Ramp up Awareness: Psychological Impact of Acquired Lower Limb Amputations

by

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Abstract

This capstone project delves into the physical, social, and psychological elements of individuals' lives with acquired lower limb amputations. The research strongly suggests that for the lower limb amputee, physical aspects of pain affect people's social environment and, therefore, has an impact on a person's psychological adjustment. Stigma and the labelling of being disabled causes some psychological and identity issues in those with acquired amputation. Barriers to social equity and resources cause many individuals with physical disabilities to struggle financially and psychologically as the lack of these social necessities increase stress levels. Lack of education and integration of disability knowledge has meant that amputees often only have physical support or limited peer support when engaged with organizations specific to amputee resources. As social ableism is often overlooked, there is a higher risk for individuals with physical disabilities to be further stigmatized in clinical practice. As someone who is often mistaken for having an acquired amputation, I have weaved my own personal narrative alongside the literature reviewed. Priority of further training for clinical counsellors and the need for social change is discussed.

Keywords: ableism, amputation, inclusion, physical disability

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Chapter 1: Introduction

Our society has exploded with diversity in a very short time span. This is good. People of colour and members of the LGBTQ2+ community have all been able to come together and fight to be seen as worthy participants in society. I have been in workplaces that have even gone as far as to integrate specific standards in hiring a certain amount of BIPOC individuals. The same is true of most universities. Social organizations brag of their diversity model. How diverse is it though? Although disability is the largest minority group, there are still incredibly unjust policies and strongly rooted beliefs about physical disability in our society. These injustices undoubtedly have an impact on the psyche of an individual. In this chapter, I delve into these areas of injustices to shed light on where we. as a society. need to go, in order to fully understand the experiences of marginalized individuals – specifically those with acquired amputations – in order to create an environment of equity and dignity.

Overview of the Topic

Perhaps one of the most difficult things in writing the literature review in Chapter 2 has been organizing the information. It has been difficult to know what topic fits under each heading. The focus of lower limb amputation has been difficult to dissect because there are so many variables that interact with each other and so many possible outcomes, all depending on various other intersectionalities and societal environments. In hoping to grasp some sort of organization in this capstone, the literature review has primarily been grouped by using the biopsychosocial perspective.

Biological Lens. This perspective concerns itself with the physical. In the case of acquired lower limb amputations, the biological lens places importance on the physicality and specificity of the mobility that can be reached. For the lower limb amputee this means that the

focus is on how to create a way for the person to be able to be mobile enough that it creates a positive correlation with quality of life. The use and proper fit of a prothesis is the tool which creates this possibility of higher levels of mobility for individuals.

Social Lens. This lens concerns itself with the impact of the social environment surrounding the amputee. This lens includes the impact of society beliefs around disability. These beliefs around disability are then made aware through stereotypes created lack of resources and an inability to provide adequate policies to protect those with disabilities. In interviews of amputees due to diabetic foot ulcers, Bergenholtz et al. (2021) discovered that three of the four themes found in their data were related to the social impact of losing one's lower limb. The themes of what others in society will think of the amputee, thoughts of being labelled either a *tough one* or *the one that whines*, and lastly, the limitations and opportunities that are created or left out by society (Bergenholtz et al., 2021).

Psychological Lens. This lens concerns itself with quality of life, body image and levels of depression and anxiety within the individual of a lower limb amputation. For the amputee, the psychological can vary dramatically as it is intertwined and its complexities with the social environment available at any given moment in time.

Research Problem

The physical aspects of having a disability are logically easier to correlate with psychological impact. The complexities of a social environment, however, are more difficult to correlate with psychological impact. Social environments play an incredibly important role in the psychological impact of lower limb amputation. Rather than shying away from a complex problem, in the literature review in chapter two I aim to face the problem of societal structures that should be further evaluated on multiple levels, in order to lessen societal burden of amputees.

Purpose Statement

In this capstone I seek to explore the psychological impact that acquired amputation has on individuals. I explore the ways in which physical pain and mobility are associated with the psyche of a person. I seek to reveal various ways in which social environment and resources may strongly influence the development of depression and anxiety in an individual. I have intentionally woven personal stories into the literature review as a way of allowing the reader to better understand the impact that these theories and themes can have on an individual's lived reality.

Intended Audience

Counsellors. One of the intended audiences for this capstone are counsellors. To do well by their clients, counsellors must be self-reflective of their own biases and ways of being in the world. It is necessary for counsellors to be knowledgeable of the themes associated with disability. Specifically, this capstone could benefit counsellors in furthering their understanding of the psychological difficulties of a client exploring their possible identity shift from being an able-bodied individual, to a person with a disability. Better understanding the real stigma that exists in a person's world, allows the counsellor to serve their client justly.

Policy Makers. Policy makers are an intended audience for this capstone. Disability is a spectrum. It is imperative that people with amputation are not overlooked in the process of policy making. It has been my experience that the needs of people with amputation are often overlooked because amputation can be seen as a relatively privileged disability, especially if the individual is able to use a prosthesis.

The Able Bodied. Another intended audience for this capstone are people with able bodies. I strongly believe that people are inherently good and intend no harm and I believe that good intensions can also create harm. This capstone includes themes that may have never been

thought of before by an able-bodied individual. My hope is that this capstone allows the able-bodied individual to desire to see the disabled person's perspective and be able to integrate it into their life.

Those with Amputation. I strongly believe that amputees need to understand that they are not alone in how they may be feeling. Microaggressions and stigma do still exist and they can influence a person's psyche. For many years I thought that I was too sensitive and second guessed the impact my environment had on me. In sharing some personal stories throughout this capstone, my hope is that those with amputation will also stand up and voice their societal experience of amputation.

Conceptual Framework

In the literature review I chose to explore the topic of acquired amputation through a transformative paradigm. Those with physical disabilities, and specifically those with amputation hold complex experiences that are only realized through qualitative research. Qualitative research is also necessary for this topic as those with amputation are a minority group, therefore, it is difficult to collect reliable data with a small and complex group of people.

In the literature review I use the biopsychosocial model of disability as the lens to review the research. Furthermore, in this capstone I place special attention toward the aspects of society that impact individuals with lower limb amputation.

Questions of Inquiry

People with physical disabilities are often negatively labelled as disabled by society. Is this true of most of the lower limb amputee population? How do people with disabilities, specifically those with amputation, understand the term of disability? Physically, what aspect of amputation effects a person's psyche? What aspect of our social environment affects amputees

negatively and positively? Have we, as a society, grown in areas of representation, stigma and microaggression towards people with physical disabilities? What supports are lacking for amputees?

Contribution to the Field

According to *Active Living Alliance for Canadians with a Disability* (2021), there is an estimated population of 227, 000 Canadians living with amputation. According to Diabetes Canada (2024), approximately 70% of acquired amputations are caused by diabetes. Diabetes Canada also predicts an increase in this percentage in the coming years.

The organizations that exist, as a support to amputees, appear to be either primarily focused on the physical and practical needs of amputees or simply offer peer support to those with amputation. There appears to be very little room for individuals with amputation to process their shift in identity, especially as it relates to their social environment. As well, many organizations will simply suggest counselling with no specific connections with the counselling field.

The definition of disability can look quite different depending on what lens one uses when interacting with it. For some, disability is seen through a social lens. This means that a person is only disabled by society's inability to make places accessible. Also, some people only identity as disabled to the extent of receiving the help and resources needed, in order to live in equity, among others.

As someone that uses a prosthesis on a daily basis, I can say that there is a high element of stigmatization that this population endures daily. For the person with a visible disability, there is no rest form the questions, stares, and uneducated and harmful comments received from complete strangers.

As individuals with disabilities are a stigmatized and steadily growing population, counsellors must be aware of their own ableist ideas and microaggressions towards those with amputations, and in the wider spectrum of disability as a whole. The concept of ableism is unknowingly rooted in our ways of thinking. It is my opinion that, it appears to be an 'ism' that hasn't been 'cool' enough to receive enough social awareness and social justice advocacy.

As organizations are sending amputees to counselling services, it is imperative that counsellors are equipped to be aware of their own biases and stigma related to this population. If counsellors are not aware of their attitudes and biases, they risk further isolating and harming this population. It is through this self-reflective work where counsellors can challenge not just their own beliefs, but also the societal and systemic beliefs that keep those with amputation stigmatized and oppressed. In this capstone project I aim to contribute to the current body of research by highlighting personal stories that relate to the psychological impact of the experience of physical disability.

Reflectivity and Positionality Statement

In full disclosure, I don't have the experience of an acquired amputation. My disability was congenital, and the procedure I have experienced is called *van ness rotation plasty*, which occurred when I was about two years old. As I have mentioned earlier, for the literature review, I have also incorporated some of my own experiences. At one point in this journey of writing this capstone, I became really stuck in the writing process. After reflecting on this, I realized that one reason I was stuck was because I was very aware that I don't have the same reason for using a prosthesis as those who I'm researching. This conflicted me for months. I didn't want to be misrepresenting their experience as mine. Then one day I got in a conversation with a man on the bus. Without receiving any information from me, he continued to tell me what would be good for me and my leg. He assumed that I had an acquired amputation. This happens to me often. The

surgery I had is rare, so rare that I often have to explain my leg to most medical professionals. That interaction with that man made me realize that although there are differences between my experience and those with acquired amputation, how we are viewed by society may not differ all that much. This is the base for my belief that my experiences are both reliable and valid to be woven into the literature review.

I also want to disclose that as someone who has a disability, I have always been of low-income status. It has only been in the last year that I have been receiving income assistance from the person with disability (PWD) program. I have found that education often means that people are more willing to listen to your experiences. My experience of being low income and being on disability sheds light on the inadequacies of our policies and current systems.

It is my hope that this research further highlights the need for more education and advocacy for amputees, and in the broader spectrum of physical disabilities. I have experienced my psychological needs being overlooked, as it related to my disability, because there seems to be this assumption that if my physical needs are met, I have everything I need to persist and succeed. We need to get past the idea that accessibility for people with physical disabilities is simply just a physical issue. Ramps, elevators, and disability seating does very little to support the psychological impact of physical disability.

Chapter 2 and 3 Summaries

In Chapter 2 I aim to highlight the biological, social, and psychological experiences of those with acquired amputations. Firstly though, the literature review will provide the reader with Canadian statistics of lower limb amputations. The biological lens will focus on the physical difficulties that may appear for some individuals undergoing lower limb amputation. Pain such as lower back pain and phantom pain will be discussed. Next in the literature review I will look at the social aspects surrounding attitudes and beliefs about physical disability. These

will include: the terms of ‘ableism’ and ‘stigma’ and how these are incorporated into our society by way of microaggressions, representation, labels of identity, the use of language, sexuality and age as they all relate to physical disability and acquired amputation specifically. Finally, in chapter 2 I will look at the possible psychological impacts of lower limb amputation. These will include: discussing quality of life, body image, depression and anxiety, and financial obstacles as we live in a society where finances dictate your lived reality. I conclude by summarizing some specific social supports that are available to amputees as well as disclosing some areas where there is a lack of support.

In Chapter 3 I aim to take the knowledge gained in Chapter 2 and incorporate it into recommendations for going forward. As many organizations are passing off the psychological part of having a lower limb amputation, these recommendations will focus primarily on the work of counsellors. The areas of personal growth and the need for supervision will be discussed. For individual counselling, the topics of accessibility, finances, and accessibility will be touched on. The advantages of group counselling will be discussed. As they relate to physical and acquired amputation, ethical and cultural considerations will be discussed. From a broader perspective, discussion of recommendations for wider society will be explored. These will include how able-bodied people can be allies with people with disabilities, and how workplaces may better view their employees with physical disabilities. Lastly, recommendations for policy makers will be addressed.

Definition of Terms

The following are a list of key terms to further the understanding of the present research and themes discussed.

Ableism is a systematic oppression of individuals with impairments/disabilities on the basis of their disabilities (Concover et al., 2017).

Goldilocks dilemma is when something needs to be precisely right. In the case of disability resources, the idea of one's disability being 'just right' in order for a person to qualify for such resources (Areheart, 2008).

Inspiration porn is a type of language that allows able-bodied individuals to objectify disabled people and benefit stereotypical thinking. It is often observed in the media. When someone with a disability achieves something, it is inspiring (Young, 2014).

Lower limb amputation is the surgical removal of one's leg. (Davidson and Lamberge, 2020).

Microaggressions are subtle social forms of discrimination. These can include verbal, non verbal and environmental insults (Ditchman et al., 2019). These insults are based on stereotypes of a specific group.

Phantom pain refers to pain in the amputated limb. Phantom pain is nerve pain. This nerve pain has varying impacts on individuals. Some may have phantom pain that is short lasting, painful shocks in a missing body part, on the rare occasion, while other individuals can be in excruciating pain on a daily basis (Flor et al., 2006).

Chapter 2: Literature Review

Introduction

There have been ramps built and elevators installed. Places of both work and play are stamped with the handicap logo and, therefore, viewed as being accessible and inclusive spaces for those with physical disability. Much of the conversation on how to best support those with physical disability has ended, due to this simple and assuming logo that displays accessible infrastructure. There seems to be this underlying belief that the only barrier people with physical disabilities come against is in the concrete world to which one resides and moves around within. It has often been seen as a physical issue with little regard to the emotional or psychological effects of such a situation. The reality is that the physical accessibility of a space is only the first step in becoming an inclusive society where people with physical disabilities are treated with dignity and equity. There is a need for North American societies to consider the emotional and psychological damage that can occur while living in an ableist society. In this paper I aim to highlight the literature that explores the lived experiences of people with acquired lower limb amputations. The literature review will briefly explore the physical elements of an amputee's experience as well as delve into the social environment that may negatively impact one's psychological state in an ableist world.

The Physical and Medical Context

Canadian Context

Between the years of 2006 and 2009 Forbes et al. (2015) compiled medical documents from 207 hospitals across Canada. The records excluded both paediatric and traumatic amputations. According to these records, the largest group of patients to undergo lower limb amputations were patients admitted for diabetic complications, at 81%. Patients undergoing amputation due to

cardiovascular disease came in at 6 %, while 3% were cancer patients. Males represented 68% of this population. A couple years later, Eng et al. (2017) collected data from the Canadian Institute for Health Information between the years of 2006 to 2012. During this time span 44,430 lower limb amputations occurred, while amputations due to diabetes were at 68%. Furthermore, there was an increase of lower limb amputations from 7,331 in 2006, to 7,708 in 2011. Diabetes Canada (2023) has also confirmed that 70% of all amputations are due to diabetes complications. Specifically, an Ontario study by Aljabri et al. (2019) sought to figure out whether lower limb amputations caused by either peripheral artery disease or diabetes were on the rise in the province. The researchers used data collected between 2005 and 2016. Results indicated that in the last decade, lower limb amputations had increased. Although this data is dated it is parallel to Diabetes Canada (2023), who contest that both type 1 and type 2 diabetes will continue to rise in the next decade. Diabetes Canada (2023) has also confirmed that 70% of all amputations are due to diabetes complications. Taking these statistics into account, it is safe to conclude that lower limb amputations are also on the rise, not just in Ontario, but throughout Canada.

In her first pregnancy, my mom was diagnosed with gestational diabetes. Unfortunately, this formed into type 2 diabetes. I vividly remember a conversation I had with her when I was around twelve years old. We were on a long car ride, and she started sharing with me the impact diabetes could have on her the longer she lived. She seemed to have this strong knowing that she would die younger than most. She went through a list of possible medical outcomes in the coming years. She talked about the fear of loss of eyesight. She argued with herself that deafness would be easier than losing one's sight. She listed the things she would miss seeing: the expansive prairie blue sky, the pop of colour that occurs in spring, the layer of pure white snow after a snowstorm. She talked of the grief that would occur as a result of the loss of sight. She was able to be aware of that possible loss and still see light in continuing to live. Next in her

mind came the thought of amputation. There was an evident shift in her voice as she talked about gangrene and the often-inevitable amputation that is forewarned by medical physicians. Without hesitation, she turned to me and said that she would rather die than to have to go through lower limb amputation. Approximately 4 years after this conversation, she began to go blind. After about a decade of being legally blind, her doctors were preparing for her lower leg to be soon attacked by gangrene. She died before that could happen. To this day I wonder if she chose to give up and die, as to not have to endure lower limb amputation.

Raspovic et.al. (2018) were curious to identity the most feared diabetes complications in those with diabetes. The study included 461 patients with diabetes, 254 patients of which had no diabetic foot complications, while the remaining 254 patients had diabetic foot problems. Their findings revealed that amputation was feared significantly more than death by the patients with diabetic foot disease. It was one thing for me to hear this fear from my mom as I could make numerous subjective reasons why this may have been the case. However, to find research that this fear is common amongst those with diabetic foot disease is alarming. I imagine that this fear is complex and, therefore, not fully known or understood.

The Medical Model

One of the major struggles for people with a disability lies within the medical model. As proponents of the medical model would argue, disabilities need to be remedied and the problem is seen to be the individual. D'Angelo and Eiler (2020) define the disability model's function as a way in which medical professionals can diagnose individual flaws from the norm, fix them as they are able, or to label how the individual will be able to participate in society, if at all. Russell (2019) argues that the medical model is intertwined with capitalism by creating this notion that bodies should function similar to machines and be fixed or thrown away. It is my opinion that, the medical model has resulted in people with disabilities being robbed of their basic human

right of being human. Being biologically different is not something that is chosen, it ‘happens’ or is ‘acquired’ without consent. Some form of disability, whether temporary or permanent, is reality for all, if one is to live long enough. Hence, to deem someone’s body as pathological is to deem all of humanity as the same.

There are physical hardships and physical nuisances within each individual case of amputation. It is important to understand that not all amputees use a prosthesis. This is based on multiple factors. The use of a prosthesis requires a person to go through a learning curve that may not be realistic or desired for them. The healing of the stump may decrease the viability of a prosthesis to be an option. Inadequate tissue around the bone may also mean a prosthetic is not a good option for an individual. Research by Briggs et al. (2018) reported that prosthetic use was higher for patients with distal amputations, that is amputations further away from where the leg attaches to the body, compared with proximal amputations, which are amputations closer to where the leg attaches to the body. Regardless of the reason, the decision to use a prosthesis remains a conversation between the patient, their body, and their medical team.

The use of a prosthetic requires more physical effort and stamina as compared to an anatomical limb (Murray, 2005). This then can affect one’s desire and capacity to utilize a prosthesis on a regular basis (Murray, 2005). In both cases where one chooses to not use a prosthetic limb or one is not able to use one, the effect is often social isolation (Anderson et al., 2017).

Physical Pain

There seems to be little social awareness of the physical pain attributed to amputation. This may come from a lack of long-term research into the measure of pain over several years following the amputation. Döring et al. (2021) successfully gathered data from 21 patients who had amputation surgery between the years of 1961 and 1995. They found that after more than 20

years post-surgery, 81% reported back pain and phantom pain in the last year. Residual limb pain in the last year was also reported by 71% of participants. The median score of phantom pain was at a 7 out of 10 for intensity, while residual limb pain was 4 and back pain was at a 4.6 out of 10. Specific to back pain, in patients who had traumatic lower limb amputations, Adams (2003) found that the participants with above the knee amputation suffered more back pain than that of below the knee amputation. Taking all these results into account, it is clear that amputation surgery does not have a temporary impact. There is a physical reality and risk of back pain, phantom pain, and residual limb pain even decades after surgery. This undoubtedly affects a person's psyche.

Beisheim et al. (2021) researched the possible differences in multisite pain by comparing males to females. Their data revealed that 73% of their female participants experienced multisite pain, compared to 57% of male participants. This multisite pain refers to pain in more than two areas of the body, such as lower back, and phantom pain among others. These researchers argue that there are not only biological reasons for this, such as hormone differences, however, social, cultural and gender specific ways of reporting pain that have the potential to separate data from females to males dramatically. As Beisheim et al. (2021) reflected, so much of the research available is often collected from a higher percentage of males. Due to these findings, these researchers argued that it is important that specific research is done to support females as their pain can be hidden and dismissed. It is my opinion that although this information seems legitimate, I believe similar statements could be made for males. Biological men may not have hormone fluctuations, however, in the Western context, it is important to recognize that as pain can be seen as an emotional response, men may not be honest or consciously aware of their pain levels. Personally, I have also found myself under reporting my own lower back pain because pain can be so chronic that it is a norm that one gets accustomed to, so it becomes baseline.

Research by Ehde et al. (2007) found that age was not correlated with severity of pain in patients with an amputation. The reasons for amputation in this selected group of participants were varied. The researchers suggested that the reason for severity of pain not being related to age was due to older patients being less bothered by their pain. Briggs et al (2015) gathered research from participants who were amputees due to cancer specifically. In utilizing the Toronto Extremity Salvage Score (TESS), which determines functionality, Briggs et al. (2015) reported that older age and higher levels of pain had a negative impact on functionality and mobility. This then is one factor that can lead people with amputations being more isolated from social engagement.

The Social Context

Stigma and Ableism

Dovidio et al. (2008) categorize stigma as having three functions: the first is to exploit, the second is to enforce social norms and lastly, stigma avoids disease by way of excluding others. As further described by Dovidio et al. (2009), stigma keeps people down, keeps people in and keeps people away. Ableism, in its most broad term, is discrimination and stigma that is based on disability. Personally, I think it essential that we understand that this is a learned concept and behaviour.

It is in my experience that I say this. Many adults fear interacting with disability. Children often do not and are instead curious. The common experience I have with a parent and their child is that the child stares and when the parent notices, the parent scolds the child. Similarly, children have often walked up to me and asked me what happened to my leg, only to be dragged away by their parent. These interactions make me sad. Why is it that children can ask the questions that make adults so uncomfortable? By not allowing a child to ask questions, you are potentially furthering discriminating against the disability. I also understand that everyone has a

right to not disclose, but I, as a person with the disability, should be the one to choose whether I answer the child or not. I believe that if we, as a society, were able to have open and clear conversations with one other, with the goal being to try to understand each other's perspectives, ableism and stigma would decrease dramatically.

Microaggressions

Microaggressions are micro actions that preserve stereotypes and inequities (Kattari, 2020). Microaggressions, therefore, fit under the umbrella of ableism. There is currently no standardised scale to measure the effects of microaggressions toward people with disabilities. As a beginning step towards this, Concover et al. (2017) created a scale to measure the distress that ableist microaggressions place on individuals with physical disabilities. Due to the personal nature of, and difference amongst, disabilities, these researchers created the content of this quantitative study by utilizing first, qualitative studies whereby individuals were interviewed and expressed similar themes. These themes then were integrated into quantitative survey questions in order to correlate people's stress levels and their interactions with their surrounding society. This research is important because it creates a way for disabled people to be validated in their experiences. Ableist microaggressions are ways in which people with disabilities are discriminated against in a social environment.

In my random interactions with others, I have noticed an inability to sit with uncomfortable realities. A year ago, I sat next to a stranger on a bus bench. My prosthetic leg was clearly visible as I was wearing shorts that day. She leaned over to me and asked what happened to my leg. As an older Millennial, this questioning is quite common in my experience. I do not label it as good or bad, but rather simply curiously human. I answered her question explaining that my artificial leg was the result of birth defects. She went a little quiet then told me that learning to have a prosthetic leg as a child must be much easier as I wouldn't have had to go

through as much trauma or struggle in adapting to it later in life. This wasn't the first occurrence I have had in hearing this belief. I believe that this stranger meant no harm and was simply uncomfortable with my reality. Still, I believe that this was a microaggression because this stranger questioned my disability experience.

In my experience, I have found that people are generally uncomfortable with taking my help. Only a few weeks ago I met up with a woman in her eighties. Her ability to get out to pick up bare essentials is limited. I had mentioned that I was on my way to pick up a few groceries. I offered to pick up anything she may want and drop it off to her. She was hesitant. Finally, she told me that she would never ask me to do that for her. I reminded her that she hadn't asked, I offered. Still, she wasn't willing to receive help from me. When I think of experiences such as this one, I realize how much damage the charity model has impacted people's willingness to see people with disabilities as capable humans that have the capacity to give rather than be the constant receiver of an able-bodied giver.

Sometimes, I have moments, usually with children, where not being correctly understood makes me smile and appreciate my prosthesis. On this day at work, I walked a mother and 5-year-old son over to a different building to pack a food hamper for them. I lead them up the stairs to some couches. I went and gathered the bags of food and handed them to the mother. They continued towards the door and the child whispered to me: "I saw it", trying not to attract attention from his mother. I whispered back: "oh, what did you see?." With big eyes he said, "I saw your robot leg". I grinned and motioned for him to keep it a secret.

Inspiration Porn

Inspiration porn is a type of microaggression toward people with disabilities. It is an image of a person with a disability, doing something completely ordinary, being used as

inspiration for an able-bodied person to be thankful or pressure to do better (Baran & Jana, 2020). It is a form of objectification.

I grew up in a small city in Saskatchewan. In my elementary and middle school years, I was the only child with a physical disability. This meant that in social situations, I was always aware of my disability. Using some adaptability, I could still do most things, just in slightly different ways. These different ways often shocked the able-bodied people around me. One memory stands out to me. I was in grade one and it was gym period. Our physical activity for that class was to climb a play structure that stood 4 feet tall. The class lined up and one by one each child took a running start and gripped their shoes over the play structure. It was my turn and as the other kids did, I ran for it. The running wasn't a help to me, and I stopped dead in front of the obstacle. I stretched my arms over the top and gripped tightly. I used all the arm strength I had and pulled myself over the box. I looked at the shocked expression on my teacher's face. I did it. It was evident that my teacher wasn't expecting me to succeed. I did it differently than everyone else and I still succeeded. The next class of students arrived, and my teacher asked me to stay back. My teacher led the other class of students to sit in a line in front of the wooden box. As this other class watched, my teacher told me to do it again. I did. The class, like my teacher, was again amazed at my performance. They applauded my ability.

Stella Young, a comedian and advocate of accessibility, was an active and well-known public figure until her death in 2014. In one of her most known speaking contributions, Young spoke of the frustration of consistently being seen as an inspiration to those outside of her family relationships and friendships (Tracey, 2014). To society, she had been objectified, to be a source of inspiration for able-bodied individuals who were not aware of their own biases. Young could pick up on the felt sense of being targeted in this way. Young spoke of what she described as

'good intentions' of the people around her, while also a need for her to truly be seen as a person who deserved equity, not a person who had to put up with patronizing behaviour.

To the untrained eye, inspiration porn is believed to be a positive and uplifting way to support those with a disability. Gagliardi (2017) speaks of the nature of inspiration porn being a form of subtle discrimination because it can easily be mistaken for kindness. Inspiration porn objectifies people with disabilities by celebrating the most mundane of daily activities or that of normal social activities.

I personally haven't found much difference in having to deal with inspiration porn as an adult, compared to being a child. I once worked as an outreach worker who would make up bags of food, hygiene and clothing items for people who were systemically poor. In doing this job, I noticed that I would often get asked if I was a volunteer or a staff member. My confirmation of being a staff member jarred the person inquiring. They would either stumble with their response or respond in a way as to label me as an inspiration for others to follow.

Representation

The type of representation matters. For disabled people, representations in mainstream media have largely been stereotypical characters (Parsons et al., 2017). Characters in films with disabilities are often either made to be the evil protagonist or that of the one to be pitied. Bogdan (2012) echoes other researchers in noticing the link that the horror film industry has always made with disability. When looking closely at horror films, one will notice that character development combines physical and mental disabilities with violence, terror, and murder (Bogdan, 2012).

These stereotypical depictions are also found in Disney and Pixar animation movies. Holcomb (2022) studied twenty of these animations between the years of 2008-2018. Although Disney and Pixar have been applauded for becoming more representative of cultural backgrounds, this is not the case in the representation of disability, whether mental or physical.

Holcomb's thematic content analysis of the movies reveal that those characters with physical disabilities continue to be stereotypes as evil, old, broken, and evoke either feelings of pity or laughter of the disabled characters presented (Holcomb, 2022). This is an issue. People with disabilities make up the largest minority group (Holcomb, 2022) and yet, this population continues to be misrepresented.

Access to children's toys that encompass a wide diversity of representation of body types and abilities is extremely important in diminishing fears related to the unknown. *Mattel* is a well-known American toy manufacturer with one of their most well-known brands being *Barbie*. This brand's goal has been to empower women to become anything they want to be. On their website, Mattel tells us that one of their main priorities is that of representation. It is, therefore, not surprising to see a recent growth in their variety of representation throughout their line of *Barbie* dolls. However, we must remember that Mattel is a business. Its goal is to bring in money and make a profit. The company's first launch into disability representation with their *Barbie* line occurred in 1997. 'Share-a-smile-Becky' was brought in by Mattel not as *Barbie* but Barbie's friend, a photographer and wheelchair user. At that time, *Mattel* wasn't willing to allow Barbie herself be disabled (Ahamed, 2020). The Becky line didn't last long though, as consumers began to realize that the doll could not fit into other *Barbie* accessories, such as the elevator in *Barbie's DreamHouse* (Nast, 2023). Rather than re-making the accessories, Mattel discontinued the doll (Ahamed, 2020). This exclusion still happens today in our real world. Physical accessibility is often seen as costing too much and far too inconvenient to pursue. Years later, however, Mattel decided that Barbie could finally be disabled herself, along with varied diversity profiles in Barbie's 2019 Fashionistas line (Nast, 2023). As a little girl who loved Barbies in my younger years, and now as a grown adult, I am not afraid to admit that I own a Barbie that represents my disability of using a prosthesis. Like I said earlier - Mattel is in it for the money; though they can

boast that their representation has widened - it is quite unequal. Currently, there are three dolls with lower limb prosthesis, meanwhile not one using an upper limb prosthesis.

Barr and Bracchitta (2015) research reveals a possible effect of lack of social representation. These researchers combined the literature available at the time and found able bodied people were more likely to initiate connection with a person of physical disability as compared to those with intellectual and behavioural disabilities. These authors dove deeper into the literature and concluded that contact itself was not the determining factor of positive outcomes. The key to these connections were in the quality of interaction. The more an individual was able to have a personal conversation and connection with the person with a disability, the more they were able to dispel any biases or stereotypical beliefs about those with similar disabilities. What was not mentioned in these findings were the perspectives of those with the disability. Were there parts of the conversations where microaggressions were unintentionally occurring? What direction did the conversation take and who took on more of a leader role in this? By exploring these types of questions, we are allowing ourselves to dig deeper into our possible unintentional ways of interacting with people that have varying disabilities. Furthermore, it is my opinion that, in the spectrum of varying disabilities, amputations are a relatively privileged disability. Although I am pleased that we have made great strides towards people with disabilities being represented within society, not every category is represented.

Identity

It is my understanding that identity is strongly related to our specific social world. These social worlds create stereotypes of people. Black and Hayes (2003) talk of the ‘supercrip’ who overcomes all odds. This identity places an expectation on all people with disabilities to rise above in an individualistic way. The issue with the script of the supercrip is that it ignores our humanity. This humanity is held by both able and disabled bodies. Black and Hayes (2003)

advocate for all humankind to accept the fact that all humans need help – it is not just the 'disabled'.

Heavey (2013) was curious to research how amputees identify themselves, as so much of the medical model has formed the social label of being a disabled person. This qualitative research first explored whether the amputees identified with the label of disability and secondly, what in fact did the amputees believe qualified them to be labelled as someone with a disability. Out of nine participants, one did not mention disability in any form, while the other eight participants utilized the term in sharing their narratives. Heavey (2013) discovered three similar definitions of disability within the participants' stories. Included in these definitions of disability were: personal ability and inability to physically do things, how others viewed their bodies in contrast to how they saw themselves and lastly the participants defined disability as related to an official label whereby resources were granted. Seven of the nine participants proposed that disability was a spectrum. This meaning that, the more activities a person was able to accomplish, the less disabled they were and vice versa. The stories evoked by these participants compared their abilities to their own lived experience, rather than universal measures. Another theme that arose in six of the nine interviews, was that the absence of a limb created a mask of stigma. These participants felt that their outward appearance created a false image of their abilities that was very contrary to how they viewed their own abilities.

We have touched on that not all amputees define themselves as disabled and would therefore argue that they can do anything an able-bodied person can. It is my opinion that this is more true of younger amputees than older amputees. As age deteriorates one's body – the amputee now must psychologically experience a shift of ability, and thus a shift in identity. I think that this shift of identity does not always fully happen right after amputation. I think for some, where their ability isn't impacted too much, this identity shift can happen years later.

As I touched on earlier, I only 'felt' my disability when I wasn't able to do specific tasks/activities. As one is more flexible as a child, added with my stubbornness, those experiences were limited. I could run, hop, play any sport I was interested in. Years later though, it hit me. When I was twenty-five years old, the effects of using a prosthesis set in. I was in tremendous pain and after being checked out, I was told that I had arthritis in the leg that occupied my prosthesis. My surgeon told me that surgery would be near impossible and my only option at this point was to begin to use a cane. In an attempt to soften the blow, he told me that there are a variety of 'pretty' canes on the market. I could get a pretty pink one, if I wanted. The messages I received as a child told me that if I tried hard enough, I could accomplish anything. I had been told over and over again about how much of an inspiration I was because I was independent. It has only been in the last five years that I have realized how hurtful those messages have been. The subtleties of these words told me that my worth as a human being could only be found in rising above the disability. My disability should not define me. In my experience, the two issues with this messaging are: the only way to deal with painful emotions that contradict this messaging is to hide them. Secondly, this messaging creates a disconnect with my body. It tells me that I need to be in battle with my body. It is not my friend nor an ally. It is not trustworthy. It doesn't know how to provide for me.

Socially, people with disabilities have historically been oppressed and viewed as weak, in need of help. In light of my experience, I have often wondered how much of this history plays into people not wanting to be defined in such a way because there may be a fear of becoming the victim, as in 'one of the oppressed' and dependent. Such thought patterns can be recognized in amputees such as one participant of Oxcetin and Seyman (2022) research. One specific participant shared their experience of falling in public:

> Once I was walking on a crowded street with my prosthesis and suddenly fell

> and could not stand. The people came and helped me. It was in that moment when I realized I was disabled. I was very upset, but I did not have the ability to make it better. (p.514)

This story hits home in myself when I too, have fallen so many times. I know the embarrassment and feeling of defeat that follows such a fall. Truth be told though, there is a certain satisfaction when I see an able-bodied person fall to the ground. There's just this sense of human commonality that's shared – even just for a brief moment.

In recent years, disability advocates have been working to reclaim the word 'cripple.' Instead of the term taking on notions of an oppressed people, this term is now a movement towards dignity and people with disabilities being unapologetic of their bodies. This way of looking at disability has become known as "Disability Identity" (Forber-Pratt et al., 2017). It views disability as an identity, just like that of race, gender, and sexuality. This identity of being disabled allows people to find affirmation and helps to make sense of their experiences.

North American urban cities tend to be fast paced. We are busy working. Grabbing food on the go. Checking our phones to see the latest email or notification. Productivity is a god. The more one does, the more value they hold. I cannot live up to that standard. My body will not let me. I used to hold an enormous amount of guilt about not being able to be physically fast enough to keep up with the pace of others. People would walk with me, and I'd spend so much energy trying to keep up with them that any conversation that they had with me only filtered to my brain as white noise. When I realized and accepted the pace my body could handle, I not only found contentment, I found a beauty that is only evident when you slow down. My body was regulated. I felt more confident. I began to know the beauty of real presence with not just myself but others. I believe this concept is parallel to the work of counselling.

Impact of Language

There is a lot of effort put into journeying with someone who goes through amputation. And it is absolutely necessary for these individuals to be supported. In looking through hundreds of article titles, I have found myself troubled by how the term of 'burden' tends to be used. For example, one article is titled: "The global burden of traumatic amputation in 204 countries and territories" (Gu, 2023). Titles like this exist and we wonder why those with amputation don't want to identify themselves as disabled or find it difficult to ask for help. If our disabilities, a piece of our identity, are consistently seen as burdens and afflictions on our society and others, how are we expected to respond? This idea of being a burden comes from the medical model. There is something wrong with someone who is disabled and needs help. To my knowledge, there is very little literature available to understand the psychological impact of feelings of being a burden on someone. Sirois and Voth (2009) were interested in finding out if self-blame was associated with poor adjustment to illness, specifically in their study, in the diagnosis of inflammatory bowel disease. Their study found that poor adjustment was a result of increased avoidant coping, which arose due to self-blame. I wonder if these findings could relate to people who have had amputations due to type 2 diabetes. I suspect that at least some, if not most of those amputees would admit to self-blame as type 2 diabetes is possibly preventable with the right diet and exercise. Based on my own experience of having seasons where I have felt like I was a burden in my family, in my friend groups, and to the medical system, my guess would be that this is something that most people with an amputation struggle with, whether consciously or unconsciously.

Sexuality

The concept of sexuality is quite prevalent when hearing stories of disabled people. The beliefs and values built in the surrounding society are rooted very deeply into human beings. Often, these beliefs, values and biases are not inwardly disrupted until faced with a 'difference'.

Even then, self-awareness can be severely lacking. According to Murray et al. (2017), one of the most prevalent behaviours that people with disabilities have to endure is the notion that people with disabilities are perpetual children. This. therefore, results in able-bodied individuals believing that disabled people don't have the capacity to live sexual lives, among other assumptions of lack of capacities. Furthermore, this notion plays out in two different areas which are: a belief that disabled people don't have sexual anatomy that has the capacity to perform, while also believing that people with disabilities do not also have the mental desire for intimacy and the pleasure of sex. Often, these false assumptions render this group of people as incorrectly being assumed to be asexual (Crowley et al., 2018). This can go as far as to cause psychological turmoil as disabled people are human and still do desire sexual intimacy and pleasure.

Parsons et al. (2017) completed a North American study aimed at evaluating sexual perceptions of disability in media advertisements, and how or if the findings showed a difference between genders. The study proved that there were substantial differences regarding gender roles. On the basis of attraction, women with a disability were rated far lower than that of physically disabled men. Parsons et al. indicate these findings are due to the imaging and societal messages given consistently.

Often the result of such stereotypical thinking is that people with physical disabilities, among other kinds of disabilities, are often overlooked and rejected when trying to initiate romantic relationships. This in turn, affects people's sense of self and can drastically lower confidence levels, while having a strong impact on one's emotional wellbeing. Heterosexual disabled women are at higher risk of being rejected in romantic relationships and this is based on gender stereotypes (Parsons et al., 2017). These researchers also concluded in their study that; heterosexual men have negative attitudes towards the sexuality of women with physical

disabilities. For heterosexual women seeking a partner, this reality could cause emotional distress.

I am single and, in an attempt to meet someone, I joined a dating app a couple of years ago. I filled out the profile transparently, explaining about my prosthesis clearly and directly. After a few months I started chatting with a guy. He shared with me his struggles with anxiety and depression. He talked about how women in his past expected him to live up to some male stereotype that was strong and heroic. After chatting for a few days, we started to make plans to meet up. Then one day I received a message from him asking confirmation that I actually had a prothesis. I answered back with a simple yes. The next day I went into my messages for confirm when we were going to meet up. The messages were gone. I had been blocked. I'm aware of the horror stories of dating apps and still, this experience really hurt me. I saw no problem with a man who struggled with anxiety and depression, while he couldn't accept a part of my body that I have absolutely no control over.

Mazur (2022) was interested in online dating experiences of people that held both identities of being disabled and LGBTQ+. The qualitative data revealed in this study highlighted that online dating platforms typically perpetuate normative ideas in all areas of ability, sexuality, and gender. The data also revealed that many of the participants struggled with timing of disability disclosure. Bennette et al. (2017) researched specifically into the area of disability disclosure in online dating communities. Their research indicated a wide range of ways of disclosure, primarily being based on severity of disability. The severity was based on visible and invisible disability and the data revealed that those with physical disability felt a higher expectation of discloser than those with an invisible disability. Bennet et al. (2017) uncovered that compared to those without disabilities, these participants had to perform additional labour and navigate more complex norms of society in order to pursue personal connection online.

Ageing

McPherson and Wister (2019) argue that in this day and age, ageing adults face a lot of pressure to stay youthful in being physically active, while trying to look younger in any way possible. The capacity to accomplish this diminishes over time and so these ageing adults will often try to soften the blow by comparing each other to their peers, or confine themselves to their homes, isolating themselves from social gatherings. If the average able-bodied ageing adult is reacting in this way, how much more for the ageing adult with an amputation?

In my experience, the process of ageing is a key factor that must be considered when a physical disability is involved. Statistics published by Diabetes Canada (2015) citing amputations in Ontario indicate that the most common age for amputation is 65-69 years of age. In the literature I have come across, there seems to be a lack of research in the psychological impact of the ageing process as it intersects with acquired physical disability. Part of this may be just down to numbers. Disability takes up most of the reason for amputation, which occurs more later in life, so there may not be enough data to compare the process of amputation as it compares to age.

Belsi et al. (2022) conducted interviews with ten lower limb amputees going through the rehabilitation phase of amputation. One of the themes that arose in their conversations was the impact their lower limb amputation had on work and social life. As the prosthesis was new, there were issues with the prothesis not fitting well, causing pain. Adjusting to using a prosthesis is prone to causing fatigue. Thus, many of those interviewed talked about the need to remove the prosthesis to take a break or in order to make adjustments to it. This act of removing one's prosthesis in public is often difficult, due to social stigma. I think that this goes beyond the rehabilitation period. I find myself incredibly stunned when I see others remove their prosthesis for swimming purposes. I am not that brave. For a long time if I shared a room with someone, I

would even go as far as to hide my prosthesis, never mind my leg without the prosthesis. I have memories of being younger and being told to cover my leg up at sleepovers.

Psychological Context

Quality of Life

Casanova et al. (2021) highlight that the influences of quality of life has been extensively researched. The accepted definition of quality of life in literature comes from the World Health Organization (1998) and they define it as "an individual's perception of his/her position in circumstance of the culture and values in which he or she lives and with respect to his/her goals, expectations, principles and concerns." In their research, they noticed a split between what researchers believed to be factors that influenced quality of life. One set of researchers believed that sex, age, type of amputation and duration of time since surgery all influenced quality of life, while others argued that these factors did not influence quality of life. According to Casanova et al., these researchers did agree that both pain level and mobility level played a large role in amputee's quality of life.

Body Image

Blaszczynski et al. (2021) raise the point that although bodies have the potential to change when faced with health problems, body image itself is a relatively undervalued topic of research. Cool et al. (1995) were interested to research how much of a role body image and perceived social stigma could predict one's psychosocial adjustment to lower limb amputation. Their research concluded that body image was a considerable factor in how well one adjusted after a lower limb amputation. Even when considering other factors like age, time since the amputation, and social support, body image still played a significant role. Perceived stigmatization by society also affected how depressed people felt, however, it wasn't as important

for other aspects of adjustment.

Depression and Anxiety

Qualitative interviews with twelve participants were undertaken by Oxcetin and Seyman (2022) in Turkey and although there may be cultural differences, I believe there is reliability in what came of their research. The experiences of these twelve individuals can shed some light on the internal processes that have the potential to occur after lower limb amputation. The mean age of these participants was 61, with an average variation being 10 years older or younger. Three themes emerged in the interviews. The participants compared their physical abilities, before and after amputation. Loss of physical function caused most participants to feel as though they were losing control over their life. This is the first theme that emerged in the interviews. This perceived loss of physical function created high levels of both grief and regret. The second theme that emerged from the study was dreams vs the new reality of life. All participants talked of a desire to continue their life in a similar manner to which they had prior to surgery, and all participants found that this was not possible for them. The third theme to arise had to do with their future perceptions. This data revealed that the effects of lower limb amputation can dramatically lower self-esteem and create negative perceptions of the future. The human condition of vulnerability arose in many of the interviews. Participants faced uncertainty of their future due to being far less independent after lower limb amputation. It is worthy to note that these interviews were taken at least six months after amputation. One participant shared vulnerably:

> There is an unknown process in front of us. I cannot be sure how I can cope with all these changes and what life will bring, but it is certain that after lower limb amputation, nothing will ever be the same. I guess, I will not even work with the excitement and the motivation I had before. (p.

515)

In an investigation by Hunter et al. (2007), data concluded that anxiety and depression upon admission for surgery dropped shortly after amputation and lowered even more after inpatient rehabilitation. In a similar study, Hunter et al. (2009), levels of anxiety and depressive symptoms were high after amputation, then during rehabilitation the levels dropped to nearly zero, then rose again after being discharged. Based on these findings, these researchers recommend that physicians be following up on lower limb amputees' psychological process in the similar way that amputees have their prosthesis looked over.

A study by Abdel et al. (2022) aimed their study at identifying whether level of amputation influenced psychological morbidity. Their study revealed that those who were getting their leg amputated below the knee were more anxious than those who were having above the knee amputation. The data in depression scores were similar in both groups.

I strongly believe that anxiety and depression in amputees are underreported. As someone who uses a prosthesis, much of the messaging given to me has been that of moving forward and 'getting over it.' And as much as I understand a piece of this, I also understand that amputation is a huge adjustment. My heart drops when I read words from another amputee: "*I say to myself, it is over, but its marks never gone, I am still trying to walk. I lost everything. It is really hard to be dependent, be in need of someone, even for very simple things. I wish I could have my leg"* (Oxcetin & Seyman, 2021, p. 514).

Financial Resources

The use of a prosthesis can causes pain and fatigue and the simple need to remove the prosthesis to make adjustments can affect employment. Workplaces give only so many sick days, and for the prosthesis user – the person is either using those sick days or taking additional time off work.

Approximately a year ago, I applied for permanent disability to receive PWD (person with disability) provincial financial assistance. I have never felt more dehumanized and backed into a corner. In 2021 I made one of the toughest decisions of my life. Due to feeling unsafe at my workplace, with no support from their Human Resources department, I left my job. The act of quitting a job may not seem significant, however, it is a different story for someone with a physical disability. The workforce can be arduous for those with a disability. The law prohibits employers from asking about someone's disability. So, for those with a noticeable disability, to get any sort of chance of getting a job, one has no choice but to disclose specifics of their disability to the workplace. Then logically, most workplaces will not hire the person because their disability may result in the workplace having to adapt to the employee. Employers, in a capitalist world, do not often choose this route as it will cost them time and money. Of course, to prove this is nearly impossible. Being an amputee doesn't automatically mean that you can't work. Visible disabilities, however, disclose social prejudice that can often dramatically limit one's possible job opportunities. As with other visible disabilities, those with amputation are often viewed as disabled socially, however, one may not qualify for disability income assistance. Areheart (2015), based in the United States, places the topic of persons with disabilities as a 'Goldilocks dilemma' that was created by the systems in power. The premise of the 'Godlilocks dilemma', as it pertains to disability, is the idea that those in power create such narrowing definitions of disability that a person only qualifies under certain circumstances. The situation in Canada is similar in the legalities. For a person with a physical disability in Canada to be eligible for PWD, the person must adequately fill out a form, with their doctor, indicating one's abilities. The majority of the questions are based on ability within one's home and under the best of circumstances, i.e.: walking on level ground. To say that a person is able to work if they can get dressed without help, does not equal the ability to work in a capitalist society. This system also

does not consider the prejudice people with disabilities face when applying for jobs. This system of financial support creates the Goldilocks dilemma, which in turn, has the potential to create psychological distress in the person with the disability. Individuals with physical disabilities are forced to either go beyond what is physically possible for their bodies to endure over a longer period of time, or they need to be the stereotypical disabled person who is completely dependent on others and the system. As Goldilocks would say it - the disability needs to be 'just right'.

DiMario and Petlock (2021) bring forward the issue of inadequate funding concerns of Canadian amputees who are able and in need of a prosthetic limb. They argue that provincial health care coverage is not sufficient. A common experience for me, as an amputee, is my need for socks, for use in my prosthetic leg. The socks on average cost $30 each. BC MSP coverage will only cover the cost of twelve socks in a year. In the summer months I need to change my sock two or three times daily. I live a low to medium active lifestyle and those 12 socks, will wear and tear within three to four months. When I do not replace these socks often enough, I am at risk for bruising, sores, and painful skin irritations that can sometimes even cause me to limit how much I wear my prosthetic as these wounds heal. As DiMario and Petlock (2021) recognize that the coverage given in each province is grossly uneven and often inadequate when practically surveying the daily needs of a prosthetic user, they reveal that once again, as many systems do, there is a total lack of research being done to understand the needs of amputees.

Resources, grants and financial programs are often selective and require a person to persist through a lot of red tape or they seem to have requirements that are unfair. For example, I have always had a disability, and I have not always qualified for financial help. For many years, I chose to work part-time, instead of applying for disability assistance. This meant that I did not qualify for the BC bus pass program. It seems as though there is no incentive for people that could work – to work. However, the amount of money given for disability assistance in BC does

not cover living expenses, forcing many people with permanent disabilities to work, with of course having a limit to how much one is allowed to work.

Social Support

In Canada, one of the most prominent supports for amputees is an organization called the War Amps. This non-profit organization offers financial support for prosthetic limbs and practical information for those going through amputation surgery. The War Amps are known for their encouragement to young amputees. In an effort to support those with amputation, their pre-covid activities included seminars and the chance for amputees to be ambassadors to the War Amps *play safe* message on parade floats across the Nation. I appreciated being a part of these activities in my younger years. As I had not had much experience socializing with other children with disabilities, it was comforting to be seen as 'normal', or at least, not abnormal. At those gatherings, social stigma didn't exist, and everyone felt like they belonged.

In researching for this capstone project, I contacted disability organizations that were specific to amputation. These included: the War Amps, Amputee Coalition of Canada, and Amputee Coalition of BC. I received one of two responses from each organization. The first was no response and the second was being sent to another organization, only to be returned to the same organization. This experience is similar to experience's shared at the Vancouver Newcomer's with Disability forum held in November 2022. There were 91 participants in this forum and one of the key barriers reflected in the experiences shared was a lack of awareness of what resources existed and how to access them. This lack of awareness not only existed in newcomer organizations but disability organizations themselves. Many of these newcomers were told to 'google it yourself' or were overwhelmed with a lengthy list for them to sift through themselves. I have also noticed a common thread amongst disability websites. There is a severe lack of resources given for counselling help. If there are resources given on the organization's

website, it is incredibly broad and unhelpful. There seems to be an assumption that family doctors, prosthetic workers are connected to the counselling world. They often, are not.

I have always felt the most comfortable about my prosthetic leg in the buildings where I have had my prothesis' made and repaired. It has always been a public space where I have never feared being seen without my prosthetic leg on. I easily take it off, find myself a chair with wheels, and I'm off. I could never do this in a grocery store, my university building or even a friend's house. I have often heard people argue with the term 'normal', and to me it just means a person is in the majority. My body is normal when I'm in a space with others like me and there's something tremendously healing and freeing about this.

Anderson (2017) et al. examined the impact perceived social support had on daily living and depressive symptoms throughout the first year after lower limb amputation. Their findings revealed that those that had low mobility in performing daily tasks combined with low social support were more at risk of depression.

A study by Yang (2000) collected data from 1986 to 1992 and found that for patients who have amputation surgery later in life: having a confidant, satisfaction with their support network, a sense of control and self-esteem all played a mediating role in depressive symptoms.

As a receptionist at a nonprofit, I quickly learned that there is a lack of support for those with physical disabilities. Specifically, accessibility to get resources is quite non-existent. I used to have quite a few calls from people who were housebound due to having a fall or recovering from surgery. Many of these individuals were told to go to Red Cross to get the equipment to help aid and keep them safe. Those who don't have family, friends or extra income can severely struggle in receiving the support they require.

There was a severe lack of emotional support for my experience of growing up, using a prosthesis. I understood the messaging of positivity and acceptance of the use of my prosthesis,

however, there had not been made space for grief of the things I could not do, and no room for sitting with the discomfort of living in an ableist society. I was told repeatedly that I could do anything I wanted. In season, and for a season, all I wanted was support to grieve and be seen for how difficult it is to have a prosthesis, not as a form of pity but as a deep acknowledgement that living with a prosthesis wasn't going to be easy, but that I could be given the freedom to express the battling emotions within. Many of the organizations that deal with the physical needs of disability will either not mention the psychological element related to disability, or they will casually suggest one attends counselling. This issue with this is that the common counsellor with a master's degree has very little training on how to journey with someone with a disability.

Summary

Overall, chapter two of the capstone reviewed literature about physical disability as a whole, as well as how it is experienced as someone with a lower limb amputation. The capstone literature first looked at amputation as a disability from the biological/physical perspective. According to the scholarly resources, phantom pain and back pain were highlighted as being physical difficulties that amputees often have to endure (Döring et al., 2021). Briefly, the medical model was discussed as a problematic way to view disability as it views disability as something that needs to be fixed and that the problem lies in the individual (D'Angelo & Eiler, 2020). Next, the literature review looked at disability and amputation specifically from a social perspective. Oppression in the forms of stigmatisation, ableism and microaggressions were explored. Inspiration porn, a term coined by Stella Young, can be viewed as kind, and encouraging; however, it is problematic as it objectifies people with disabilities (Tracey, 2014). Poor representation in mainstream media has influenced and helped to maintain ableism. In recent years, however, there has been a growth of representation. One particular study's (Heavey, 2013), examinations of amputees' definition of disability and their use of identifying as

disabled discovered the majority of the participants only identified with the term disability as a way to have access to resources. The idea of reclaiming the word *cripple* was briefly discussed as something that could have a positive impact on those with disabilities. Observation of the concept of the amputee being labelled a burden upon their loved ones was suggested to be problematic. Furthermore, conversation around sexuality and online dating were explored. People with disability are often not seen as sexual beings. The literature reviewed what it is like for people with disabilities and those who also identify as LGBTQ+ to go online and have to put effort into fighting norms of society and often struggle with the element of having to disclose their disability (Mazur, 2022). Ageing is also another intersectionality that can create more complexities in how the individual deals with coping with losing a lower limb. Grief and loss seem especially difficult for this group of amputees. Within the psychological context quality of life and body image were explored. It was found that researchers don't agree on many of the factors which influence quality of life, however, they do agree that pain and mobility does influence quality of life (Casanova et al., 2021). Body image was found to play a significant role in an amputee's psychosocial adjustment. The literature on depression and anxiety suggested that levels of anxiety and depression rise and fall while in the hospital, and upon returning home, the levels rise again. It was suggested that physicians need to maintain more follow-up appointments with amputees to keep an eye on depression and anxiety levels (Hunter et al., 2009). In terms of financial resources, it can be difficult for amputees to return to work as there remains stigma mixed with new needs stemming from the amputation. Government disability funding can be dehumanizing and difficult to qualify for as disability definitions are quite narrow. Health care coverage across Canada is lacking for those with amputation. The War Amps is a Canadian organization that has filled in the gaps of financially covering the needs of amputees across the nation. There seems to be a large gap in psychological support in the disability community,

particularly those with amputation. Research into the benefit of social support of amputee has found that amputees who are connected and feel a sense of support help to moderate symptoms of depression (Anderson, 2017).

The grief and loss associated with acquired lower limb amputations is only one part of the experience of the amputee. Social awareness of disability stigma continues to be an issue for those with lower limb amputations. It is my opinion that representation, openness to talk about the experiences of this group of people, openness to change microaggressive behaviour, an increase in social supports, and proper education of counsellors are all key components in getting to the root of this concern.

Chapter 3: Discussion and Application

Summary of Findings

Diabetes accounts for 70% for amputations in Canada (Diabetes Canada, 2023). From the biological point of view, amputees often struggle with phantom pain and back pain. Socially, people with amputation can find themselves struggling to identify as disabled because they've simply found different ways of doing things they use to do. Those with physical disabilities also can find it difficult to take on the identity of 'disabled' because for so long, much of society has allowed stigma and microaggressions to be rooted within our environments. Problems with accessibility mean people with disabilities don't take part. Stereotypes of the supercrip and the helpless one have created unnecessary pressure for the person with a disability to be someone they are not. Individuals who cannot fit into the needs of the workplace are forced onto a financial disability system that only further oppresses them by adding poverty to their life's challenges. Yet slowly changes are being made. More honest representations of disability and amputation have been made. For decades, the War Amps have made up for the financial disparities of provincial health care systems. Taking all these areas into consideration, in this chapter I will share some implications for clinical practice and make some recommendations for clinical practice and society.

Implications for Clinical Practice

The work of a counsellor has both an ethical and legal responsibility to provide care that doesn't harm their clients (Canadian Psychological Association, 2024). Social stigma and beliefs regarding disability have been emphasized in the literature review as being harmful for the individual with a disability. The counsellor must be self-reflective and eager to change any

biases and unjust beliefs they may hold about people with disabilities. In not doing so they will be doing harm to their client.

Disability is a vast topic and even when you narrow it down to amputation, it is still a complex issue. A counsellor with a client undergoing amputation may need to advocate more for them compared to an able-bodied client. Especially in the post-amputation phase, the counsellor needs to be prepared to talk through and advocate for any support needed in being able to get back to socializing, avoiding the temptation to be isolated from support.

Counsellors who desire to work with people who have disabilities may have to take a pay cut by either working in a non-profit organization or by incorporating sliding scale pricing into their private practice. Currently in British Columbia, counselling services are not a mental health service that is covered by BC's medical service plan. For the client on *Person with Disability* government income, the cost of the commonly priced counselling sessions is completely out of the question. This is something a counsellor should be aware of and act according to one's privilege while also acknowledging the monetary value of counselling.

Recommendations for Clinical Practice

One recommendation for counsellors is to attend training courses and workshops led by people with varying disabilities. It is important to integrate multiple experiences of the disabled community to get a clearer understanding of the spectrum of disability that exists. This idea also gives the opportunity for counsellors to learn about varying intersectionalities and the possible impacts on a person with a disability. By attending these training courses, counsellors are then given the opportunity to self-reflect and grow both professionally and personally. Deroche et al. (2020) researched disability competence, disability-related life experience and multicultural course completion with master's level counselling students to find out more about the relationship between them. The study found that having personal experience with disability

predicted competence in counselling people with disabilities. It is also interesting to note that the research also revealed that taking a course about disability only helped improve master level students' self-perceived knowledge, not skill in counselling people with disabilities. Whereas experience with disabled people creates an opportunity for a counsellor to be more self-aware and skilled in working with this population. Based on these findings, it is recommended that counsellors further their experience with disabled people by taking part in advocacy work.

At all levels of one's journey of being a counsellor, supervision is one of the key factors in ethical practice. We are human beings. Even after self-reflection, we don't always see our mistakes and biases. With good rapport, the counsellor is willing to receive feedback on possible errors in microaggressive behaviour or ableist beliefs. Good supervision can then help the counsellor in their continuing journey of cultural competence.

As this capstone project focuses on disability as an identity, it is important to remind the reader that disability is only one part of a person's identity. It is, therefore, crucial for rapport building that a counsellor invites the client to talk about their identity as a person with a disability in their own time. Only seeing the client as a disabled person is a microaggression on its own and should be avoided as to not harm the individual.

Lastly, there is currently little research into what modalities may be most beneficial for those with disabilities. However, I would recommend group counselling for those with amputation. There is some research on the benefits of support groups for people with disabilities. Although this data seems to be positive, I recommend that trained counsellors are present and leading the group sessions. I am cautious of solely peer lead support groups as amputation could be traumatizing for some individuals, I believe that having a professional in charge is an ethical decision that should be made on behalf of the amputee. Group counselling could go a long way in creating a supportive environment where the experience of amputation is 'normal', thus de-

stigmatizing the situation. Furthermore, group counselling can be a way for amputees to be social in a safe environment, being able to discuss practical issues such as caring to one's stump, relationship challenges, concerns of sexual functioning, and the range of differing emotions as one settles into their new identity (Bauman & Shaw, 2016).

Recommendations for Society

At the Micro Level

As North American society is quite ableist in its societal beliefs and policies, one recommendation, at a micro level, begins with the individual. In order to understand that one's beliefs are indeed microaggressions and stigmatizing to those with disabilities, one must be willing to admit to these errors to sufficiently change future behavior, thereby destigmatizing the person with a disability. One of my most recent personal experiences with this occurred with my internship supervisor. Early in my internship, we chatted about my capstone topic. I explained to her a recent experience I had in class. There had been a joke said in class about losing one's ability as one ages. I went on to tell Marla[1] how cringeworthy it was for me to sit amongst a class of counsellors in training, laughing at an ableist comment. Marla commented on how hurtful it sounded and how that moment could have served as a beautiful moment for me to speak up and bring awareness to such an overlooked comment. The week after this conversation, we met for group supervision. Marla and 3 interns were present. This meeting was the last for one of the interns. In the last minutes of our time together, Marla turns to the intern leaving and says something like: "Well, we have enjoyed having you and will miss all that you bring to our group supervision sessions. We will limp along until others join us." In my next individual supervision

[1] Permission has been granted by Marla McLellan to share this, via verbal and email consent.

session, I knew I had to bring it up. Although we had a previous conversation about the need for microaggressions to be brought into the light, I was extremely nervous. I had previously tried to make others in my life aware of macroaggressions I have witnessed, only to be told that they meant no harm, so I should have kept quiet. Thankfully, my nervousness was evident, and Marla called me on it. I began the conversation asking her what she meant by the statement, 'limp along.' Marla explained and we both were quiet. Marla groaned aloud. She invited me to say what I needed to say. I explained how sayings like that were at their core, ableist. She agreed and could easily and openly acknowledge her mistake. What was extremely helpful for me in this situation was Marla's willingness to own her mistake, not justify it by disregarding my view of it. For Marla, what helped her was how I approached the conversation. I asked her to explain further, instead of jumping on her with judgement. I genuinely believe that ableism could be eliminated if we were all willing to engage in tough conversations in this way.

Using Our Collective Voice

People with disabilities and their allies need to join forces to advocate together. I have often wondered how LGBTQ community has been able to join together and receive such support when the disability community hasn't been able to gain as much traction. Perhaps the needs of both groups are drastically different. Nevertheless, we as a community of differing disabilities need to join together as one whole unit and support each other, rather than splitting ourselves into small minorities.

In the literature review I covered the importance of representation. To receive representation in our society, we must act. For instance, in the literature review I brought up the accessibility of *Barbie* dolls with disabilities. As Mattel makes a profit on merchandise, they are going to make decisions on what's represented based on demand for the product. As a society, we need to start expecting and asking for products of disability representation. According to

Mattel, they were flooded with requests for a Barbie with hearing aids, and in 2022 she was released (Ford, 2022).

The Workforce

Research by Brisebois et al. (2018) indicated that for people with a disability, the more severe the disability, the less likely the ability to work. Their research also found that only 3 out of 10 people with a higher disability rating could hold down a job. Furthermore, of the most able-bodied individuals with disabilities, men held higher rates of employment within every age group as compared to women. As holding a job creates meaning and purpose in one's life, it is essential that the government place more supports and incentives in hiring people with disabilities. It is also necessary for the workforce to see value in hiring someone with a disability, and choose to allow people to fill the roles they are skilled in, instead of assuming that all people bring the same skills into a job.

Policy Upgrades

In Canada, many of the systems and organizations that are put in place to help people, lack communication with each other. This may be due to privacy concerns, however, these systems of operation should be rectified in order to lessen, rather than increase, stress levels of the population to which they serve. A simple example of this is when I had to quit my job, my employment insurance took 6 months to get processed. During this waiting period, I was not allowed to apply for persons with disability assistance until I was paid out by employment insurance. When I applied for persons with disability insurance, the application took an extra 4 months to be processed. I am privileged, I survived using what little I received from student loans, my income tax return, holiday payout and a little from friends.

People with disabilities live in poverty that is severely imbalanced (Berrigan et al., 2022). Consequently, it is recommended that the financial needs of people with disabilities are

reassessed. Along the same lines, Canada needs to reconsider provincial differences in healthcare coverage all across the country. Furthermore, in making these changes policy makers need to recognize that people with disabilities need to be a part of the conversation, otherwise policies are not serving or protecting those they set out to.

A Network of Communication

Organizations like the War Amps and the Amputee Coalition of Canada, need to be communicating so that they are doing best by the amputees that they serve. Being sent back and forth for information is frustrating when someone is of good mental health, never mind the amputee who is struggling to settle into a new identity. Opportunities for these organizations to hire qualified counsellors for their sites would also eliminate the need for amputees to have to stress over finding counsellors through other means.

University Education

The multicultural lens includes that of the identity of disability. Although this has been added into resources such as university textbooks, Emir Öksüz, and Brubaker (2020) argue that the information provided for training is largely based on the medical model. This is extremely troublesome as it sees disability as a deficit and something to be fixed. These researchers go further to argue that disability training that splits disabilities up into their small labels, such as blindness or deafness, is a continued reflection of the medical model. I have not seen this displayed at City University; however, I did witness preference given to other minority group training. It saddens me because, I think to some extent, training seems to be parallel with what's cutting edge and popular in our society. Therefore, I recommend that universities revisit how they train counsellors to work with people with disabilities and how much time they put towards teaching about disability. Ideally, I would recommend that there be a full 8-week course on

disability. This would be enough time for students to digest the information and have meaningful conversations about the content.

Professional Development

The following are some recommendations for current and new counsellors.

I recommend making intentional time to listen to stories from people with disabilities. This could be watching a video, listening to a podcast, or initiating a one-to-one conversation with someone who has a disability. If it is the latter, be clear in your intention of wanting to know more about their perspective and the lived experiences they've been through.

I recommend making time to reflect on your belief about disability. Ask yourself where these beliefs come from. Ask yourself if any of those beliefs are problematic. Reflect on interactions you've had with differing disabilities. In this process, be both kind and honest with yourself.

When given the opportunity, I recommend choosing to interact with people of differing abilities. Furthermore, take part in social events and advocacy. Take part in red shirt day - a day of being in solidarity with those with disabilities.

Lastly, I recommend creating day/weekend workshops to further education counsellors on the several nuances of working with people with disabilities. As each disability brings its own set of knowledge needed, it would be good to bring in people with those specific needs to share their stories, to further ground the knowledge given. Allowing a space for discussing practical ways of engaging with people who have certain disabilities would be beneficial to the rapport of the counsellor and client. For example, I have had clients with brain injury and in some cases, it is necessary to create a different way of communicating with one another. With one client I was seeing over zoom, we discussed her struggle with staying focused on one train of thought. Together, we figured out that when I noticed her thoughts wavering, I would wave my hand in

front of the camera. Workshops could be a place where counsellors could come together to discuss the practical ways to solve issues that arise due to differing disabilities and normalize that. Workshops could also give an opportunity for role play, as some counsellors may be uncomfortable or nervous about interacting with certain disabilities.

Conclusions

In chapter 1 of the capstone, information was given to begin to name some of the difficulties that arise in an ableist society, specifically for those with amputation. Introduction to the physical, social, and psychological perspectives of disability was introduced. It was stated that social environments strongly influence the psychological impact of lower limb amputation. As amputations are on the rise, due to diabetes being on the rise, attention needs to be given to this situation to better support those with amputation. In chapter 2 of the capstone I introduced literature that highlighted experiences of those with amputation. From the physical perspective, back pain and phantom pain both tend to be stressors in the lives of amputees. From the social perspective, stigma and ableism adds burden on those with disabilities. For the amputee, identification of disability is personal and can occur at separate times in their personal and social life. Next, in chapter 2 I reviewed literature pertaining to the psychological perspective of amputation. Finances were found to raise issues for the amputee. Neither the workforce nor the government's disability income is at a place where those with disabilities are being treated with dignity. Social support was found to have a moderating effect on depressive symptoms. However, much of the support for amputees is only within the time of amputation. There is a need for more long-term support given. Lastly, there seems to be a gap in psychological support that should be acted upon. In chapter 3, I purposed long term goals in the areas of change in society's beliefs towards those with disability, using our collective voice to push for more representation, a change in workplace hiring practices, and policy changes that would decrease

the amount of red tape a person need to persevere through to justify their disability. Lastly, I recommend disability workshops for counsellors to learn more about their own biases and how to work with differing disabilities in a dignifying way.

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