to drive for 13 months was the hardest for her to adjust to, as she felt that it restricted her, and she did not want to have to rely on other people such as her children to have to drive her around everywhere. This mirrors a study done by Hoogerdijk et al. (2011) that indicated that brain injured individuals felt shame from not being able to do tasks they were once able to, especially if they now have to rely on others to complete that task (126). Barbara felt that for her, “driving is a god send...it keeps me sane”, even claiming that “if I couldn’t drive, I don’t think I’d be here”. In this example, the act of driving was a part of Barbara’s life and identity, and the loss of it resulted in anger, shame, and sadness. Once she regained the ability to drive, she was much happier and able to do more of the things she enjoyed.

In other situations, such as Marco’s, one’s injury could occur in the workplace and make you unable to return to your job. Marco was at work one day when he fell twenty feet off of an order picking truck onto the cement floor. He suffered an open head injury that put him in a coma for three weeks. He went through extensive rehabilitation to help him recover, but he was unable to return to work because of his injuries and was pensioned off. Along with having to adjust to not working anymore, Marco also had to learn to adapt to his new lifestyle. His injury mainly affected his memory and behaviour, which posed many challenges in his everyday life. Since Marco has such a large family including 24 cousins, he has had trouble remembering their names and faces, and felt overwhelmed when more than one person was talking in a group. He had found ways to adapt to his new self, such as creating strict schedules and routines, disclosing to people in certain situations that he has a brain injury, using aids such as writing in notebooks, utilizing his smart phone, and always asking questions.

When discussing identity, Marco stated that when you have a brain injury, “you want to be like how you were before the accident, and on the whole ... most of the people will never be back where we were before because the injury is what it is.” He wished that he were able to do the things he could before his accident, especially physically like playing sports, but realized that he may never be how he was, and has found ways to adjust to his new lifestyle. Marco made an interesting comment on how people can even benefit from a brain injury, stating “I’ve met people who were absolute idiots before they got hurt, and because their injury has made them forget about being a crack-head, they’ve become a better person, so they like their brain injury now because they are more law abiding.” None of my participants had expressed any benefits stemming from their changes after a brain injury, but it may be possible that people could experience a positive change in their sense of self, as Marco expressed with his friend.

A common feature that is found when studying individuals who have experienced a change in self due to brain injury is discontent with their current ‘new’ self, and thus a desire to return to one’s previous identity or self. Hoogerdijk et al. (2011) states that in order for a brain injured individual to regain agency, they need to accept their disabilities, reevaluate their life, and adapt to these new changes in order to continue meaningful occupations (122). They learn about their disabilities and limitations and how they will affect their lives through trial and error, experience and self-reflection (Hoogerdijk et al. 2011). Jennifer, a member of TBI Network Forum, provided many examples of how she has had to learn from her injury and adapt to these new changes in her life. Rather than working a full-time job, she switched to working part-time in order to have a few days to rest in between, as she would get fatigued after working. She still

enjoyed working though, even part-time, because it kept her occupied and she could still contribute financially to her household. Another adjustment she made was in regards to driving, as she was not able to drive directly after her injury. She eventually was able to drive again, but had to make certain adjustments, such as eliminating all distractions like the radio, as she now requires constant attention while driving. Jennifer has even had to make adjustments to activities she used to perform in her free time, such as altering her yoga practice as she found it much more difficult post injury. She had even introduced tools such as a voice recorder, planners, lists, and practicing Lumosity in order to help with her memory, which was affected after her brain injury. Jennifer had effectively found new ways to adapt and live with the consequences of her brain injury, while reassessing the activities and priorities in her life in order to develop her new identity (Hoogerdijk et al. 2011: 125).

Mental Illness

Depression and anxiety are also very common symptoms following a brain injury. The increase in depression and anxiety can be due to the physical or emotional distress from the trauma, which can in turn “deplete the mental energy and motivation needed for both recovering from the depression itself and adapting to the physical, social, and emotional consequences of trauma with brain injury” (Guillamondegui et al. 2011). Brain injured individuals who are no longer employed are left with more time on their hands and less to do. They may also face financial strains from lack of work or medical and rehabilitation bills, which could cause increased stress levels and increased levels of depression or anxiety. Not being able to physically or mentally do the things you were

once able to do can affect one's self confidence and emotions. For many brain injured individuals, accepting their injury and their new self is extremely difficult and can cause anger and depression. This was the case for Barbara, who was very angry and depressed the first year following her stroke, due to not wanting to accept what had happened to her as well as the many changes and challenges that came along with it, such as losing the use of her arm, having to retire from work, and not being able to drive for 13 months after her stroke. Barbara's anger and depression affected her ability to recover, and it took her over a year to begin to accept what had happened to her. Only after she was able to accept her stroke and her new lifestyle did she begin looking into brain training programs and other activities to help her cognitively and emotionally.

Things that help brain injury survivors feel better and ease their depression was engaging in interaction with others, being active, and even the use of brain training programs. Many of my participants had expressed to me the enjoyment they receive from playing brain training games, especially when they were advancing in the levels. This reaction is not uncommon, considering games can satisfy psychological needs and be used as "persuasive behaviour changing tools," specifically the positive feedback that one receives from a game that can positively affect behaviour through motivation and need satisfaction (Burgers et al. 2015). A study by Burgers et al. (2015) showed that positive feedback in brain training games could positively influence the player, making them feel more competent and autonomous, and thus have more of a desire to play more games in the future. The study even showed that games that are more challenging tend to keep players interested because if players do poorly, it makes them feel less competent, and therefore they desire to keep playing in order to improve or redeem themselves (Burgers

et al. 2015). A lot of brain training games are designed to be fun and have motivational features that make you want to keep playing. For example, you can increase in levels and your overall score and percentage goes up the more you play and the better you get at the games, which gives people more incentive to continue playing and reach new levels. The games are also entertaining, visually and mentally, which keeps you wanting to play. The graphics entice you to play more, as every game you win or level you increase, there may be celebratory graphics or animations that makes you feel like you are doing well and encourage you to keep winning.

Brain training games also make people feel better about themselves because they feel that they are doing something beneficial for their brain and their overall health. Rather than spending time lounging or watching television, they are actively stimulating their minds and participating in an activity that claims to benefit your brain health and overall cognitive status. This sense of pleasure and satisfaction that comes from playing brain training games motivates individuals to continue to play the games, even if they are not receiving any physical rewards from the game, such as money or awards (Burgers et al. 2015). Hannah claimed that when she did well in the games “I feel better about myself, I feel like I can do this ... it can actually lift my spirits up when I get something very difficult.” Hannah was in a tough place in her life when we met, with her various health problems and financial concerns causing her stress and sadness. She also attributed the increase in her depression with her stroke, which occurred in the Amygdala region of her brain, and thus affected her emotions. She claimed that “I’m so much more emotional than I ever was before... its uncontrollable, if I start crying it escalates into like really bad sobbing.” She told me that before her stroke she was never an emotional person, but now

she cannot control her emotions and had to be careful when she began to feel emotional. Her change in emotional status has made brain training games even more meaningful to her, stating that “the emotional component of these games is a big deal, because you feel better [about yourself] when you know you’ve gotten a correct answer, or you’ve made that connection.”

Pharmaceuticals

Pharmaceuticals play a large role in the lives of many brain injury survivors, and can range in need. Many individuals rely on medications to help them throughout their day-to-day lives, or for specific activities where they may need more help concentrating or relaxing. Common symptoms of brain injuries that required medication include attention deficit, anti-seizure medication, depression and anxiety, among others. A common theme that was shared with my participants and that I also found present in the online brain injury forums was the use of pharmaceuticals to help individuals deal with troubles in their everyday lives and struggles. These drugs could help survivors deal with chronic pain they are facing from their injuries, as well as preventing further injury to occur, such as another stroke. Pharmaceuticals can also have many amazing effects on some people and be the main thing they rely on for relief. This was the case for Timothy, who took caffeine and caffeine compounds Tired and NoDoz daily to help him with his attention, alertness, and working memory. When it came to finding the right medication, Timothy tried many different drugs to try and relieve his symptoms such as Ritalin, Adderall and Dexedrine, but found that caffeine compounds were the only drugs that made a difference. He also tried non-pharmaceutical methods to help with his brain

injury, such as psychologist appointments, exercise, and brain training programs, none of which really helped him, but he claimed that “bottom line, the only thing that helps me a little with my inattentive ADHD symptoms is using the right FDA approved alertness aid.”

Hannah was on Plavix, which is used to prevent blood clots after a stroke, as well as Metformin for her type two diabetes. She relied on these medications for her everyday and long term health. Not only did Hannah have to deal with the aftereffects of her stroke, she also had three different types of cancer and was scheduled for liver surgery and chemotherapy. Barbara mentioned that she was on anti-depressant medication to help with her depression, which occurred after her stroke. Anti-depressants are common among people who have suffered an acquired brain injury due to the heightened likelihood for anxiety and depression, which I have discussed in the previous section. Finally, Marco took Tegretol to stop him from having seizures, a side effect of the scar tissue on his brain. He used to take Dilantin, but disliked the side effects of the drug, which he claimed made him feel like a zombie, gain weight, and unable to function properly. Marco’s opinion of pharmaceutical drugs was that “you are trying to go forward but the medicine is bringing you down. There are always side effects to whatever medicine you take, some is good side effects and some is bad side effects.” Although he had to take medication to stop him from having seizures, he also had to deal with the negative side effects that provided challenges in his life.

Financial Issues

While conducting my research, the one common theme I was the most surprised to find with brain injured individuals was the financial issues they faced. Issues with finances also was a major theme at the ABI Conference in Toronto, specifically with managing finances, finances affecting social role return, and issues accessing rehabilitative care in Ontario. The struggle with finances after injury were mainly due to the fact that many of my participants could not return to work, were forced to retire or switch to less demanding jobs and receive significantly lower wages, or because they had to pay for various medical fees, therapies or medications that were not covered by insurance. The financial struggles were even more difficult for individuals who were not married because there was no other source of income that they could rely on when their income was disrupted. The financial issues my participants faced also influenced their choice to use brain training programs, and even what specific programs they used, such as free online brain training programs or apps as opposed to paid subscription programs.

While many brain injured individuals use brain training programs as a supplement to their traditional clinical therapy, others who do not have access to clinical therapy use it as their primary source of therapy. Restrictions to access clinical brain injury therapy include lack of finances, lack of availability to therapy due to location, or long wait lists to access therapy. Some patients may even be restricted to accessing therapy because their injuries are not deemed severe enough in relation to other individuals. For my participants, the lack of funds and long wait lists due to level of severity of their injury were the top reasons for not being able to access traditional clinical therapy. While lack of access due to location is an issue for many individuals

living in remote areas of Ontario, all of my participants resided in and around the Greater Toronto Area (GTA), where there are a large number of therapy offices available close by, as well as many at home services available for individuals who cannot drive or leave the house due to their injuries. While a couple of my participants discussed issues such as being on long waiting lists or not being regarded as severe enough to receive therapy, the main issue that I heard in regards to access to therapy had to do with the cost.

Financial issues also informed my participants decisions related to brain training games. In one way, brain training games offered an inexpensive alternative to clinical rehabilitation that they could not gain access to. Another decision that was informed by money was which specific brain training games they played. The most popular brain training games on the market are not free, and typically require a monthly or yearly paid subscription. At the time of writing this, Lumosity costs around \$11.95 CAD a month; yearly it would cost \$59.95 CAD upfront, and \$299.95 CAD for a lifetime subscription. Only two of my participants- Nancy and Timothy- had ever paid for a subscription to Lumosity or other brain training programs. My participants Marco, Barbara, and Hannah all had tried the free demo of Lumosity, but felt that it was not worth paying the monthly subscription service due to financial constraints and the availability of free brain training program options. Marco stated that Lumosity “got confusing for me...and then you had to start paying for it and I’m not into paying for it”, whereas Hannah enjoyed the games and thought it was a good program, but explained that “the only true determinant was the cost for me.”

The individuals who decided not to pay for brain training games were not missing out of the brain training experience though, because there were a plethora of free

online brain training games and apps that were available to them. From what I have found through playing both paid and free brain training games, the main difference between the free and paid games are the personalization of the games. Lumosity has very detailed charts and graphs that measure your progress over time, what you need to work on, and comparison charts to other members in your age range. Some of the free brain training games do not have these features, while others have similar progress charts and graphs but not as detailed or personalized. If these graphs and charts make a difference in overall performance or effectiveness of the games is uncertain. The other difference with the paid subscription games verses the free games is the claims made by the games. Lumosity states that their games were created by neuroscientists and are shown through studies to improve cognitive abilities, and while the validity of these statements is not legitimately proven and often time disputed, most of the free brain training games do not make these claims. Other features that members may be paying extra for are the graphics of the games, the upkeep of maintaining the programs and any bug fixes, and the general improvement of the game over time, with the introduction of new games or adding new levels to present games.

After my participant Marco was pensioned off from work, he faced many issues with the Worker's Compensation board to get properly reimbursed for various surgeries he had for his injuries as well as for his yearly pension. He claimed the pension he was making at the time of our meeting was based off of what he was making in 1986 when he had his work accident, and he only received a .05% interest every year. He felt worn out from fighting the compensation board, and even had to hire lawyers to try and gain the money that was owed to him from the board. The compensation board would not

fully cover the costs of the therapy he needs, only providing \$9 a visit for chiropractic and physiotherapy – therapies which average \$100 a visit- so he was forced to pay the rest out of pocket if he wished to continue therapy. Marco could not afford to pay for his therapy out of pocket so was forced to go without it, and suffered pain and disturbed sleep due to his injuries. Marco also admitted that he only began playing brain training games “as a therapy because the compensation board wouldn't give me the therapy that I want.” He also could not afford to pay for the paid subscription brain training games, thus used free games that he could find on Facebook and various gaming sites. For Marco, the brain games were used as a replacement for the therapy that he wished he had but could not afford, and thus were not his first option. He began using them as a form of recreation and to get away from the difficult clinical therapy sessions he used to attend, but once he stopped therapy due to lack of funds, they became one of his primary forms of cognitive rehabilitation.

Hannah also used free brain training games as a replacement for clinical therapy due to lack of funds and accessibility. She only received a few physiotherapy sessions and one occupational therapy session while in the hospital after her stroke, and was not deemed injured enough to be sent to a rehabilitation centre so was sent home. She did not receive any speech therapy for her aphasia, and stated that she was still on a waiting list for social work counseling. Hannah claimed that she did her own rehabilitation by forcing herself to read subtitles on the television in the hospital, and by avidly using online brain training games and puzzles. After her stroke, she was no longer able to work due to her symptoms, and at the time of our interview was living off of government benefits, which did not even cover the cost of her rent. Her job at the Health

Research Centre eliminated long-term disability benefits just three weeks before her stroke, thus she was not receiving any disability from her former employer. She used up all of her savings, and sold most of her valuable items such as her car and jewelry in order to pay for basic necessities. Her financial situation was very dire, and she felt that “everything I have worked for, for 32 years was gone...I’m almost destitute...life is not great right now.” Since she was not receiving therapy, Hannah swore by the website Jetpunk, an online quiz and trivia website. Although it is not marketed as a brain training program, it has different quizzes and games of every category including science, history, and geography that work in a similar way to brain games. It also has charts that compare your scores and correct answers to the average of other users. If you become a member of the site you also can earn levels the more you advance, and are given the option to create your own quizzes and games that, if approved, others can play. Hannah even stated that she believed that Jetpunk was superior to the paid alternative Lumosity for helping with brain injuries, because while Lumosity helps spatial reaction time, Jetpunk affects one’s recall, which she felt was the key for brain injuries. She was grateful to have found Jetpunk because she claimed that “this (Jetpunk) is all I have for cognitive stuff- there is not a lot out there, I do a lot of word seeks and word puzzles on paper but they add up in money too.” Although Hannah was not willing to pay for the monthly subscription for Lumosity, she did admit to me that if the program was free she would be using it, as she felt that it could be beneficial for her, especially since she knew some highly educated friends who use it.

Barbara also had issues with accessing therapy, stating that the public Ontario Health Insurance Plan (OHIP) would not cover therapy unless there was a

specific need for it, and then you are put on such a long waiting list that it was not worth it for her. In order to access therapy, she would have had to pay out of pocket, which she claimed was too expensive with sessions averaging around \$75-\$100 an hour. When I asked Barbara if she would spend the money on therapy, she stated: “I don’t want to spend my money on that, I want to go and do whatever I want to do...I’m not young... and I want to go off and I want to either do day trips of travel where I can.” Using what funds she had on therapy was not worth it for Barbara, who would rather spend the money travelling and doing things that make her happy, especially since she felt that she was getting older and would not be able to do those things for much longer.

The divide between participants who paid for brain training verses those who did not is important to note because it highlights the variety of financial situations that brain injured individuals face after injury. Nancy did not see the yearly subscription fee as a burden or an issue because she used the program on a daily basis and paid for a lifetime subscription, which is the cheapest option in the long term. Nancy was also one of the only participants who was married, and thus had her partner’s income to assist with costs even when she was not able to work due to her brain injury. Nancy also received some compensation from the accident that caused her brain injury, and had access to various in-home rehabilitative care. Although she had to pay out of pocket for certain therapies after her insurance money ran out, she could afford to do so, and she felt that the therapy was necessary for her recovery. Although at the time we talked Nancy was no longer receiving much therapy other than occasional chiropractic work and occupational therapy, she used Lumosity as a supplement to clinical therapy. She justified paying for the subscription because she believed that it costs money to create the games and put it on

the market, and she enjoyed it and believed it can and already had benefitted her. She also thought the money spent was worth it because compared to other free games, Lumosity often changes their games and adds new levels, as well as having the comparative features where she could track how she had improved on games, and how she compares to others, a feature that kept her interested and hooked on the games. On the online brain injury support groups I also found individuals who paid for brain training games, and all who agree that the subscription fee is worth it because of the quality of the games and the fact that you can track your improvement.

Adjusting to One's New Self

Brain injured individuals also create other strategies of coping with their injuries which become essential to their everyday living and recovery process. Usually as a result of losing one's job, ability to drive, or ability to perform certain tasks that one used to do pre-injury, new activities or relationships are created to replace time spent on former activities, or to fill a need created by the injury. This could include joining a support group or social club specifically for brain injured individuals, participating in new extracurricular activities, and creating new hobbies and skills. These activities help them cope and deal with the changes resulting from their injury, as well as adjusting to their new selves. This also implies that "they are in a continuing process of exploring possible selves," trying to find out who they are now and how they can contribute to the world after their brain injury (Hoogerdijk et al. 2011).

Barbara expressed the difficulty she experienced after her stroke due to the loss of use of her arm, specifically the loss of her job, which left her with a lot of free

time. In order to keep herself stimulated and her time occupied, she joined various support groups, and even started a support group of her own. She also joined various extracurricular activities such as wood-burning, darts, and even volunteered at a local hospital to help out other individuals who are going through stroke recovery. These activities helped with her depression, and kept her free time occupied, because she enjoys being busy. She also mentioned using brain games and various crosswords and puzzle games such as Mahjong to keep her occupied, although she felt that some brain training games were quite tedious and repetitive after a while.

Some of my participants also saw brain training games as a coping mechanism. Marco felt that Brain training games were “a form of recreation... and to get away, because when you are doing therapy in the therapist room its taxing, its hard on your head because you have to think and concentrate so much and this is the part that you can get away from all of that”. Marco was also involved in extracurricular activities. He used to run a charity basketball game for brain injury associations in Toronto, and would raise money for the organizations. He also got into Paralympic sports a few years after his injury, training and competing in various events and going on to win gold medals in sprinting. He was also a member of various brain injury support groups, and participated in the bowling tournaments they held every year. He believed that bowling “is a great exercise for rehab because you have to balance and you have to be able to have aim and concentration...and there are no rules ... you just have fun.” He also felt that extracurricular activities were important because the aim is to get you out of the home and out of the clinical therapy setting.

Reasons for Playing Brain Training Games

As I've outlined in the various themes that I found, there were many factors that helped explain why brain injured individuals used brain training programs. The most common reason the people in my study used brain training games them was that they believed they strengthened their cognitive abilities and helped them return to their pre-injury cognitive state. Their reasoning was based on the scientific claim that the neuroplastic brain could be retrained and enhanced in terms of cognitive abilities, including speed, memory, and attention. Most brain injured individuals are unable to return to work, or are unable to perform their jobs and everyday tasks and routines as they could before their injury, thus they experience a change in identity. Losing the ability to work or perform everyday tasks can make one feel inferior, and unable to contribute to their families or live up to their potential as a citizen, thus they turn to brain training programs. Brain training provides brain injured individuals with 'work', as they are spending time training and dedicating time out of their days to improve at the games and thus their cognitive states. Their hope is also that by working at brain training, they are improving themselves, and are getting closer to regaining their pre-injury identity.

Others used brain training to replace traditional brain injury rehabilitation due to financial concerns, as brain training was inexpensive if not free, and was easily accessible. Individuals just need a computer, smart phone, or tablet in order to download and play these games, and can do so in the comfort of their own home or on the go. The financial issues that my participants and many other brain injured individuals faced definitely played a role in their decision to practice self-rehabilitation such as brain training. They were not provided with the proper clinical therapy that they need, and were

neglected by the state to receive proper health care, thus they were forced to find their own means of rehabilitation. With little to no access to clinical rehabilitation and limited funds to pay for it out of pocket, brain training became almost a last resort for individuals.

Another reason individuals played brain training, and also a reason that kept them playing them regularly was the fact that they found the programs to be fun and entertaining. This was particularly true with individuals who suffered from various forms of depression, anxiety, or who were having a hard time coming to terms with their injuries and new lifestyle. The brain games provided them with entertainment, and could even lift their moods when they were having a bad day. Improving at the games and reaching new levels and accomplishments gave them satisfaction and enjoyment, which kept them coming back. The emotional reasons that individuals use brain training can also relate to the theme of regaining a previous identity and also the act of ‘working’. Brain training can be seen as work that brain injured individuals do to improve both their emotional state, and cognitive state, which they hope will result in a return to their previous self. Using brain training programs can provide a sense of productivity and a sense of gratification that brain injured individuals are working to better themselves and work on both their cognitive abilities and emotional well-being.

A less common motive for using brain training programs was to fill time and provide something for brain injured individuals to do. This motivation was common with brain injured individuals like Barbara and Nancy, who were unable to work after their injury and were left with a lot of free time that they were unsure how to fill. Brain training provided them with a way to occupy their time in a way that felt productive and

beneficial, rather than wasting it doing other activities. Brain injured individuals like my participants who have lost employment fill their time working on brain training, just as they would work at a job. They would spend part of their day training and trying to improve on these games, in attempt to become more competent or even master them. This ability to ‘work’ is significant to individuals because it is such a big part of a neoliberal identity. Finally, behind all of these reasons that ABI patients had for playing brain training programs, there were a level of hope that they could return to who they were and how they were before their brain injury. All of the reasons that I have just outlined regarding why individuals use brain training games reflect the main themes that I have discovered in my research, which are hope of returning to a previous self, ‘working’, and self-rehabilitation, which I will discuss in detail in the subsequent chapter.

Chapter 5: Achieving Hope through Self Rehabilitation

As discussed in Chapter 4, people who suffer acquired brain injuries experience major changes in lifestyle, routine, and occupations. One of the main reasons my participants gave for using brain training programs was to try to return to their pre-injury cognitive state and identity. They are unhappy with the cognitive changes they have experienced in the way they think and react, as well as their memory and attention span. With the introduction of brain training and neuroplasticity, people with ABI are offered an inexpensive and convenient way to work their brains in hope of returning to their previous selves. They also expressed other benefits and reasons for playing brain training games, such as the entertainment value, having a constructive way to occupy their time while at the same time exercising their brains, and the positive way it makes them feel. For brain injury survivors, brain training became more than just a vehicle to work their brains, it became a symbol of hope for them. Specifically, through brain training, they hope to regain their pre-injury identities, becoming productive members of society once more. They are hoping that they can better themselves and their health within the setting of their own homes, and even if they cannot afford traditional rehabilitation. Brain training also provides brain injured individuals with something to ‘work’ on, which is particularly beneficial for individuals who are unable to return to their occupations due to their injuries. By having a task to work on daily and to improve on, they feel like they are doing something positive to benefit themselves, and also fulfilling their roles as productive ‘healthy’ citizens.

It is important to note that not all brain injury survivors that I interviewed enjoyed using brain training programs, or even found them to be useful, but they still expressed a

desire and hope to return to the person they were before their accident, even if they did not believe that brain training would help them get there. This chapter will explore two themes regarding the aspirations of brain-injured individuals: the hope to return to a previous self, and the desire to ‘work’. In regards to hope, I will examine the narratives of hope that my participants and ABI forum members shared, and how brain training is a vehicle of hope for returning to a previous self. I will also discuss my participants’ realistic attitudes, and even negative attitudes towards brain training, and explore how hope can still be strong in these instances, yet achieved through other media. I will then look at brain injured individuals’ desire to ‘work’, how it is informed by neoliberal norms, and how brain training can be used to fulfill this desire. Finally, I will discuss the outcome of trying to achieve these desires, which is through self-rehabilitation, specifically brain training programs. Self-rehabilitation as a theme is significant because it exposes the deeper issues associated with brain injuries and clinical rehabilitation, such as lack of clinical care and the domestication of health.

Hope of Returning to Your ‘True’ Self

As discussed in chapter 2, since they first came onto the market, scientists and scholars have been debating the effectiveness of brain training games and if they actually work to increase cognitive abilities in individuals, and also if game progress results in real improvement in the outside world. While most of the studies seem to discredit the marketing claims made by the brain training games, many individuals who play them seem to think otherwise. When I asked my participants if they believe that the games have helped them or have improved certain skills such as memory, mental speed and

flexibility, most of them had positive responses. On the traumatic brain injury forums that I frequented, I found generally the same positive evaluation of brain training games and their results.

Hannah believes that playing brain training games for several hours a day has helped her dramatically, saying that “I know the connections have been made stronger for me ... something I couldn’t do prior to starting this, I could easily do now... it’s changed me.” Specifically, she believes that it has helped her memory, her visualization, her recall, and has even helped her emotionally. She also believes that the skills she has learned from the games have transferred into her daily life, such as the reading comprehension, visualization, and memory specifically, “so if my memory improves, that improves almost all aspects of my life. I can remember what I stopped at the store for... I used to have a lot of little strategies to help me cope. I find I use [them] less and less because the recall is there now.” She expressed the benefits of playing brain training games, such as the ease of use, being able to play them anywhere from her phone, that she is able to alter the level of difficulty in the games depending on her cognitive state, the fact that the games are free, and that they help her cognitively as well as emotionally. Hannah believes that the games have helped her in many profound ways, but especially emotionally, because she claims “when I do good I feel better about myself, I feel like I can do this, on a bad day when I’m not doing so well... it can actually lift my spirits up when I get something very difficult.”

Nancy also shared the benefits she has experienced from playing Lumosity on a daily basis. She states that “I think that it does work the brain...my word finding I think has probably improved, my spelling for sure has improved, my memory is probably a

little bit better than it used to be...I have seen some improvements.” She plays the games every day because she finds them fun and addictive, and they also give her something to do when she is at home, so they also keep her occupied. She believes that these games do probably transfer to her daily skills to some degree, although she is unsure of how much, claiming that “if I didn’t do them, I probably would be even worse with everyday issues.” She recommends brain training for anyone with a brain injury, and even people without one, because she believes is important to train the brain and stay active and cognitive, especially with the aging population. Her opinion of neuroplasticity and brain training is that “its never too late, there’s always a chance to improve if you keep working at it.”

Marco also spoke highly of the benefits of playing brain training games, such as the way it helps him to “think like an ordinary person.” The main ways he believes the games have helped him is with his memory, concentration, speed, and expanding his brain. At first he said that he played the games as a form of recreation and to take a break from clinical therapy, and it was a method of relaxation for him, which eventually turned into a fun activity that he was able to learn from. The fact that he plays it everyday and it has become a routine for him is also significant, because he believes that routine is the most important feature of his recovery, as it aids in his memory by becoming a pattern and habit for him. When asked if he believes his progress in the games have translated into his everyday life, he said that he hopes so, “so if I can use it as a game that I can think outside my little square and expand my balloon ... hopefully when I get outside and people ask questions I can think different and try to maybe think faster.” He also enjoys the fact that the games are convenient to play, that he has access to free games, and that the games he can play online are interactive, which he prefers over individual single-

player games.

Members of the online TBI forums that I was exploring also had generally positive responses about their experience with Brain training games. In a forum post titled “Have You Tried Lumosity?” many members shared their experiences playing Lumosity and other brain training programs, such as Angie, who claimed that Lumosity has given her her life back by healing her problematic areas such as her attention, speed, memory, flexibility and problem solving. Jeff stated that he tried and “prospered from Lumosity, this game has improved my short term memory very quickly...I know I’m healing naturally also but I know this has sped up the process.” Jennifer tried both Lumosity and Happy Neuron, and although she “struggled greatly with a number of the games early on...I definitely saw improvement over time”, and believes that “both programs helped me a lot, especially my attention, mental flexibility and processing speed.” Jennifer also claims that although playing the games were more challenging due to her brain injury, the statistics on the website helped measure her improvement which became very motivating.

The majority of positive responses to brain training games had me wondering if the games were indeed helping these individuals cognitively, or if there were other factors that made these individuals have such positive reactions. George and Whitehouse (2011) argue that self-ratings for brain training are typically inaccurate and influenced by various biases such as various justifications that the games do work because individuals have spent so much time, effort, and even money using them. Yet it is apparent that these games can do more than help improve cognitive skills like they claim, they also provide entertainment, improve the player’s mood, and provide hope to brain injury survivors.

The games are created to be fun and entertaining, which increases enjoyment for the user, and which also builds their desire to continue playing. When training tasks are tedious and dull, the player is less likely to want to keep playing and the final outcome will not be as effective (Green and Bavelier 2008). It has also been shown that brain training can significantly decrease the anxiety levels of middle-aged users, specifically anxiety related to aging and loss of cognitive and mental abilities (Branscombe-Caird 2011). These features alone are enough to justify the use of brain training games, especially for brain-injured individuals.

When asked what neuroplasticity was and what it means to them, most of my participants lit up with excitement. Every participant had heard of the term neuroplasticity before, and most could provide a general definition or description of the term. Marco believes that through the use of brain training and therapy, he is retraining a different part of his brain to do what the injured part used to do, because “the old part that’s damaged- the electricity won’t get there... but the part you retrained, the electricity goes round in a circle and everything works”, which he claims is the basis of neuroplasticity. In the TBI forum, a member named Jennifer discussed neuroplasticity, stating: “just knowing that the brain can heal, adapt and rewire itself is utterly hopeful and amazing; knowing just that much about neuroplasticity has helped me get through a lot of frustration and despair, and helped me hold onto the belief that more is possible in time.” Angie also described using neuroplasticity to lift her spirits, stating “one of the things I tell myself when I am down...and I do get down...[is that] you will be back and better than you were before...to be better than that, its gonna to take some work.”

I began to understand that neuroplasticity represents hope to brain injured individuals, hope that they can retrain their flexible brains to regain lost functionality and skills, and return to the person they were before their brain injury. It also became clear that brain training games were seen as a tool that can be used to achieve neuroplasticity, and thus brain training games were as association, representations of hope to brain injured individuals. Even if the games do not actually work as they claim, this sense of hope that brain training provides should not be overlooked. Hope is a very strong and powerful tool for the injured and ill, it is strengthening and protective, and provides brain injured individuals with the possibility that they will get better. According to Antelius (2007), it has been said that if one has enough hope, it can change the outcome of their illness, which can in turn promote healing. This theme of hope is also closely tied to biomedical and Christian western culture, in which illnesses and injuries are meant to be cured, and that hope is tied to the cure, or in this case, rehabilitation. Although it is not likely that individuals with severe brain injury will be able to return to the same cognitive function and skills they had before their injury, neuroplasticity and brain training gives some people their own personal experience of improvement in memory, reaction time and problem solving and can give them the hope that if they work hard, they could. Thus, the feeling of hope that they have helps instill motivation and hard work, because “it is with the possibility of action that we can create hope” (Antelius 2007).

Realism

While many of my participants expressed using brain training games because they believed that they were helping them, and believe in the power of neuroplasticity, almost

all of them expressed the limits of these games and what they can do, while others expressed more negative opinions overall on the effects of brain training. Both Barbara and Timothy felt that brain training programs did not work for them, and they both stopped using them because of that. Barbara used the games for a while after her stroke, but did not think there was any change in her cognitive abilities. She also felt that the games were tedious and not challenging enough for her, which made her lose interest. Another factor that made her stop playing brain training games was that she could not progress into more difficult levels because her injured arm restricted her from playing certain games. She felt that the games could integrate accessibility features in order to make it easier to use for people with disabilities. Overall, she believed that certain people may be able to benefit from brain training, but one would need to practice the games all the time in order to maintain it, and that eventually- if you do improve- you will return to your previous cognitive status and old habits, if not even worse than before due to aging. The two brain training programs that Timothy tried had also failed for him, and he believes that neuroplasticity is a false promise. He claims that the word neuroplasticity “is oversold today on purpose as a way to get customers into consultants’ offices to make money,” yet feels that brain training can help some people, specifically by giving them a vocabulary to work with.

Although Timothy and Barbara felt that brain training did not work for them, they both maintained hope that they would be able to improve their health and return to their pre-injury selves through means other than brain training. For example, Timothy used caffeine compounds Tired and NoDoz on a daily basis, which he has found the most effective in helping his symptoms of inattention, balance, and sensory integration. He

also has an interest in organic foods and spiritual healing through the concept of Divine and Unconditional Love. Barbara has also found other means to maintain hope, such as attending stroke support groups and participating in other activities such as wood burning, darts, and puzzle games such as Mahjong and Sudoku. Barbara expressed that not only are these activities working her brain, they also keep her occupied and give her an opportunity for socializing, which really helps with her mental and emotional health. I will argue that these activities are also self-rehabilitation, and they provide my participants with hope and also a sense of ‘work’, because these methods need to be practiced and they believe that over time, it will help them heal and will aid in the process of returning to their old selves. I also argue that these methods they attempted after trying brain training are part of the domestication of health, as they found alternative ways outside of the biomedical context to rehabilitate themselves after they were either neglected by clinical rehabilitation or if traditional therapy did not work for them.

Other participants still felt that brain training worked, but were not sure if the programs lived up to all that they claimed in their marketing campaigns. Nancy felt that the games helped her, but when I asked her if the skills she learnt in the games transferred into her daily life, she began to question it. She claims that she had improved in many of the games, and her score was a lot higher than when she began, but sometimes the scores may give you a false hope because although she has improved drastically in the memory section of the game, she still finds herself having many memory issues throughout her day. Because of these discrepancies, she claims that she won’t take these games and their claims “exactly at face value and be too caught up with it.” She also realizes that although the physical injuries from her accident have healed, she is still having difficulty

with her cognitive issues, which she feels may take longer to improve, and that she will probably have a lot of those issues for the rest of her life. Nancy has a realistic view of her injury and cognitive abilities, realizing that this could be something she will be dealing for the rest of her life, yet she still has hope that if she continues to work on herself and use brain training games, “I’m not going to get rid of my issues ... if I keep training at least they’re not going to get worse, that’s my hope.”

Hannah has similar views as Nancy on her brain injury. She claims that “there are parts [of my brain] that are damaged that are always going to be damaged...like this is never going to help me regain emotional control”. Although she believes that the games have helped her more than any rehabilitation, and have improved her recall and memory, she also sees the limits of the games, and believes that it will not restore one’s life back to how it was. She stated “this is going to help me in a game like this, some stuff goes on in to my personal life ... but in the end this helps me increase my score on my games.”

Hannah also expressed that many people tend to misinterpret what these games can actually do, believing that they can improve your overall intelligence and IQ, but that is a misconception, and although she believes you can learn things from these games, they do not make you smarter. She also spelled out some negatives of the brain games that she uses, such as Jetpunk, stating that she wishes it were more challenging, as some games are geared towards certain educational levels, and she would prefer harder content in order to be challenged more and to get more from the games.

Marco has been playing online brain games for many years, and prefers to play interactive games with other players around the world. Although he expressed the benefits of playing and his belief that it is helping him, he thinks that “if it can help

somebody it'd be great, and if it doesn't help anybody it doesn't mean its bad, it didn't work for that one person." Brain training games started off as a recreational activity for him to relieve stress and frustration from clinical therapy, but evolved into a form of therapy itself. He believes that the games have helped him in many ways, but "you want to be like how you were before the accident and...most of the people will never be back where we were before because the injury is what it is," and therefore not even brain training games can get you to your pre-injury self. Although he realizes the limits of his recovery, he also expressed his opinion on the importance of hope, and how people with a brain injury "don't want to get better yesterday, we want to be better a month ago...and that's totally acceptable because if you want to be better tomorrow than you have lost." This statement was evocative for me because it represented how brain injured individuals look at hope and healing, that if there is desire and the hope to get better then you will most likely succeed, whereas if you do not try or have hope, you have already lost.

Although there were individuals that felt that brain training has its limits and will most likely not get you to your pre-injury status, many still continued to play because they still had hope that they would improve, and even regain certain skills that they used to have, even if they may not be the same person they once were. This is not to say that individuals who do not advocate brain training games do not have hope that they can improve or help themselves return to their former selves, it just means that they have sought other means to do so. My participants Barbara and Timothy had both attempted brain training programs because they were hopeful that it could be a vehicle to their healing, but discovered that it was not beneficial for them. They both expressed to me that although it did not work for them, the programs are useful and could potentially work

for other people, they were just doubtful of the effects on themselves. They had both found other means of working their brain and feeling more like themselves, such as Timothy's use of pharmaceuticals and organic food consumption, and Barbara's wood-burning and darts classes.

“You Owe it to Yourself”

The loss of one's job, skills, and hobbies after an injury can be quite disruptive to one's life and self-worth. Especially in a capitalist society, when one is no longer able to work and contribute to their household, or when they have to rely on others to do things they were once capable of doing, it may affect how they feel in relation to their own autonomy as well as their overall contribution to the state. I argue that the reasons brain injured individuals consumed and practiced brain training programs were influenced by living in a capitalist society and from a desire to be productive and socially accepted citizens, and although my participants never vocalized these feelings exactly, it was an underlying theme in some of their responses and attitudes. Wanting to be a productive member of society relates to the theme of returning to one's previous self because most brain injured individuals were actively participating in society before their injuries by having jobs, not relying on the state for income or services, and actively bettering themselves everyday either through exercise, obtaining knowledge, or helping out others.

One feature of our Western capitalist society is individualism, and the idea that everyone must work hard and constantly be trying to better themselves and contribute to society in some way. When an individual becomes injured or ill, they lose the ability to contribute to society in the same way that they used to, which can affect the way they see

themselves –and how others see them- as productive citizens. Parsons (1978) argues that the diagnoses of illness allows the ill individuals and the society they are a member of to accept the fact that they may not be contributing to that society, yet, in order to justify this fact, the ill individual must do everything they can to return to their once productive self. Thus, by brain injured individuals actively using brain training programs, they are putting in the effort to better themselves, and also attempting to return to their previous selves- which were more beneficial to the state and those around them. Crawford (1994) uses the term ‘unhealthy other’ to describe the ill or injured individuals in the capitalist society, who “lack[s] discipline and will power to maintain or restore health” (1359). In a self-disciplined and self-regulating society, the ill individual gets blamed for their unhealthy state or their lack of effort in becoming a healthier individual. This neoliberal perspective bases individuals’ identities on their skills and traits, and that “they are a collection of assets that must be continually invested in, nurtured, managed and developed” (Gershon 2011). Individuals are seen as businesses, who view their own skills and qualities as assets that they own and can improve on, such as how one runs and manages a business (Gershon 2011: 542). Gershon (2011) uses the term neoliberal agency to further describe this idea, claiming that neoliberal agents are responsible for managing their abilities and alliances, as well as their futures, which they create through their own decisions and agency (540). This also means that they are responsible for both their successes and failures, regardless of their disadvantages or setbacks. Thus, brain injured individuals are seen as responsible agents of their own health and success, and they must work hard to gain back and develop skills that have been lost from their injuries.

The idea of returning to one's previous and 'normal' self who was once a productive member of society is where hope becomes a very important feature, according to Anetlius (2007). One must have hope in order to be able to imagine their future, and see themselves as being a better and more productive member of society, which motivates them to continue bettering themselves. Hope in returning to a previous self and 'working' towards it is also important in improving self-worth and emotional well-being, which can affect brain injured individual's quality of life. I witnessed many examples of a loss of self worth with my participants when they were talking about their lives after their brain injury. Barbara discussed how she hated having to rely on her children to drive her places when she was not able to drive herself after her stroke, and how incapable she felt after not being able to perform at work and eventually having to leave her job. Hannah also expressed the disappointment she had of not being able to return to work, and her fear that she may not be employable in the future. Eleanor from the TBI Network Forum discussed how she still has not accepted the fact that she will never be able to be in a high paying and high stress job because of her injury, which had occurred 40 years ago. For Eleanor, having a high stress and high paying job is ideal and something that she wishes she could have, but knows she will never be able to attain because of her brain injury. Some participants even expressed the frustration they had with not being able to manage their own health, such as gaining a lot of weight after their injury due to the medications they were on, or their inability to be active because of fatigue or physical disabilities.

While none of my participants directly expressed playing brain training games to benefit the state, many did exclaim that they were doing it to benefit themselves, and that

they deserved to work on their brains. Ashley from the TBI Network Forum claimed that using brain training games was empowering for her, stating: “every time I do something I know is good for my brain, I feel good knowing that I am helping myself to have a better brain and better quality of life today and down the road”. Michael also stated that “you owe it to yourself” to use brain training games, and that “your gains should mean so much more to you knowing you’re fighting back.” My participant Hannah felt that only people who actually care enough to better themselves are likely to use brain training games because “someone who cares enough to train their brain, they’re already a few steps ahead.” She also felt that people who use these games “tend to be a little more intelligent, because they want to know what they don’t know, and they are aware of what they don’t know.” It is interesting that by using brain games, someone can be seen as more intelligent and more responsible than someone who doesn’t use them because they actually care about their health and well-being. The fact that they believe that they are using the games to solely better themselves, but do not see any connection with the betterment of the state, is part of the marketing goals of these brain training products.

Popular brain training programs like Lumosity uses language that promotes self-discipline and bettering oneself, such as actual advertisements that say “reclaim your brain”, “activate a better you”, and “unlock your potential”. This language reflects capitalist culture we live in and the makers of Lumosity market it this way to get customers to use their products. Rather than marketing the games as being entertaining and a form of leisure, they are marketed as a form of work that one must do to improve themselves, to be good citizens and to reach their highest potential. For brain injured individuals, the games are a tool for them to ‘reclaim their brains’ and to return to the

productive people they were before they were injured, or at least to put in the work to do so. The brain training market benefits from capitalist societal values because people are constantly looking for ways to better themselves - and their products claim to do just that for a small monthly fee - which is why it is a multi-million dollar market. Yet, the capitalist market also benefits from brain training programs because they are producing self-disciplined citizens who are actively putting in effort to become better members of society. I will also argue that the consumers are also benefitting from brain training games because not only do the programs make people feel better about themselves, they give them the satisfaction that they are becoming better and smarter people, despite what actual results the games produce. Brain games are especially appealing to brain injured individuals who are specifically looking to better their brains, the area that has been affected and that has altered their lives.

Self-Rehabilitation

In order to achieve the hope that brain injured survivors have of returning to a previous self and being able to ‘work’, individuals go outside of the clinical setting and perform what I will describe as self-rehabilitation. I have introduced the concept of self-rehabilitation to represent the various acts of ‘work’ that brain injured individuals perform at home in place of clinical rehabilitation, such as brain training programs, puzzles, use of online forums, etc. The reasons self-rehabilitation is employed and often added to clinical rehabilitation is because brain injured individuals may be neglected by the healthcare system and thus are not provided with proper clinical rehabilitation, or they are provided with some rehabilitation but find that it is not enough. The first two themes

in this chapter of hope and ‘work’ lead to the introduction of self-rehabilitation. Brain injured individuals have hope in neuroplasticity, and the theory that they can regain lost cognitive function and possibly return to the person they were before the accident, which is why they try to use brain training programs. Finally, they miss being able to do things they did before their injury, such as the ability to work, whether it is an occupation, a skill, or a trait. Self-rehabilitation for brain injured individuals is an important theme which I will relate to Adriana Petryna’s concept of biological citizenship, as well as the concept of the domestication of health.

The main reason my participants turned to self-rehabilitation was the fact that they were not receiving proper clinical rehabilitation. Although their individual cases were different, the main reason they weren’t receiving care was because the healthcare providers did not feel that the care was needed for them, although my participants felt differently. Another main reason they were not receiving care was because they had run out of funds, even if they had been determined as in need of rehabilitation, and thus any remaining rehabilitation that was needed was required to be paid out of pocket by the patient. For brain injured patients in Ontario, their access to therapy is limited to the decisions of the healthcare workers who justify their level of need for care. The income and amount of care people with disabilities receive if they are unable to work is strongly determined by the cause and reason of their disability. For example, for individuals who were injured at work, such as my participant Marco, the provincial Worker’s Compensation Board – a provincial body into which all employers must contribute by law and that covers all workers who are injured on the job -- would provide coverage, and if they were injured in a motor vehicle accident, such as my participant Nancy, her

private motor vehicle insurance would provide compensation (Casey and Jongbloed 2007).

Worker's Compensation and motor vehicle insurance legislation does not cover brain injuries obtained through other means, but individuals may be eligible to claim Canada Pension Plan disability benefits or private disability insurance if they are unable to return to work. However, Jongbloed and Wendland (2002) claim that "many people with disabilities depend on social assistance for income" (145). On average, individuals who are covered by worker's compensation, auto insurance or other insurance receive better benefits and more services than individuals who were injured in other ways (Casey and Jongbloed 2007). Therefore, access to occupational therapy and other rehabilitation is better for those whose disability occurred at work or in a motor vehicle accident, or for those who are wealthy enough to afford to pay for private rehabilitation out of pocket. I found this to be true for my participants, for individuals such as Marco and Nancy- who were provided coverage by the worker's compensation board and motor vehicle insurance- were offered more rehabilitation and for a longer period than my participants who were injured by other means. Yet they still had to fight to prove that they were in need of the rehabilitation, and Marco claimed that he required more rehabilitation but after his funds ran out he could not afford to pay for it out of pocket. Regardless of the cause of their injury, all of my participants felt that they should have received more rehabilitation, and some expressed that it would have made a positive difference in the recovery of their brain injury.

Biological Citizenship

Adriana Petryna's ethnography on biological citizenship in Chernobyl provides an example of a state that is neglecting health care to its citizens who are in need of it, and providing unequal care to sick individuals. Although it highlights an extreme circumstance, individuals who were affected by the Chernobyl nuclear accident were grouped in different categories based on severity of injury, and it became common knowledge that an individual categorized as "disabled" would be compensated and cared for a lot more than someone categorized as a "sufferer" (Petryna 2002). Therefore, being a healthy citizen basically meant being "abandoned by the state, left exposed to the market, and without social supports" (Petryna 2002: 85). Having a severe illness almost guarantees receiving care from the state, and obtaining biological citizenship, which Petryna (2002) describes as the social practice where the biology of citizens has become a part of a political process and form of governance, and the suffering of individuals is a means of membership and citizenship.

In order to gain access to health care that they desperately needed, citizens of Chernobyl became experts in scientific knowledge and medical terminology in attempt to work around the state's defined categories of suffering, as well as trying to influence and work the system of policy makers and health officials who hold power (Petryna 2002: 118). Citizens needed to know the symptoms and correct categorizes of suffering that will give them rights, and the additional perks of power, money, and social or political influence would help them get there. In desperate instances, individuals even caused themselves and their health more harm in order to receive more or better care from the state. As seen in the aftermath of Chernobyl, biological citizenship transforms injury into

something political, and makes some types of suffering more legitimate than others (Cole 2011).

Just as citizens in Chernobyl found ways to get care and work around the system out of desperation, so did my brain injured participants who were neglected care. They look to self-rehabilitation to fulfill the therapy that they need, sometimes as an add on to clinical therapy, or out of desperation to replace clinical therapy that they can either not afford or not access due to eligibility. Some of my participants even fought for more funds and more clinical rehabilitation, such as Marco who sued the worker's compensation board to receive more benefits that they failed to provide with him, and Hannah who regularly visited clinics and rehabilitation offices in order to receive more rehabilitation, even after being put on a waiting list because she was not seen as a high-priority patient. These individuals refused to be completely cut off of any rehabilitation, and as an alternative to clinical therapy, they sought brain training and other self-rehabilitation that could help them recover from their injuries. Although brain training is not seen as traditional rehabilitation for a brain injury, many programs boast claims of improving cognitive abilities through neuroplasticity. All of my participants had some knowledge of neuroplasticity and knew the claims made by brain training programs, which proved that they had done research and were putting in the effort to recover from their injuries and regain the cognitive abilities they had lost, even after they had been cut off of clinical therapy from the state. As discussed earlier, Canada's health care system creates inequalities of care for disabled and brain injured individuals, and provides individuals who were injured in a particular setting or who are financially well-off with more care -and sometimes better care- than others. These inconsistencies and inequalities

are what cause individuals to seek their own care outside of the clinical realm, and is a perfect example of biological citizenship, and legitimizing certain types of suffering over others.

Domestication of Self-Rehabilitation

Another aspect of self-rehabilitation that my brain injured participants participated in was becoming experts of their own health, or what I will refer to as the domestication of rehabilitation. Childerhose and MacDonald (2013) discuss the domestication of health in regards to the at-home pregnancy test, in which women become their own experts in relation to their pregnancy. They argue that consuming domesticated biomedical products is biopolitical work that individuals are expected to utilize in order to maintain healthy bodies (Childerhose and MacDonald 2013). Brain training programs have become domesticated as self-rehabilitation tools that cognitively impaired users as well as healthy users can consume in their own homes. Just as the at-home pregnancy test removes the physician from the situation, consumers of brain training products replace the clinical experts and become their own experts: choosing what programs work best for them, creating a schedule to use the tools, and interpreting their own results and progress.

My brain injured participants turned to self-rehabilitation through the use of brain training programs as a response to the lack of rehabilitation, or as an addition to clinical rehabilitation. This domestication of health and self-rehabilitation can be beneficial for individuals, by having more independence and input into one's own rehabilitation, agency, privacy, and choice (Childerhose and MacDonald 2013). Brain training programs

can be accessed by anyone who has a computer or smartphone, and does not need the help of a medical professional or physician to be used or operated. The programs are user friendly and able to be used in the privacy of one's home. Individuals have the ability and choice to try out different brain training products on the market and pick which one is best for them based on their own personal opinions. They also have the choice of how often they want to use these products and for how long, based around their schedules and desire to practice. Most programs also have statistical features that show your improvement and achievements in the games, which allow the users to see their progress and become their own experts of their self-rehabilitation. This contrasts clinical rehabilitation where you have to attend a strictly scheduled appointment with a professional who informs you of what exercises they want you to do, and whom are the ones who assess your progress and tell you how you have improved.

Although there are plenty of benefits of domesticating health, there are also negatives. Typically, at-home brain training programs are a last resort for individuals who cannot access clinical therapy, but who still want some form of rehabilitation. These individuals would rather participate in traditional clinical therapy, but out of desperation, turn to brain training programs because of their accessibility and ease of use. Also, the effectiveness of these programs has not been sufficiently proven, specifically as rehabilitation for brain injuries, and various scientific studies have actually argued against their effectiveness, as discussed in Chapter 2. Thus, it is not certain that all of the time and effort spent using these brain training programs is actually helping individuals, or is equivalent to time spent in clinical rehabilitation. Finally, although brain training programs are widely available, many of the highest rated or most effective programs

according to the media and/or scientific community require paid subscriptions, which limits the choice and accessibility for brain injured individuals. This discrepancy in paid and free programs creates unequal access, and thus those who can afford the paid programs may be using better or more effective programs than those who cannot afford them. Many of my participants who could not afford the paid programs turned to the free alternatives, which they expressed may have not been as effective than the paid alternatives.

Childerhose and MacDonald (2013) argue that domesticating biomedical devices forms the creation of new meanings and symbolism for these devices that differs from their intended uses. Brain training programs, primarily marketed for stimulating the brain and increasing cognitive skills, become replacements for traditional rehabilitation, something to ‘work’ and improve on, and symbols of hope for brain injured individuals. In this same idea, the technologies that are used to play these games, such as computers, cellphones, and tablets, are also given new meanings and uses by the individuals who are consuming them. Rather than being used for their manufactured and intended purposes such as communication devices, processing tools, or for entertainment purposes, these technologies are adapted into apparatuses for self- rehabilitation by brain-injured individuals.

Self-rehabilitation is an important theme for my research on brain injured individuals because it represented the outcome of trying to achieve both the hope of returning to a previous self, and a return to ‘working’. Brain injured individuals were sold on the idea of neuroplasticity and turned to brain training to try and re-train their brains to how they were before their injury, and also used them as a form of work to improve

themselves and their health. Self-rehabilitation also exposes other issues that affected my participants such as being denied clinical therapy from the healthcare system, the financial issues that restricted them from clinical therapy, and the struggles with mental health that they faced.

Conclusion

While I was once skeptical of the brain training market and their mighty claims of altering the brain through neuroplasticity, I emerged after conducting this anthropological study with a new understanding of these programs and their significance and affect on individuals with acquired brain injuries. The objective of my research was to understand how and why brain injured individuals used brain training programs, and to see if they actually believed that the programs were helping them, cognitively or otherwise. I also wished to explore the significance of the programs themselves, to see why they are advertised the way they are, and how their claims relate to both the cultural meaning we place on brain as the centre of the self, as well as the actual experiences of my participants. Although I still may not be sold that these programs can indeed retrain your brain or make you smarter, I have come to learn the benefits and therapeutic nature that these programs provide for individuals who have suffered brain injuries. I have also come to learn that many technologies may not be used in their intended manner, or may not provide the results they claim, but may actually provide alternative benefits created by the consumer. While the initial goal of my research was to explore the effectiveness and significance of brain training programs for brain injury, I discovered many other important issues that are part of a much bigger picture in relation to brain injuries, illness and individualism.

Research Findings

My research was conducted through semi-structured interviews with brain injured individuals who use brain training programs, along with information that I obtained from

online ABI forums, my own experience playing the games, and various ABI support groups and events I attended. I observed the various descriptions that my participants shared, such as expressing a change in identity after injury, financial concerns, mental illness, use of pharmaceuticals and a variety of coping mechanisms that they used to deal with their brain injuries. I found connections between these shared descriptions and the reasons that they began using brain training programs, such as trying to return to their old selves, being unable to afford clinical rehabilitation due to finances, the way the games were entertaining and improved their moods, and as a productive way to fill their free time, as they were unable to return to work or their usual activities. Brain training programs were seen as an instrument of hope that can be used in attempt of retrieving the past self, which brain injured individuals strive for. They were unhappy with the changes in their life and sense of self that their brain injury has caused, and were hoping that brain training and neuroplasticity could help them to retrain their brains back to how they were, or at least better than they are presently. Another motivator for using brain training games was to fulfill a desire to ‘work’ and be productive citizens, which I argued is based off a neoliberal principle of individualism and bettering one’s self and the state. While being unable to return to their employment after their injuries, my participants were left with a lot of time to fill, and a yearning to get back to the skills and work that they used to do. Brain training provided them with an activity to work and progress on, while at the same time giving them the satisfaction that they are working on their health and trying to be better more productive citizens.

After talking to brain injured individuals, I realized what brain training programs represented and symbolized for them. Brain training programs were a method of self-

rehabilitation, which is a form of rehabilitation that they can perform in the privacy of their homes, based on tools and techniques that they have discovered themselves, in a setting outside of the clinical realm. The medical expert is removed from the therapy, and the brain injured individuals become their own experts. They choose what programs to use, and how often to use them, and they are able to judge their own progress and results from the statistics typically provided in the training programs. I referred to this action as the domestication of rehabilitation, based off of the theory of the domestication of health that is becoming more prevalent in our society (Chiderhose and MacDonald 2013). The fact that my participants were domesticating their rehabilitation exposed the deeper issues of accessing rehabilitation services in Ontario. There is unequal access to clinical rehabilitation for brain injury patients, and many individuals are completely neglected from receiving care and thus forced to pay for the services out of pocket. This neglect and abandonment by the health care system forced my participants to turn to self-rehabilitation to help themselves recover from their brain injuries.

Limitations to My Research

My research did have limitations that could have affected the results that I obtained. For example, my sample size was quite small, which limited the variability in participants that I had. My participants were all over the age of 50, so their opinions and experiences may be different than individuals who are in university or who just entered the workplace. Participants within the age range of 20-40 would have been beneficial to talk to as they may have been more exposed to new technology, and might have a different experience using brain training programs. Also, a younger age group would still

have many years left working in a traditional occupation, thus if their injuries affected their ability to work it may have affected them more than my participants, who are closer to the age of retirement, which is typically around 65. It also would have been interesting to have a larger group of participants who range in ethnicity, gender, and class, to see if there were any discrepancies between the various categories.

Another limitation to my research was the difficulty in studying individuals with acquired brain injuries. ABI's are so diverse and individuals experience so many different symptoms and outcomes that it is hard to group them together for comparison. A brain injury can occur in various areas of the brain and with different severities, thus the struggles and medical issues that my participants faced were quite diverse, as was the origin of their injuries. Because my participants all had different medical issues, the rehabilitation they needed was different for each person, and so were the reasons they had for using brain training programs. They also all had quite different experiences of dealing with their brain injuries and how it affected their lives. With a larger sample size I may have been able to find more similarities between participants that would form better comparisons.

Further Research

For future research I would begin to look at the functionality of the games on actual cognitive performance for a deeper understanding of the power of brain training games. My research thus far has explored how brain training programs effect brain injured individuals and make them feel, and the deeper significance of those reactions, but it would be valuable to further the research and see how the games effect them in a

physical and cognitive level. I was not concerned in this paper with if and how brain-training games actually work, but it would provide an interesting perspective, especially when comparing it to the changes that they felt were being made. This type of research would be quantitative clinical research that social scientists would not conduct, but I also feel that social scientists can contribute to further research on brain training for brain injuries.

I believe that qualitative research on brain injuries and self-rehabilitation is very important, and should be given more attention by social scientists with larger studies that are more long-term, to get the most effective results. It would also be interesting to do research on individuals who have very similar types of brain injuries and symptoms, such as stroke patients or individuals who all experienced aphasia. The results may be more accurate if the participants all share similar injuries as a better method of comparison, rather than a diverse group of brain injured individuals. Finally, further social science research should pay attention to how self-rehabilitative products such as brain training are marketed to consumers, along with how consumers use and make meaning out of these products. Studies like these can be very significant, not only for the social sciences but also for clinicians, social workers, and the insurers who work hands-on with brain injured individuals.

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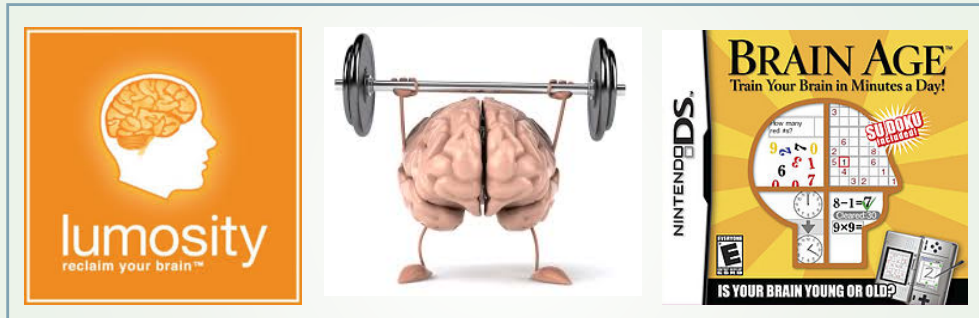
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Appendix A: Research Participation Flyer

DO YOU USE BRAIN TRAINING GAMES?

We are seeking volunteers with an Acquired Brain Injury (ABI) to participate in a short study investigating the use of at home brain-training programs as a form of personal rehabilitation. These programs include online subscription services such as Lumosity, CogniFit; mobile App's such as Brain Wars and Fit Brains Trainer; and also console video games such as Brain Age on Nintendo DS.

The study will consist of a short 30-60 minute informal questionnaire about your use and experience with these programs, specifically in relation to your injury and rehabilitation.



Eligibility to Participate

- Must be at least 18 years of age
- Must have a mild-moderate Acquired Brain Injury (ABI)
- Use (or have used) at-home Brain training programs (such as Lumosity, Brain Age, Brian HQ, Brain Wars, etc)
- Are able to participate in a 30-60 minute interview/questionnaire

IF YOU ARE INTERESTED IN PARTICIPATING PLEASE CONTACT:

Elaine Cagliostro, M.A., York University

Principal Investigator

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This project is being conducted by Elaine Cagliostro (Student Principal Investigator) and Dr. Margaret Macdonald (Faculty Supervisor) at York University and has been approved by the York University Office of Research Ethics.

Appendix B: Brain Training Interview Questions

1. Tell me a bit about yourself/your injury.
2. What rehabilitation did you do directly after your injury? And what are you still doing?
3. What at-home rehabilitation methods (brain training programs) did you use or do you currently use for your injury?
 - are they free/paid subscription?
 - how long after your injury did you start using them?
 - how long have you been using them?
4. How did you find out about at-home brain training programs?
5. How often do you/did you use brain training programs?
 - How long do you play per day/week?
6. Why do you use brain-training programs? What do you like/dislike about them?
7. What is your expectation of these programs? Was this different than your initial expectation?
8. Do you think the brain training programs have affected your recovery from your brain injury? If so, how?
9. As you continue to play these games you improve at them, do you feel that these skills transfer into your every day life?
10. How do you feel about being able to use these programs in the setting of you on home or even on the go?
11. Out of every method of rehabilitation you have used for your injury, which did you find most effective? Least effective? Why?
12. How do you feel about the term neuroplasticity? Does it play a role in your recovery/your use of brain training programs?