

The Experiences of Adults with an Upper Limb Loss/Difference

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## Abstract

Living with a congenital upper limb difference or an acquired upper limb loss is a complex and challenging experience. Physical, psychological, social, and economic barriers can lead to decreased quality of life and well-being. To understand the challenges faced by those living with an upper limb loss/difference (ULLD) and subsequently improve their quality of life, the perspectives of these individuals must be explored. Thus, the purpose of this research study was to describe the essence or meaning of everyday life for persons with ULLD. Five participants shared their experiences of living with ULLD with the researcher. Approval from the Research Ethics Board was obtained prior to the recruitment of participants. Descriptions were analyzed according to Giorgi's descriptive phenomenological method as described by Giorgi & Giorgi (2003) and Aquino-Russell (2006). The Canadian Model of Occupational Performance and Engagement was utilized as the theoretical framework (Polatajko, Townsend, & Craik, 2007). The core finding of the study was: *Acceptance is marked by cognitive well-being and influenced by the environment. Stereotypes present challenges to well-being; however, defying stereotypes imparts feelings of pride. Peer support is desired among persons with ULLD but is found wanting. Completing difficult tasks often requires determination and modification. As well, aging introduces new concerns for some individuals with ULLD. Finally, the prosthesis is viewed as either part of the person, part of the environment, or a combination of both.* This study provides valuable information to expand understanding and inform future practices, policies, and research, with important implications for helping individuals with ULLD.

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# Chapter 1

## Introduction

### *Justification for the Study*

Limb absence is a condition characterized by the loss of a limb due to either congenital anomalies or amputation. Second to congenital heart disease, limb differences are one of the most common defects found at birth (Tayel et al., 2005). Genetic abnormalities, environmental factors, and gene-environment interactions can all lead to a congenital limb difference (CLD) (Ephraim, Dillingham, Sector, Pezzin, & MacKenzie, 2003).

The prevalence of CLD is well-recorded globally, with rates varying between countries. Upper limb congenital differences are more common than lower, occurring at a 2:1 ratio (Vasluian, Van Der Sluis, et al., 2013). In Japan, approximately 4.15 per 10,000 infants are born with CLD, with a higher incident of upper limb differences than lower limb differences (Mano et al., 2018). For the time period from 2010-2014, the United States (U.S.) reported CLD prevalence of 5.15 per 10,000 live births (Mai et al., 2019). From 2004-2006, the prevalence rates of upper and lower limb differences in the U.S. were 3.49 and 1.68 per 10,000 live births, respectively (Mai et al., 2019). Finally, from 1980-2012, Alberta, Canada recorded a prevalence of 5.6 CLD per 10,000 total births (Bedard, Lowry, Sibbald, Kiefer, & Metcalfe, 2015). Of these, 63.9% involved only upper limb anomalies, 25.3% involved only lower limb anomalies, and 10.8% involved both upper and lower limb anomalies (Bedard et al., 2015). Thus, CLD affects individuals worldwide, with most cases involving an upper limb difference.

Acquired limb loss refers to the amputation of a limb, a practice dating back to ancient times with descriptions of the procedure appearing as early as the first century Common Era (Sachs, Bojunga, & Encke, 1999). Traumatic limb loss can be disabling for individuals and have devastating effects on their health and well-being; thus, amputation is regarded as a last resort. Amputation is utilized only under the circumstances of severe illness or injury wherein the limb cannot be saved.

Acquired limb loss affects millions of people globally, from all walks of life. Despite global recognition of limb loss as a significant health issue, not all countries track limb loss information (Ephraim et al., 2003). Thus, global limb loss prevalence rates remain difficult to ascertain. Furthermore, most research focuses primarily on lower limb loss, thereby impeding the assessment of upper limb loss and total limb loss statistics. In 2005 in the U.S., a total of approximately 185,000 upper and lower amputations occurred annually (Ziegler-Graham, MacKenzie, Ephraim, Trivison, & Brookmeyer, 2008). Additionally, an estimated 1.6 million individuals from the U.S. live with the loss of a limb; this number is expected to increase to 3.6 million persons by 2050 (Ziegler-Graham et al., 2008). In Australia, approximately 8000 lower limb amputations are performed annually; this number has not decreased despite targeted interventions introduced by the national government (Dillon, Fortington, Akram, Erbas, & Kohler, 2017). In 2013 in the Netherlands, the incidence of lower limb amputation was found to be 8.8 per 100,000 persons, unchanged since 1992 (Fortington et al., 2013). Finally, in Canada, an average of 22.9 per 100,000 persons have undergone lower limb amputation (Imam, Miller, Finlayson, Eng, & Jarus, 2017).

In developed countries, the number of persons living with a limb loss is expected to increase substantially (Ziegler-Graham et al., 2008). This trend is a reflection of the longer life expectancy of these populations (Sarvestani & Azam, 2013). The number of amputations performed increases with age bracket, as the elderly are more susceptible to developing illnesses, such as dysvascular conditions, leading to the need for amputation (Sarvestani & Azam, 2013).

Despite the increasing rate of acquired limb loss and the significant prevalence of CLD, the body of literature surrounding limb absences is wanting. Notably, due to the greater occurrence of upper CLD and the inadequacy of literature surrounding acquired upper limb loss, additional research regarding upper limb absences is necessary to better understand how to improve the well-being of these individuals. Therefore, this research endeavours to address these gaps and expand knowledge on the effects of living with an upper limb loss/difference (ULLD), which can subsequently aid in improving overall quality of life for persons with ULLD.

Research demonstrates that individuals with CLD are at increased risk of impaired psychosocial functioning and subsequent lower quality of life (Michielsen, Van Wijk, & Ketelaar, 2010). Similarly, research shows that losing a limb has severe physical, psychological, social, and economic consequences for individuals (Knežević et al., 2015). These effects are dynamic and interrelated, influencing one another. A higher prevalence of mental health issues, such as anxiety and depression, has been correlated with acquired limb loss (Bhutani, Bhutani, Chhabra, & Uppal, 2016; Østlie, Magnus, Skjeldal, Garfelt, & Tambs, 2011). Due to factors such as body image anxiety and decreased self-esteem, social functioning is yet another challenge faced by individuals

(Horgan & MacLachlan, 2004). Additionally, stigmatization, both self-imposed as well as from society, further influences one's social functioning (Murray, 2005). Finally, living without a limb can have devastating effects on the economic status of individuals. The loss of a limb can result in a long delay before returning to work as well as difficulty finding appropriate jobs (Schoppen et al., 2001). Furthermore, prostheses are quite costly, potentially adding to the financial strain experienced by those with a limb absence if adequate insurance coverage is not present (Chini & Boemer, 2007; P Gallagher & Maclachlan, 2001). Due to these factors among others, living with a limb absence can be very challenging.

Quantitative research has investigated the physical and technical aspects of ULLD, producing valuable statistical information regarding these factors. However, to gain a full understanding of the experiences of individuals living with ULLD, the psychological, social, and economic issues must be examined as well. Thus, a descriptive phenomenological approach will be used in this study to uncover the meaning of the experiences of those with ULLD.

### ***Methodology***

Descriptive phenomenology endeavours to describe the essence of life for persons who have experienced the phenomenon of interest (Creswell & Poth, 2018). This methodology emphasizes understanding individuals' experiences and the meaning they ascribe to them, rather than attempting to explain or theorize. Descriptive phenomenology embraces a holistic and non-reductionist view of the person (Giorgi, 2012). Acknowledging the interconnectedness of physical, mental, spiritual, and

environmental factors aids in developing a comprehensive and detailed description of the essence (or meaning) of a phenomenon. To further accentuate the significance of these factors, the Canadian Model of Occupational Performance and Engagement (CMOP-E) was utilized as the theoretical framework in this study; this model also embraces a holistic view of the person.

Researchers utilizing a descriptive phenomenological approach reject the notion of a subjective-objective dichotomy, acknowledging both the existence of multiple realities (subjective) and the existence of a common meaning (objective). Through collection of data from participants (subjective) and the subsequent generation of common themes (objective), phenomenologists have the capacity to provide great insight into the very nature and essence of a phenomenon.

The ability to provide such insight using a phenomenological approach is especially important in health care settings. In the health care field, patients' voices are often obscured or undervalued (Brown, Sorrell, McClaren, & Creswell, 2006). The use of a phenomenological approach, however, ensures that the voices of individuals are heard, and their perspectives shared. Additionally, insight into the shared experiences of patient groups can provide therapists and other health care providers with valuable information to expand understanding and inform future practices.

### ***Purpose of the Study***

Living with ULLD is a complex and challenging experience. Physical, psychological, social, and economic barriers can lead to decreased quality of life and overall well-being. To understand the challenges faced by those living without a limb

and subsequently improve their quality of life, the perspectives of these individuals must be explored. Thus, the purpose of this descriptive phenomenological study is to describe the essence, or meaning, of everyday life for adults with ULLD.

### *Summary*

This chapter introduced the phenomenon of interest and provided a justification for the study. Additionally, the chapter described the methodology chosen to guide this research, along with philosophical assumptions. Finally, the purpose of the study was stated. A review of extant literature follows in Chapter 2.

## Chapter 2

### Literature Review

#### *Introduction*

The literature surrounding limb absences is primarily quantitative in nature. This important research has detailed various topics of interest such as the surgical guidelines for individuals requiring amputation, the underlying mechanism of prosthetics, and the statistics surrounding the demographics of those living with a limb absence. Although quantitative research has focused primarily on the physical, statistical, and technical aspects of limb absences, some quantitative studies have endeavoured to explore the psychological and social effects of living with a limb absence as well. For example, Montesinos-Magraner et al. (2016) utilized cross-sectional surveys to investigate psychosocial aspects of life for adults who had experienced lower limb amputation during childhood or lower limb congenital difference. The authors found that most adults were able to maintain stable jobs and live independently (Montesinos-Magraner et al., 2016). However, 43.75% of participants reported considerable discomfort in situations that involved revealing their body (Montesinos-Magraner et al., 2016). In another quantitative study, researchers explored the relationship between level of upper limb loss (e.g. below versus above elbow) and psychological well-being (Kearns, Jackson, Elliott, Ryan, & Armstrong, 2018). Results demonstrated that the level of upper limb loss was significantly correlated with vulnerability to developing post-traumatic stress disorder and intensity of emotional reaction to their limb loss condition.

These studies provide valuable insight to the psychosocial challenges faced by individuals with a limb absence and identify relationships between variables that can help predict behaviours and outcomes. However, what are the meanings underlying these trends as they relate to the individual? Quantitative researchers may speculate on these meanings, but qualitative research provides a true opportunity to explore a phenomenon and its meaning for those who have experienced it firsthand.

To gain a comprehensive understanding of the current literature pertaining to the psychosocial effects of life with ULLD, a literature review for qualitative studies on the matter was conducted in April 2019. PubMed, Google Scholar, ProQuest, PsycINFO, and CINAHL databases were searched for qualitative studies that explore the lived experiences of those with a limb absence. Keywords that were utilized included *phenomenology*, *congenital limb deficiency*, *limb loss*, *upper limb loss*, *psychosocial*, *qualitative study*, and *qualitative research*. This search produced an array of articles with a wide variety of focuses such as phantom limb pain, the effectiveness of various rehabilitation programs, and prosthetic-related research. Relevant articles that investigated some aspect of the psychological, social, or economic effects surrounding limb absences were identified and further analyzed.

Review of these articles demonstrated that most qualitative studies examine the effects of only lower limb absences, acquired limb loss, or a child's CLD. Therefore, by studying the experiences of adults with either a congenital upper limb difference or acquired upper limb loss, this research contributes to this field of literature and helps to fill the gaps currently present. Following an in-depth review of the results of the literature search, five main themes of research topics were established: the effects of



CLD on children, the amputation, the adjustment process, issues surrounding prostheses, and the essence of everyday life. To contextualize this research, these topics will be discussed. The latter topic, *the essence of everyday life*, will be discussed in depth as its content is the most reflective of this research.

### ***Experiences of Children with a Congenital Limb Difference***

Most qualitative research pertaining specifically to CLD focuses on the psychosocial effects of this condition on children and youth, rather than adults. Research demonstrates that an upper CLD presents little interference regarding children's ability to participate in activities (de Jong, Reinders-Messelink, Tates, et al., 2012). Although some activities require creative solutions, children report that no task is completely impossible (de Jong, Reinders-Messelink, Tates, et al., 2012). Generally, it is the actions of others that impedes the participation of children and youth in activities. For example, children described how teachers would alter lessons for them, even though the children felt they were capable of completing the activity without modifications (de Jong, Reinders-Messelink, Tates, et al., 2012). In other cases, some youth with an upper CLD found difficulty in obtaining a job, reporting that even when they believed they would be suitable for a job position, potential employers were more hesitant (Lankhorst et al., 2017).

Children describe others' reactions to their upper CLD as another challenge frequently encountered (de Jong, Reinders-Messelink, Janssen, et al., 2012). For example, stares from others can impact children negatively, whereas support greatly contributes to helping children cope with their CLD (de Jong, Reinders-Messelink,

Janssen, et al., 2012). Many youth report cosmesis (the augmentation or restoration of physical appearance) as the primary reason they choose to wear a prosthesis, as prostheses aid in deterring the negative reactions of others (Vasluian, de Jong, et al., 2013).

Finally, research on the psychosocial effects of CLD has also examined the experiences of the parents of children with CLD. Findings from this research highlight the importance of both educational and emotional support for parents (Andrews, Williams, VandeCreek, & Allen, 2009). Families report that contact with other parents of children with an upper CLD aids in reducing stress and providing both educational and emotional support (Kerr & McIntosh, 2000). As well, additional resources that are provided by health care professionals also provide important support for parents (Campbell et al., 2019).

This research provides important information on the psychosocial effects that CLD can have on both children and their parents. As well, this research offers valuable insight regarding effective tools and coping strategies for these individuals. However, additional research is necessary to gain an understanding of what life is like for adults with CLD.

### ***Research Related to the Amputation Itself***

In addition to CLD, limb absences may be the result of amputation. As this experience carries significant meaning to many of those living without a limb, some researchers have chosen to focus on this aspect of acquired limb loss. In a phenomenological study by Chini & Boemer (2007), the researchers identified

amputation as their phenomenon of interest. To investigate, the researchers conducted interviews with participants during the hospitalization period, both pre-operation and post-operation, until discharge. In this study, twelve participants underwent lower limb amputation and one underwent hand amputation, all due to chronic diseases. Another study by Alexandre (2018) examined the event of lower limb amputation as experienced by Haitian adults as a result of the earthquake that occurred in 2010. Following Giorgi's descriptive phenomenological methodology, the researcher asked participants to describe their experience of losing a lower limb. Finally, in a third study conducted by Senra, Oliveira, Leal, & Vieira (2012), semi-structured interviews and inductive analysis were utilized to explore the experience of lower limb amputation in the context of self-identity. Together, these three qualitative studies offer an in-depth understanding of how the process of amputation is experienced and the psychosocial factors that surround it. For example, findings from these studies demonstrate that amputation challenges the cognitive and affective well-being of individuals (Alexandre, 2018; Chini & Boemer, 2007; Senra et al., 2012). As well, many participants described the stigma associated with amputation (Alexandre, 2018; Chini & Boemer, 2007). Although this valuable research contributes to the growing body of literature pertaining to life with a limb loss, its focus is primarily on the phenomenon of lower limb amputation. Thus, while the essence of amputation is illustrated in these studies, the essence of life ULLD remains to be investigated.

### ***The Adjustment Process to Life Without a Limb***

To further investigate the various psychosocial aspects of life with a limb loss, multiple studies have chosen to focus on the adjustment process ensuing an amputation. Results from these studies illustrate that adjustment to limb loss is multifaceted and influenced by many factors. One key element of adjustment is the social context in which the process occurs for individuals. The acceptance and support from family, friends, and peers can greatly facilitate one's adjustment to life without a limb (Gallagher & Maclachlan, 2001; Saradjian, Thompson, & Datta, 2008). In contrast, social isolation can have detrimental effects on the adjustment of individuals (Hamill, Carson, & Dorahy, 2010).

The importance of a prosthesis in the adjustment process was also highlighted. Learning to efficiently use an upper limb prosthesis inherently requires a period of adjustment itself (Saradjian et al., 2008). However, the procurement and successful use of a prosthesis is positively associated with many individuals' adjustment to either upper or lower limb loss (Columbo et al., 2018; Saradjian et al., 2008). Prostheses enable the performance of functional tasks and can play an important role in the adjustment to a new body image (Columbo et al., 2018; Saradjian et al., 2008). In contrast, problems with a prosthesis, such as poor reliability or noise, can hinder adjustment (P Gallagher & Maclachlan, 2001). A qualitative study by Talbot, Carty, Jensen, and Dumanian (2019) demonstrates an inverse relationship between the level of satisfaction with one's prosthesis and their desire to obtain an upper limb transplantation. These findings suggest that individuals who successfully use a prosthesis are better adjusted to upper

limb loss, further highlighting the significant role of prostheses to the adjustment process.

Finally, another key aspect of adjusting to life without a limb is the navigation of self-identity and subsequent acceptance of a new identity (Senra et al., 2012). The loss of a limb interrupts and reduces individuals' independence, and adjustment to this unsettlement is challenging (Hamill et al., 2010). Accepting and incorporating into one's identity the status of being an amputee demonstrates adjustment to limb loss (Talbot et al., 2019). Furthermore, when individuals accept their new identity as a person with a limb loss, rehabilitation is increasingly effective (Saradjian et al., 2008). This further corroborates the importance of self-identity and acceptance to adjustment.

Some researchers have examined the specific coping mechanisms employed by individuals in relation to adjustment. Maintaining a positive attitude was found to be an effective coping mechanism that contributes effectively to adjustment (Oaksford, Frude, & Cuddihy, 2005; Stutts, Bills, Erwin, & Good, 2015). In contrast, denial and avoidance are also mechanisms utilized by persons with acquired limb loss, demonstrating poor adjustment (Sjödahl, Gard, & Jarnlo, 2004). Other common coping mechanisms include physical activity and practicing religion or spirituality (Amoah et al., 2018; Stutts et al., 2015).

This research grants valuable insight to the adjustment process surrounding life without a limb and the implications and feelings involved in such a process. However, on its own, the adjustment process does not describe the essence of everyday life for individuals with a limb loss; a recent review that investigated the needs of persons undergoing upper limb amputation supports this assertion (Shahsavari et al., 2020). This

review highlighted that a multifaceted care plan should be provided for all patients of upper limb loss both pre- and post-amputation (Shahsavari et al., 2020). For example, the importance of help in timely decision-making as well as the significance of a holistic rehabilitation program were discussed (Shahsavari et al., 2020). Thus, research on aspects of limb loss supplementary to those discussed within this section of the literature review is warranted.

### ***Issues Regarding Prostheses***

Qualitative research regarding upper and lower limb absences has also explored the lived experience of using a prosthesis, investigating the meanings and emotions ascribed to its use. Findings from various studies presented a shared sentiment from prosthesis users: that prostheses enable individuals to feel normal and live normally. This is a multifaceted sentiment, with many factors contributing to prosthesis users feeling this way. Utilizing a Grounded Theory methodology, Jefferies, Gallagher, & Philbin (2018) define normalcy in the context of prosthesis use as the ability of these individuals to continue living in a way that they view as right and adequate. Prostheses empower persons with a limb absence, providing them with the means to conceal or disclose their limb absence at their discretion (Murray, 2005, 2009a). In this way, the use of an artificial limb permits individuals to avoid unwanted attention (Widehammar, Pettersson, Janeslätt, & Hermansson, 2018).

The way in which prosthesis users view their artificial limb varies. To some, a prosthesis is a practical tool with its primary purpose being functional in nature, enabling users to perform tasks they would not otherwise be able to (Lundberg,

Hagberg, & Bullington, 2011; Murray, 2004; Widehammar et al., 2018). However, many users acknowledge the functional limitations of prostheses (Widehammar et al., 2018). For some individuals who have physically demanding professions, the functional shortcomings of an upper limb prosthesis can be so great that they prefer not to use one (Reed, 2004). To other users, a prosthesis offers a primarily cosmetic function (Lundberg et al., 2011; Murray, 2004, 2009a; Widehammar et al., 2018). For these individuals, the prosthesis is more than just a practical tool, it is a means of achieving a desired appearance. Finally, for some, a prosthesis becomes a part of them (Lundberg et al., 2011; Murray, 2004; Widehammar et al., 2018). The embodiment of a prosthesis demonstrates significant adjustment to life without a limb and considerable acceptance of oneself. Furthermore, the embodiment of a prosthesis signifies satisfaction with both the practical and cosmetic functions it offers.

Environmental factors such as social support, support from health care, financial concerns, and prosthesis performance can all influence the willingness and ability of individuals to use a prosthesis (Chini & Boemer, 2007; Widehammar et al., 2018). Despite these challenges, however, many individuals have described their experiences with a prosthesis as life changing, contributing to an overall improvement in their quality of life (Lundberg et al., 2011). In addition to enabling those with a limb absence to live in a way that they feel is fair and adequate, prostheses produce positive psychosocial effects. For example, successful adjustment to a prosthesis is associated with lower levels of body image anxiety (Desteli, İmren, Erdoğan, Sarısoy, & Coşgun, 2014). As well, the use of a prosthesis aids in reducing levels of social discomfort and isolation experienced by those with a limb absence (Murray, 2005).

This research on the lived experiences of using a prosthesis illustrates the range of effects that a prosthesis can have on the life of a person with an upper or lower limb absence. However, although a significant aspect, analysis of the factors surrounding prosthetics does not encompass the essence of life for those with a limb absence. Furthermore, not all individuals with a limb absence utilize a prosthesis. Thus, to fully contextualize and support this research, the following section will discuss literature that has examined the essence of everyday life for individuals with a limb absence.

### *The Essence of Everyday Life with a Limb Absence*

Results from this literature review search produced eight studies in alignment with the topic of the essence of everyday life for those with a limb absence (Amorelli, Yancosek, & Morris, 2019; Day, Wadey, & Strike, 2018; Grech & Debono, 2014; Ligthelm & Wright, 2014; Liu, Williams, Liu, & Chien, 2010; Livingstone, van de Mortel, & Taylor, 2011; Möhler & Schnepf, 2010; Norlyk, Martinsen, & Kjaer-Petersen, 2013). The findings presented in these studies are congruent with the previously discussed themes. However, these studies demonstrate that the effects of amputation, process of adjustment, and use of a prosthesis concurrently influence how one experiences life with a limb absence. Furthermore, this research offers additional insight to the challenges and implications of daily life for individuals with a limb absence.

Acceptance of one's current condition has been established as a challenging yet greatly rewarding aspect of living with acquired limb loss (Ligthelm & Wright, 2014). Many individuals regard it as a necessary development in the recovery from amputation



(Amorelli et al., 2019). However, before acceptance of their new reality can occur, most persons with limb loss experience an array of emotions. Many individuals express denial following the loss of a limb (Ligthelm & Wright, 2014). Other emotions consist of anger, anxiety, depression, fear, and grief (Grech & Debono, 2014; Liu et al., 2010; Livingstone et al., 2011; Norlyk et al., 2013). Conversely, persons with limb loss also exhibit qualities of hope, resiliency, and courage (Amorelli et al., 2019; Grech & Debono, 2014; Ligthelm & Wright, 2014; Livingstone et al., 2011; Norlyk et al., 2013).

Support from family members was again highlighted in this research as an important factor contributing to the experiences of those with an acquired limb loss (Grech & Debono, 2014; Ligthelm & Wright, 2014). In addition to familial support, finding support from peers positively contributes to the experiences of those with limb loss. By way of sharing of common experiences and stories, many individuals are provided with a new, more positive perspective of their circumstances (Liu et al., 2010). Socializing with fellow amputees was found to be a source of inspiration and optimism for many, and resulted in decreased levels of social isolation (Amorelli et al., 2019).

Following the loss of a limb, many individuals describe the challenges that they experience regarding changes in their level of independence. Individuals describe their newfound dependence on apparatuses such as prosthetics and wheelchairs (Möhler & Schnepf, 2010). As well, levels of reliance on others for assistance increases, and can be a source of great frustration. Some individuals describe the strain this can place on relationships between persons with limb loss and their caregivers (Grech & Debono, 2014). For many, regaining their maximal level of independence is a top priority (Liu et al., 2010; Norlyk et al., 2013). Some individuals address this challenge by viewing their

limb loss as an obstacle to surmount (Amorelli et al., 2019). As well, many persons with limb loss express that maintaining a positive attitude and demonstrating perseverance are vital factors to regaining independence (Amorelli et al., 2019).

In addition to psychosocial challenges, the loss of a limb presents physical challenges. Many individuals experience fluctuations of physical pain (Day et al., 2018). For example, phantom limb pain is an intermittent but persistent hardship faced by many with limb loss (Ligthelm & Wright, 2014; Livingstone et al., 2011). The loss of a limb can also produce many financial concerns. Depending on the nature of their occupation, individuals are at risk of losing their job (Ligthelm & Wright, 2014). Furthermore, the loss of a limb may necessitate the purchase of special clothing or prostheses, and affect the need for structural changes to homes or travel to specialists (Livingstone et al., 2011).

This research on the essence of everyday life with a limb loss provides a strong foundation on which to build and demonstrates the significance of the psychosocial effects of limb loss. The present research will contribute to the growing body of literature that is needed to raise awareness of these effects and inform health care providers how best to enhance the quality of life for those with a limb absence. Additionally, these studies present limitations that this research study aids in addressing.

For example, five of these studies investigated a sample consisting only of persons with lower limb amputations (Day et al., 2018; Liu et al., 2010; Livingstone et al., 2011; Möhler & Schnepf, 2010; Norlyk et al., 2013). The samples of two others consisted of a mix of both lower and upper limb amputations (Amorelli et al., 2019; Grech & Debono, 2014). Although similarities are shared, the challenges and

psychosocial effects experienced by individuals with a lower limb absence vary from those experienced by individuals with an upper limb absence (Desteli et al., 2014). Furthermore, of these studies, two utilized a sample of individuals who lost their limb due to a vascular disease (Livingstone et al., 2011; Möhler & Schnepf, 2010). This population of individuals encounter additional challenges due to their comorbidity; thus, their experiences likely differ from individuals without a comorbid disease (Coffey, Gallagher, Horgan, Desmond, & MacLachlan, 2009). Additionally, of these studies, only one included individuals with CLD in their sample (Day et al., 2018).

Finally, the studies discussed above took place in eight different countries, none of which were Canada. These countries included South Africa (Ligthelm & Wright, 2014), Malta (Grech & Debono, 2014), the United States (Amorelli et al., 2019), the United Kingdom (Day et al., 2018), Taiwan (Liu et al., 2010), Australia (Livingstone et al., 2011), Germany (Möhler & Schnepf, 2010), and Denmark (Norlyk et al., 2013). Thus, the present research addresses gaps in the literature and provides novel insight to the experiences specific to individuals with ULLD in Canada.

### ***Summary***

Chapter 2 provided a comprehensive review of the relevant literature and identified gaps to justify the need for additional research. Five main themes of previous studies were identified and discussed: the effects of CLD on children, the amputation, the adjustment process, issues surrounding prostheses, and the essence of everyday life. Emphasis was given to the latter as its content is most pertinent to the present study. The methodology for the research will be presented in Chapter 3.

## Chapter 3

### Methodology

#### *Research Method*

As discussed in the previous sections, qualitative research offers a unique opportunity to explore the experiences of individuals in health care settings. Through literary writing, qualitative research provides detailed accounts of issues, sharing the stories of individuals who have experienced the event firsthand. The focus of this research is to understand and describe the essence (or meaning) of life for individuals with ULLD; thus, a phenomenological method was chosen to guide the research process. Specifically, Giorgi's (Giorgi & Giorgi, 2003) descriptive phenomenological method was utilized.

Giorgi's phenomenological method is grounded in both psychology and science, and offers a non-reductionist view of a phenomenon (Giorgi, 2012). Giorgi's method provides researchers with a well-defined phenomenological framework with which to conduct their studies. This structured approach aids in increasing the rigour of a study (Whiting, 2001). Giorgi's method encourages researchers to reflect on the essence, or meaning, of the shared experiences of persons and subsequently generate in-depth descriptions, without attempting to explain or theorize. In this way, Giorgi's method facilitates the exploration and subsequent increased understanding of what it means to experience a phenomenon of interest.

The creator of this method, Amedeo Giorgi, was influenced by the work of Husserl, the founder of modern phenomenology (Giorgi, 2012). Husserl introduced

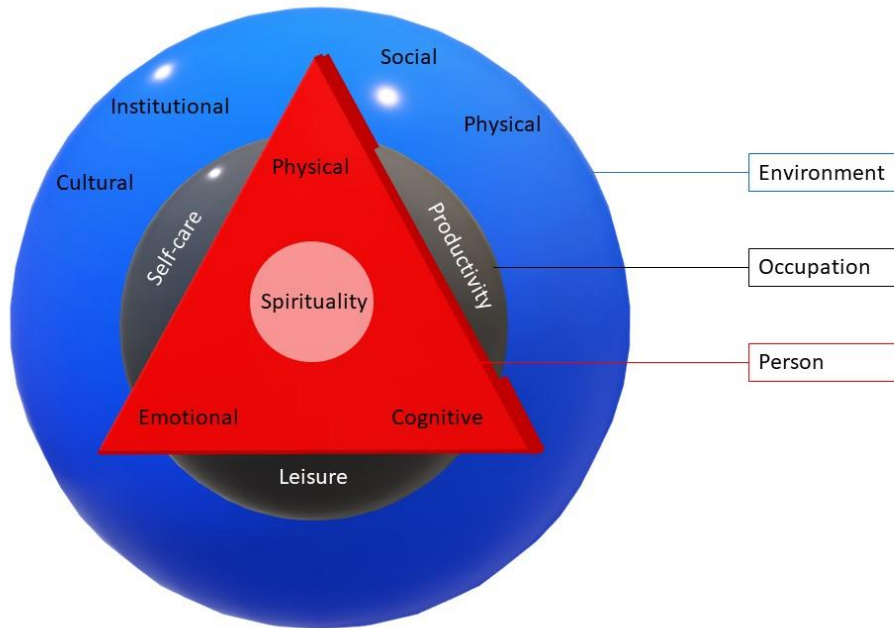
bracketing, often referred to as phenomenological reduction, a technique in which the researcher sets aside any preconceived notions they may hold regarding a phenomenon (Mitchell & Cody, 1993). This practice helps to minimize the potential influence that prior knowledge or experiences can have on the researcher's perception of the phenomenon of interest.

Giorgi differentiates between Husserl's transcendental reduction, often used by philosophers, and scientific reduction, often used by psychologists (Giorgi, Giorgi, & Morley, 2017). Transcendental reduction aims for a complete bracketing of all empirical knowledge; to achieve this, Husserl encourages bracketing of even the consciousness within which this knowledge exists (Giorgi et al., 2017). In contrast, scientific phenomenological reduction, the method that Giorgi employs, does not aim for the same degree of completion. Instead, scientific reduction recognizes that human consciousness is of importance to psychology, therefore does not attempt to bracket out its existence (Giorgi et al., 2017). Giorgi states that "The researcher still considers what is given to her but she treats it as something that is present to her consciousness and she refrains from saying that it actually is the way it presents itself to her" (Giorgi, 2012, p. 4). In doing so, the researcher can view the reality of a phenomenon only through the information that is provided by participants.

### ***Theoretical Framework***

**CMOP-E Framework.** To complement the objective of this research, the CMOP-E was chosen as a guiding theoretical framework. The CMOP-E was developed from various theories including humanistic, developmental and learning, and

environmental and has three components: the person, the environment, and the occupation (Polatajko et al., 2007). A visual representation of the model is shown in Figure 1.



**Figure 1: Components of the CMOP-E. Image adapted from "The Canadian Model of Occupational Performance and Engagement (CMOP-E)" (Polatajko, et al., 2007).**

Emphasis is given to the person, demonstrating the compatibility this model has with this study, as this research is person-centred. Furthermore, the cognitive, emotional, and physical aspects of individuals are each considered within this component. Residing at the centre of the person, the facet of spirituality embodies the individual's essence and is the source wherefrom value is derived (Polatajko et al., 2007). The inclusion of these elements highlights the holistic nature of the CMOP-E.

The environment is the component within which the person exists (Polatajko et al., 2007). This domain acknowledges the influence that various external factors can

have on both the person and the occupation (Polatajko et al., 2007). External variables are further classified into four environmental subgroups: institutional, cultural, social, and physical.

Finally, occupation enables the person to interact with the environment (Polatajko et al., 2007). Occupations refer to any activity that may occupy the person's time and are categorized as leisure, self-care, or productivity tasks. Together, these elements of the CMOP-E demonstrate the interrelated and dynamic nature of the model.

**Benefits of the CMOP-E.** The CMOP-E provides a versatile framework that enables its use across various areas of study. Due to its multifaceted origin and adaptability, the CMOP-E is compatible with Giorgi's method. Additionally, the CMOP-E is suitable for use alongside the sample of adults with ULLD present in this research study. The flexibility of the CMOP-E permits its easy application to different samples of individuals. As well, occupational therapists, by whom this model was designed, are often members of the clinical team for individuals with ULLD. This further demonstrates the appropriateness of using the CMOP-E as a guiding framework and lens for this study.

Finally, the CMOP-E is well-designed to inform health care professionals. For example, all occupational therapy staff in the United Kingdom (n = 270) employed the CMOP (the model from which the CMOP-E evolved) and reported that the model positively influenced daily practices and understanding of occupational therapy (Boniface et al., 2008). As well, the CMOP-E has been suggested as a holistic and client-centred model to guide rehabilitative health care services for Canadian veterans

(Besemann et al., 2018). Furthermore, various health-related studies have applied the CMOP-E to guide the research process. This includes, but is not limited to, research pertaining to the management of concussions, research investigating occupational performance and bariatric surgery, and research that examines the effects of using a robotic arm (Barclay & Forwell, 2018; Beaudoin, Routhier, Lettre, Archambault, & Lemay, 2015; Finn, 2019).

In these ways, the CMOP-E is compatible with this research. The versatility of the CMOP-E demonstrates the appropriateness of using this model in conjunction with the chosen method and sample in this study. As well, the use of this model augments the health-related objectives of this research: to inform health care professionals of the needs of clients and subsequently aid in improving overall quality of life for individuals with ULLD.

The use of the CMOP-E in this study helped to ensure that analyses of participants' data were congruent. As well, the CMOP-E assisted the Principal Investigator (PI) in conceptualization of the participants' experiences. Application of the CMOP-E encouraged the PI to consider the data in a holistic manner and from perspectives that may not have been considered otherwise: the CMOP-E aided in providing valuable insight regarding the essence of life for adults with ULLD.

### ***Recruitment***

Giorgi's method utilizes purposeful sampling, an example of non-probability sampling. Researchers using this technique select participants based on characteristics



related to the objective of a study. In this way, purposeful sampling ensures that the participants in a study have experienced the phenomenon of interest.

This research study recruited participants from the Atlantic Clinic for Upper Limb Prosthetics. This clinic operates within the Institute of Biomedical Engineering (IBME) at the University of New Brunswick (UNB). To ensure no sense of obligation, information about the research project was shared with potential participants through a third party, the Office Manager of the clinic. Due to exceptional circumstances caused by the COVID-19 pandemic, in-person recruitment by the Office Manager was impossible. Instead, the Office Manager distributed a flyer for the study, found in Appendix A, to 18 potential participants by email. These 18 potential participants were screened beforehand and determined to meet the eligibility criteria. Interested individuals contacted the PI by email, no inducements were offered to encourage participation. The written portion provided by the PI to be included in this email is displayed in Appendix B.

To be included in this study, individuals needed to have ULLD. As well, participants were required to be over the age of 18 and able to understand English. Individuals with any level of ULLD were eligible to participate (e.g. trans-radial or trans-humeral). However, individuals with more than one limb absence (whether they were all upper limb absences or included lower limb absences) were not be eligible to participate in this study. The experiences of individuals with multiple limb absences differ from those with a single limb absence (Pasquina et al., 2014). Therefore, the purpose of this exclusion criterion was to help to ensure that the participants all

experienced the same phenomenon. These inclusion and exclusion criteria are summarized below in Table 1.

**Table 1: Inclusion and Exclusion Criteria for the Recruitment of Participants.**

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
Age 18 and above	Below the age of 18
Understands English	Does not understand English
One limb absence	More than one limb absence
Any level of ULLD (e.g. trans-radial or trans-humeral)	

***Sample***

This research study recruited five participants from the Atlantic Clinic for Upper Limb Prosthetics. Considering qualitative research entails in-depth analyses of each participant’s data, small sample sizes are frequently utilized (Smith, Flowers, & Larkin, 2009). For instance, four of the eight studies previously discussed within the literature review, under *The essence of everyday life with an upper limb absence*, utilized a sample size of nine or fewer participants (Grech & Debono, 2014; Ligthelm & Wright, 2014; Livingstone et al., 2011; Möhler & Schnepf, 2010). Grech & Debono (2014) followed an interpretive phenomenological analysis and included four participants; Ligthelm & Wright (2014) conducted a phenomenological study with eight participants; five participants were included in the Grounded Theory study by Livingstone et al. (2011); and, finally, Möhler & Schnepf (2010) conducted a Grounded Theory study with a sample size of nine participants.

Furthermore, Giorgi recognizes that sample size does not necessarily correlate with quality of results (Englander, 2016). As such, Giorgi’s method permits flexibility regarding the sample sizes of studies. Indeed, Giorgi himself has conducted a study while utilizing a sample size of just three participants (Giorgi & Gallegos, 2005). Other researchers have also adhered to Giorgi’s method while employing sample sizes as small as three (Broomé, 2013; B. Giorgi, 2011). Thus, a small sample size is common in the literature among qualitative research and is appropriate for use in this study.

Seven potential participants contacted the PI expressing interest in participation. Two individuals discontinued the email communication, resulting in a final sample size of five participants. Each participant was assigned a pseudonym by the PI and demographic information was collected. This information included the nature of limb absence (e.g. congenital or acquired), the length of time since limb loss, whether it was the dominant or non-dominant side that was affected, and gender. Due to the small population of individuals with ULLD in this region, the level of limb absence was not recorded to avoid revealing any identifying information. The participants’ demographic information is presented below in Table 2.

**Table 2: Participant Demographics**

	<b>Pseudonym</b>	<b>Congenital or Acquired</b>	<b>Dominant or Nondominant</b>	<b>Time Since Limb Loss</b>	<b>Gender</b>
Participant 1	Alex	Congenital	N/A	N/A	Female
Participant 2	Blake	Congenital	N/A	N/A	Male
Participant 3	Chris	Congenital	N/A	N/A	Female
Participant 4	Devin	Acquired	Nondominant	26 years	Female
Participant 5	Elliot	Acquired	Dominant	34 years	Male

### ***Ethical Considerations***

This research study was classified as minimal risk. Approval from UNB's Research Ethics Board was obtained prior to the recruitment of participants. This demonstrated that the appropriate steps were in place to protect the participants.

Due to COVID-19, informed consent forms could not be reviewed and collected during in-person meetings. Instead, participants were offered three options for providing informed consent: (1) provide an electronic signature on the informed consent form that was emailed to them, (2) print and sign the informed consent form and return a copy or a photograph of the signed form, or (3) if participants chose to submit a written (typed) response, the PI considered this assumed consent. These options were approved by the UNB Ethics Department. The informed consent form can be found in Appendix C.

To ensure confidentiality and anonymity, any information about the participants use a pseudonym in place of a name. No questionnaires or surveys were utilized; however, some demographic information was collected, as summarized above in Table 2. Data and personal information were not shared outside of the research team and will be kept confidential. Eventually, the results of this study will be shared so that others who are interested may learn from the research. Confidentiality and anonymity will be upheld, however. Nothing will be attributed to the participants by name in the released research.

Information pertaining to the research is stored on a password-protected computer. Data is being kept in encrypted files and the master list of participants is concealed in a password-protected file. All emails from participants were deleted

permanently from the PI's computer. Following completion of this study, data will be kept for a minimum of seven years and then deleted.

### ***Data Collection***

Due to the nature of this research, some participants may be more comfortable sharing their experiences verbally, whereas some may prefer to provide written responses. Thus, interviews as well as written responses (i.e., typed) were offered as modes of data collection. In light of COVID-19, in-person interviews were not feasible; thus, interviews via phone or video-chat were proposed instead. The chosen response method of each participant is summarized in Table 3 below.

**Table 3: Response Method of Participants**

<b>Participant</b>	<b>Response Method</b>
Participant 1 (Alex)	Written response
Participant 2 (Blake)	Video interview
Participant 3 (Chris)	Phone interview
Participant 4 (Devin)	Video interview and written response
Participant 5 (Elliot)	Phone interview

The interrogatory statement was the same for both modes: “Please describe what it is like for you to live with an upper limb absence”. Participants who chose to provide a written response had no length recommendation or requirement. Phone and video interviews took place in private areas ensuring privacy and no distractions. Following the interrogatory statement, only open-ended questions and prompts were utilized. The

researcher's role is to actively listen to the participants tell their story, however complete or incomplete they may wish to share it. Accordingly, the PI avoided using any guiding or narrowing questions. Phone and video interviews were recorded and later transcribed verbatim by the PI.

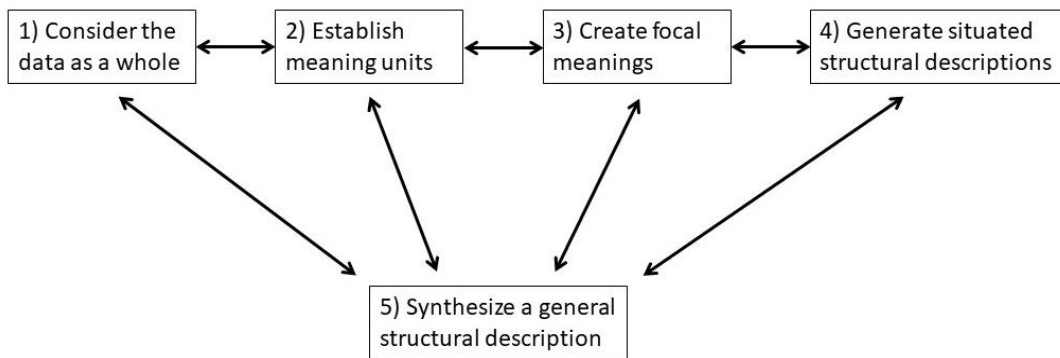
### ***Data Analysis***

Giorgi's method stipulates that the researcher must assume an attitude of scientific phenomenological reduction and remain within this mindset for the entire data analysis process (Giorgi, 2009). In later publications, Giorgi designates an entire step to this practice to emphasize its importance (Giorgi et al., 2017). To enter the mindset of scientific phenomenological reduction, the PI of this study set aside, or bracketed, any preconceptions they held regarding life with ULLD. As the PI of this study is new to the field of limb absences, lack of intimate experience with the field permitted the PI to enter and remain within this mindset easily.

Despite no previous involvement with people with ULLD, the PI was immediately interested upon learning about this research project from supervisors and views this study as an opportunity to research a meaningful topic that can have a positive impact on others. Prior to this study, the PI had informal, everyday interactions with individuals who have lost a limb traumatically, as well as with persons with CLD. Therefore, any preconceptions the PI held about life with ULLD could have been influenced by such conversations. For example, having heard of the psychological effects of limb absence and observing the occupational accomplishments of these individuals led the PI to believe that this could be the experience of all. Additionally, the

PI gained insight and knowledge to the experiences of persons with ULLD from literature searches. Therefore, to describe the essence of everyday life with ULLD as presented by the data, the PI bracketed all previous knowledge and beliefs and remained open-minded throughout interviews and data analysis.

This research study followed the data analysis procedure as described by Giorgi and Giorgi (2003) and Aquino-Russell (2006), and is depicted in Figure 2. Giorgi's method, although structured, encourages a fluid and dynamic analysis of data; steps occurring concurrently, rather than sequentially (Gordon, 2009). This is represented in Figure 2 by the double-headed arrows between steps.



**Figure 2: The data analysis process for Giorgi's descriptive phenomenological method. Image adapted from "Partner's Experience of Living with a Person Who Has Undergone Colostomy or Ileostomy Surgery: A Phenomenological Study" (Gordon, 2009).**

To begin the data analysis process, the researcher read the description in its entirety, considering the data as a whole (Giorgi & Giorgi, 2003). Subsequent data analysis could only occur when the researcher had become familiar with the data and grasped a fundamental understanding of its essence. In this way, the holistic nature of phenomenology is exemplified (Giorgi, 2012).

Subsequent to obtaining a basic understanding of the description, the PI reread the data, this time establishing parts that comprise the description (Giorgi & Giorgi, 2003). To delineate parts, the PI placed slashes at points where transitions in meaning were identified; these parts are referred to as meaning units (Giorgi & Giorgi, 2003). Next, the PI transformed these meaning units into expressions that contextualized the data descriptions, referred to as focal meanings (Aquino-Russell, 2006). At this stage, the data descriptions are no longer in the participant's own words. Instead, the PI has applied the theoretical framework to illustrate the theoretical significance of the participant's lived experiences, "rendering implicit factors explicit" (Giorgi et al., 2017, p. 182). As this was the PI's first venture into qualitative data analysis, the analysis-synthesis of Alex's, or Participant 1's, data was completed jointly by the PI and supervisors Hill and Aquino-Russell. Subsequent analysis-synthesis was completed solely by the PI.

To ensure appropriate application of the theoretical framework when creating the focal meanings, the PI spent time analyzing-synthesizing the meaning units according to the CMOP-E (theoretical framework). Specifically, the PI discerned and recorded what domains of the CMOP-E were relevant to each meaning unit. Applying the domains of the CMOP-E in such a manner encouraged consistency throughout the data analysis process. As well, distinguishing the domains pertinent to each meaning unit aided in transforming the participants' words to a higher level of discourse in the language of the theoretical framework. Concurrently, the PI ensured that the focal meanings were expressed in a language general enough so that they could easily be incorporated into a description pertaining to multiple participants (Giorgi, 2009). The transformation of



meaning units to focal meanings highlights the inductive nature of phenomenology and the corresponding advancement in levels of abstraction.

Next, the PI utilized the focal meanings to generate a situated structural description for each participant (Aquino-Russell, 2006). Situated structural descriptions provide insight to each individual's experiences with the phenomenon of interest. Finally, the PI synthesized the situated structural descriptions into a general structural description (Aquino-Russell, 2006). The general structural description describes what the participants have experienced and how they have experienced it, illustrating the essence of the phenomenon. This final passage omits any information specific to a single participant, ensuring that the description is general enough so that it may be relevant to anyone who has experienced the phenomenon of interest. To ensure congruence among the increasing levels of abstraction, the PI continually revisited the participants' words throughout the data analysis process (Aquino-Russell, 2003).

### ***Rigour***

Rigour is exemplified in qualitative research through a variety of means. Identifying and adhering to a methodological approach aids in enhancing trustworthiness and sophistication of a study (Creswell & Poth, 2018). Furthermore, an inductive, emerging design demonstrates rigour (Creswell & Poth, 2018). This research study utilizes an inductive design, as a general description is generated from individual meaning units. As well, producing a description in such a manner is indicative of an emerging design, as numerous levels of abstraction are utilized. Thus, this research

demonstrates rigour by establishing methodological congruence and using an inductive, emerging design.

To further increase rigour, the PI of this study practiced reflexivity. Reflexivity is a process of reflection in which the researcher positions themselves in the research and contemplates personal biases, experiences, and knowledge that they bring to the study (Nicholls, 2019). Doing so enables both the researcher and the reader to become aware of any factors with potential to influence the research process. By conveying personal relation and prior knowledge pertaining to the research (within the *Data Analysis* section), the PI of this study has practiced reflexivity and attempted to disclose any biases, experiences, and knowledge related to the field.

### ***Summary***

This chapter includes a discussion of the methodology chosen to guide this research, including Giorgi's descriptive phenomenological method. As well, the theoretical framework and its compatibility with the research was described. Finally, this chapter also discussed the recruitment method, sample, ethical considerations, data collection and analysis, and rigour of the study. The following chapter will illuminate the findings from the research.

## Chapter 4

### Findings

#### *Overview*

Chapter 4 details the findings from a rigorous analysis-synthesis of the data collected from five adults who are living with ULLD. This process entailed examining interview transcripts while employing Giorgi's (Giorgi & Giorgi, 2003) descriptive phenomenological method of data analysis.

A comprehensive account of the meaning units, domains, focal meanings, and situated structural descriptions for each participant is presented below, followed by a presentation of the general structural description and discussion of the eight essences that compose the general structural description.

#### *Participant 1: Alex*

##### **Meaning Units, Domains, and Focal Meanings for Alex.**

###### 1a) Meaning Unit

Living with the absence of my left arm is not something that I think of everyday. For me personally I go about my day thinking I have 2 arms some days.

###### 1a) Domains

Person – physical, cognitive

###### 1a) Focal Meaning

Throughout the day, Alex does not contemplate having a limb difference, as Alex's perception of self includes both upper limbs.

#### 1b) Meaning Unit

It doesn't bother me or stop me from doing a task at hand. The only time I would say I notice my disability is when I subconsciously try to do things with 2 hands and end up dropping items I am trying to hold, or perhaps pushing a heavy grocery cart, maybe even tying my shoes, putting on a watch, or when I need to ask someone to zip my coat up for me. I can still manage to do all of these things, they are simple to the general public-yet considered difficult tasks for me personally.

#### 1b) Domains

Occupation – self-care

#### 1b) Focal Meaning

In living a paradoxical experience, Alex finds that missing an upper limb does not interfere with performing daily occupations. However, what other people consider effortless tasks, such as self-care activities, are found to be more challenging and at times Alex chooses to seek assistance.

#### 1c) Meaning Unit

I don't look at myself as having the absence of an arm, or a disability ever. It took me a while to truly understand and accept myself as disabled, because that is what the general population sees, I just don't see myself that way. Of course I realize it more when I'm in public and people are staring at me, I wonder "What is it they're staring at?!" and I realize "Oh yeah, I'm missing an arm!!".

#### 1c) Domains

Person – spirituality, cognitive

Environment – social

1c) Focal Meaning

Alex's perception of self is surprisingly intermittently distorted, occasionally identifying as disabled due to the perception of others in social environments.

1d) Meaning Unit

When I feel my uttermost "invincible self" I like to call it, is when I am at the gym. I have realized I can do things there that EVERYONE can do there, plus more!! I see myself lifting heavier weights than some guys! My recreational device gives me the opportunity to lift heavy weights, do pull ups, jump rope, deadlift, squat, push-ups, what have you. This is my place that I feel comfortable, resilient and courageous. A place that I know I can do ANYTHING and I never have the thought coming to mind that I have an absent limb.

1d) Domains

Person – spirituality

Occupation – leisure

Environment – physical

1d) Focal Meaning

Realization of Alex's supreme self occurs at the fitness centre, with a prosthesis that enables the performance of strength-building physical activities at a level equal to or greater than peers. This environment promotes feelings of contentment, irrepressibility, and braveness for Alex. Alex is empowered with liberation from disability and the judgement of others.

### **Situated Structural Description for Alex.**

Throughout the day, Alex does not contemplate having a limb difference, as Alex's perception of self includes both upper limbs. In living a paradoxical experience, Alex finds that missing an upper limb does not interfere with performing daily occupations. However, what other people consider effortless tasks, such as self-care activities, are found to be more challenging and at times Alex chooses to seek assistance. Alex's perception of self is surprisingly intermittently distorted, occasionally identifying as disabled due to the perception of others in social environments. Yet, realization of Alex's supreme self occurs at the fitness centre, with a prosthesis that enables the performance of strength-building physical activities at a level equal to or greater than peers. This environment promotes feelings of contentment, irrepressibility, and braveness for Alex. Alex is empowered with liberation from disability and the judgement of others.

### ***Participant 2: Blake***

#### **Meaning Units, Domains, and Focal Meanings for Blake.**

##### 2a) Meaning Unit

I was born without my right hand, so you know, as a kid, I've never had it so you never miss it. So I was able to adapt, I'm going to say quite well, compared to people that have lost their limbs in accidents. At least that's my opinion anyways.

##### 2a) Domains

Person – physical

##### 2a) Focal Meaning

Blake has CLD and considers adjusting to this simpler than acclimatizing to an acquired limb loss.

2b) Meaning Unit

As a result of not having my right hand, I would say that I have dealt with adversity.

When you're young and you're a kid there's always kids that are curious, right? Or they'll ask questions or, you know, they'll look or stare. But you know what? It's human nature for people to be curious. You know what I've learned over the years, is that once people, the curiosity is gone, and they know, and they felt it and touch it and all that type of thing. You know it's just like another person.

So yea, I found as growing up that, once I was at school and once I met all kinds of people and stuff, people didn't think anything of it afterwards. It's just the initial curiosity.

2b) Domains

Environment – social

2b) Focal Meaning

Ensuing initial gazes and inquisitiveness, others' perceptions of Blake are not influenced by the limb difference.

2c) Meaning Unit

In lots of ways I say to myself, it was just one of those things that kind of happened. But it's made me a better person in lots of ways. . .

So yea, I've always been an advocate of trying to help out or participate in studies, and try and be a mentor for other kids that may have a deficiency. Yea, and you know appreciate life too for what it is. There's always, I'm a firm believer, there's always somebody worse off than yourself, right? There's even times where I've said, in some ways it's been a blessing that I do have a prosthetic or don't have a hand, just because I appreciate life a lot more.

2c) Domains

Person – spirituality

2c) Focal Meaning

Blake accepts being born without an upper limb and believes that it has led to improving as an individual as well as realizing life's value.

2d) Meaning Unit

And I consider myself that I've been successful in life. You know lots of people regardless of age, like kids and all that stuff, there's even lots of adults that have had questions and been curious. But in some ways I've inspired them because of what I've done and what I've accomplished throughout my life. . .

I do have a gift of the gab. So that's kind of helped in lots of ways too. I'm not shy so people seem to open up a little bit more I guess in that regard. If I don't mind speaking or give thoughts then people seem to be a little bit more open and will ask more. So in some ways I say well that makes other people better.

2d) Domains

Person – affective



Environment – social

2d) Focal Meaning

Blake's positive affect and numerous accomplishments promote conversation and enrich the experiences of others.

2e) Meaning Unit

Yep, so as a kid, I'm going to say when I was, I don't know, maybe two or three. I've always had a prosthetic from as long as I can remember. As a kid my folks got me involved with The War Amps. So they provided the prosthetic limb to me, basically until I was the age of 18.

It's a very good organization. And they provided the costs of the limbs, when I was a kid, right up until the age of 18, I would go to the Shriners Hospital in Montreal twice a year and I would basically just have checkups. And if I needed a prosthetic limb, it would be made right there in Montreal. . .

Sorry it was the Shriners Hospital yea, but it was The War Amps I guess when I was 18. Yea the Shriners Hospital in Montreal. If you google that it still exists today and is a real good organization. So at the time when I was a kid really there was two organizations. There was the Shriners Hospital organization and then there was The War Amps. So I don't know how at that time I got associated with Shriners? Obviously through my parents. We go up to Montreal and have my appointment twice a year. Because when you're young you're growing right. You need the prosthetic arm allots, or the fittings, more frequent. . .

Anyways I had [the hook] basically right up until I was 18. With the Shriners Hospital, it's for children right? So whenever you turn 18 years of age, the funding is done. So when I was 18 I had to start looking for other funding to basically help the costs of the prosthetic arms. My folks and my family and myself, we got in touch with The War Amps and just if they would kind of take me on or help facilitate. And at the same time I had enrolled at the University of New Brunswick . . . and that's when I initially got in touch with, what they called at that point, the Bioengineering Institute.

2e) Domains

Environment – physical, institutional

2e) Focal Meaning

Throughout life, various institutions provided Blake with the resources necessary to procure prostheses.

2f) Meaning Unit

But as a kid, I didn't have the myoelectric prosthetic hand that I have now. It was the hook. And it was fine. Obviously cosmetic-wise it's nowhere near as good as the hand. So people would ask questions about that too. . .

The hook in lots of ways was very practical and I still have that prosthetic that I use on a very limited basis nowadays. I only use it now to play hockey. Yea, I've played hockey my whole life.

2f) Domains

Occupation – leisure

Environment – social, physical

2f) Focal Meaning

Blake values both the functionality and appearance of prostheses, observing that the latter influences the reactions of others.

2g) Meaning Unit

. . .I was curious about the myoelectric hand. I had seen some documentaries, or maybe I'd seen them on TV. But initially, once I got to UNB and I knew it was there, I said I want to pursue or look into it. So that's basically when I was 18 that's when I got associated with the Bioengineering and then I think within the year I had my first myoelectric hand.

When I first went to the Bioengineering Institute they had a machine there with, basically they put the sensors all on my arm to see if the signals were there. At that time they had no idea whether the nerves were there. Right? In order to pick up the signals on the sensors. So anyways, I got down there and they hooked me all up and sure enough the nerves popped up right away.

Yea and you know what, at that time they weren't even sure themselves. Yea, they said well you're born like that, are the nerves still there or are they shriveled up – who knows right? So I think they kind of learned too because they had no idea. And I sure didn't have any idea. But anyways, they found the signal points and there was all kinds of signal there for the sensors and it was pretty straightforward from then on.

2g) Domains

Person – affective, physical

2g) Focal Meaning

Except for uncertainty surrounding whether the transition would be successful, Blake regarded the adaptation process to a myoelectric prosthesis as uncomplicated.

#### 2h) Meaning Unit

It's just an extension of my body, right? It's no different than you know, you put your glasses on or you put a pair of boots on, or shoes or. . . I don't really think about it.

When I go home in the evenings, I take my arm off if I know I'm in for the night, just to give my arm a little bit of a breather, like a rest. Like one of the things I've always said to the kids at home, we've got two daughters that are 15 and 17, I say to them "well, you know what? If you were walking around all day with a pair of rubber boots on and you didn't have any socks? Haha so you know, when I get home from work at night, I'll just take my arm off and just basically have a little break.

But you know there's times where I'll get home and for whatever reason I'll put my arm back on and I won't even know that I have it on. So it's not that it's a burden. It's like, at this point in my life, it's a part of me.

#### 2h) Domains

Person – spirituality

#### 2h) Focal Meaning

Blake demonstrates embodiment of the prosthesis, as the device has been incorporated into Blake's body schema.

#### 2i) Meaning Unit

Through life I've been able to accomplish – there's nothing that I can't do physically.

I've always been able to figure it out one way or another. Like I said I played hockey my whole life, I played sports in high school, I played soccer, I played football. Growing up I had a snowmobile and bicycles. So, I've been able to adapt. I've always been a firm believer that if there's a will there's a way. So I've been able to manage and accomplish stuff right?

2i) Domains

Occupation – leisure

2i) Focal Meaning

Blake asserts that, no matter the level of difficulty, all leisure activities are achievable through determination and modification.

2j) Meaning Unit

And playing hockey has been a blessing, my parents got me into hockey, I was at 3 or 4 years of age. So, just being involved in sports is a great – you know it's involvement, it's getting out there, it's getting involved in the community and socializing. So that's been good. You know I could see where some kids, as they're growing up, by not having a limb they may shy away and it's not good for your mental health. But anyways, I was able to overcome that, without even knowing. So anyways, here I am – [age] years later.

2j) Domains

Person – cognitive

Occupation – leisure

Environment – social

## 2j) Focal Meaning

Blake believes that participation in group activities offers an opportunity to engage in social environments that are important for cognitive well-being.

### **Situated Structural Description for Blake.**

Blake considers adjusting to CLD simpler than acclimatizing to an acquired limb loss. Moreover, Blake accepts being born with an upper limb absence and believes that it has led to improving as an individual as well as realizing life's value. Although growing up with CLD presents challenges in social environments, Blake maintains that, after initial gazes and inquisitiveness, others' perceptions are not influenced by the limb difference. Furthermore, Blake's positive affect and numerous accomplishments help to promote conversation and enrich the experiences of others.

Throughout life, various institutions provided Blake with the resources necessary to procure prostheses. Blake values both the functionality and appearance of prostheses, observing that the latter influences the reactions of others. Except for the uncertainty surrounding whether the transition would be successful, Blake regarded the adaptation process to a myoelectric prosthesis as uncomplicated. At present, Blake displays a paradoxical sentiment, demonstrating embodiment of the prosthesis while also desiring relief from the device at the end of the day.

Finally, Blake asserts that, no matter the level of difficulty, all leisure activities are achievable through determination and modification. As well, Blake believes that participation in group activities offers an opportunity to engage in social environments that are important for cognitive well-being.

### ***Participant 3: Chris***

#### **Meaning Units, Domains, and Focal Meanings for Chris.**

##### 3a) Meaning Unit

. . . it is something I've always, I've always grown, it's always been there, something I've always lived with. So I think it's tough for me [to think] of certain things in the past, but I don't know, now that I'm older tend to, haha not that I'm old, tend to notice things more. And I find, you know with missing a limb, now that I'm [age], I guess I'm noticing a few more things.

##### 3a) Domains

Person – physical

##### 3a) Focal Meaning

In adulthood, Chris perceives elements of having an upper limb absence that were not considered throughout adolescence.

##### 3b) Meaning Unit

A few things that stand out in a normal day, so I'm a [manager at a private business], so certainly little things like okay I'm missing my limb, so you know what? A little tough to do, I'm just thinking of getting ready for work, a little tough to, you know, depending on what you want to do to start the day. Doing your hair, so you know I can't, there's certain – forget doing the back of my head. That's impossible with one arm. I'm sure if I wanted to find a way I could do that. You know, asking for help, to do up the zippers depending on what I'm wearing, say if I'm wearing a dress to work with a zip up the

back. Well that might be tough for anyone with two hands but it's certainly really tough with just one arm. . .

Yea, and even, you know, it's just everyday things. So I just shared getting ready for work but then there's the whole piece of, say, I have a son and I have a partner, and say cooking supper . . . it's the little things like using a can opener to open up a can of tuna. Or even if I'm cutting up vegetables to make a salad.

### 3b) Domains

Occupation – self-care

### 3b) Focal Meaning

An upper limb absence exacerbates physical challenges presented by daily self-care activities, often requiring Chris to seek assistance.

### 3c) Meaning Unit

Finding, if I'm going to wear a suit then I have to make sure that I can even get my arms through it. Because I do wear a passive arm, I don't wear a myoelectric, I'm wearing a passive. So I never noticed that as a kid but now I guess it's more in my profession I'm noticing it more. So jeepers, I'm trying to get my arm in a suit coat and then I find if I get too hot or I need to take it off, sometimes, depending who's with me, I'll just leave my arm in my jacket, just 'cause it's a pain. And I guess I find it more of a pain as I get older. Yea, just little things like that every day. Certainly, has never bothered me. . .

I actually don't, it's funny, I don't wear my arm for doing things like that because I've cut off the fingers on my passive arm and I find it easier just to use, I call it my nub, my



little left arm. The whole thing's been cut but I've also cut that up a few times too by mistake.

3c) Domains

Occupation – self-care, productivity

Environment – physical

3c) Focal Meaning

As an adult, Chris's prosthesis introduces novel impediments to occupations and is intermittently deemed bothersome and removed.

3d) Meaning Unit

I've always always worn some type of arm, whether it was a hook when I was a kid, to a myoelectric for years, then I switched to a passive arm about 20 years ago. So, I've always worn an arm, I've never, it's been very rare where I've gone anywhere without wearing an arm. I guess part of that is just I'm getting, it's bad to say but, you know, so tired of explaining or just the looks that, you know, you certainly get from people. "what happened to your arm?" Or I still get that anyway wearing an artificial arm but I guess I'm just at a point now where, you know what? I'd rather not discuss it all the time. I've been discussing it for 44 years. . .

Well it's funny, at home I never ever wear my arm at all but when I'm out in public I do. So it's just a running joke in my family, I'm always like 'where's my arm? Have you seen my arm?' and it drives my son kind of – haha

3d) Domains

Person – affective

Environment – social, physical

3d) Focal Meaning

Chris wears an artificial limb in social environments to reduce recurrent questions and stares. In contrast, Chris declines to don a prosthesis at home and shares banter with family regarding having an upper limb absence.

3e) Meaning Unit

But I think what's kind of bringing me back and something I'm thinking about more and more is, as I age, I'm very active – run and lift weights, and had a special arm for biking and all those things. But I find now it's more of a focus, maybe more of a concern, I'm starting to get worried – what if I do something to my right arm? Or I think, my right arm has done everything for 44 years. Just the added stress and wear and tear it's taken. So, where am I going with this... haha anyway I'm getting more concerned as I age that I might have to, who knows, carpal tunnel hasn't happened (knock on wood). Just getting more concerned about what the future might bring as an adult amputee and how I'm going to be able to do things. Am I going to have to go back to using a myoelectric arm if something were to happen to my right hand? Or am I going to have to be more dependent and that'd be the absolute – because I am not – I don't like to depend on anyone. Am I going to have to ask for help more? Because I find I'm doing that a little bit more now. I really don't want to but with some things I am. And that's, you know, not a big concern but certainly something that's at the back of my mind.

3e) Domains

Person – affective, physical

Occupation – leisure

3e) Focal Meaning

The risk of injury to Chris's unaffected arm is increasingly considered with age. Chris resents the potential reliance on others and contemplates what future adjustments will be necessary.

3f) Meaning Unit

So yea, I guess, I've just always adapted, I just do things differently . . . I don't know if you know much about me, I grew – kind of the middle child of four. Grew up on a farm, mom and dad, you know I could do everything everyone else was doing no matter what so. Took up cross-country skiing at a young age, and you know but did that differently than everyone else. . .

So long story short, I've always had to adapt. Was really fortunate enough to grow up in an active family. I'd ride bikes, but sometimes my myoelectric arm would get stuck on it and then the battery would die and my arm would have to stay on the bike. Little things like that that have happened. And then a few years ago, I've always liked to run so I decided, you know, you can do anything. So I took up, you know, I could swim, but focused more on, I wanted to do a couple of triathlons. So training for those. But, I swim pretty weird with one arm. And then I was on my road bike and crashed that because I was using a passive arm, I didn't have a special arm made, and I flipped over a guardrail. So that was lots of fun. I still finished the race. So certainly, I guess, not one to give up. I've always adapted but, you know, little everyday things that sometimes – the things that I shared earlier – that get a little frustrating and certainly get in the way . . .

Oh yea and the great thing is apparently I just did a fantastic somersault. I was okay, someone stopped, and my bike was fine and I kept racing and had my fastest ever 5k run of my life. I think I was just so mad, because I passed a bunch of people on a bike. And then my parents were kind of standing on the side of the road because they were volunteering. So I went by my mom and she sees my legs all bloody and she was like ‘what did you do’ and I was like ‘I can’t talk right now’ . . .

I’m really lucky I’ve never broken my right arm too. My left arm I have, horseback riding with my brother. I fell off the horse wearing my arm and I landed on my left-hand side and passive artificial arms don’t have any give at all so when I hit the ground, just no give, and up by my left shoulder popped out. Yea a bit of a mess. I still have a big scar from it, having a compound fracture, had to put a metal plate in. That was a long time ago though.

3f) Domains

Person – affective

Occupation – leisure

Environment – social

3f) Focal Meaning

Chris’s dynamic childhood instilled traits of ambition, perseverance, and resourcefulness that are highlighted through the completion of physically strenuous leisure activities.

3g) Meaning Unit

And I was a part of the Champs program with The War Amps, which you've probably heard about. So I would often see other amputees, so I knew it was normal but I also knew, you know, I was the only one in my school, the only one in my community.

3g) Domains

Person – affective

Environment – social, institutional

3g) Focal Meaning

Institutional support aids in acceptance but does not alleviate feelings of alienation in social environments.

3h) Meaning Unit

You know what, in all honesty, and I've said this probably – not a million times – but quite a few times, I would not... I would not want to have two arms. People always say 'what if you could have one attached' or grow one or you know, weird things like that. And I'm so glad that – the big thing is my parents and how I grew up. But right now, if I had the chance to go back and to have two arms, or if all of a sudden I could have two, I wouldn't want it because it's not me. Yea, it's just not me. Think of all the things I've gotten to do, most of it's because possibly I was missing an arm. You know maybe, maybe not. I certainly take it to my advantage, it hasn't had a negative impact, except you know, your silly little everyday things that get in the way. But overall, yea I wouldn't want two arms, no way.

3h) Domains

Person – spirituality

### 3h) Focal Meaning

Having an upper limb absence is indispensable to Chris's perception of self.

### 3i) Meaning Unit

You know what I'll share . . . I haven't been in the dating scene for like 12 years, and I do have a son, so where am I going with this? So for adults that are missing limbs and going on dates, I bet you they – I know myself when I think back to many many years ago, it was more of a concern than when I was a kid. Because when I was a kid, I don't know, kids can be pretty mean, some kids can, and ask a lot of questions. That never really bothered me but I know as an adult and say meeting someone for the first time, I was really concerned. Why? I don't know, I don't think I would be now but say 15 years ago I was certainly concerned about my arm and being a bit of – you know what? A bit of a freak haha if that's the right thing to say. So dating can certainly be a little different. What if he grabs my left hand? Or sometimes people are like “you know, I never noticed” and I think ‘what are you’ – like I can't believe – it's two different colours of skin tone, one's plastic and one's not. So I think, well what if he were to grab my left arm and like ‘holy moly – that's not real’. You know, little things like that. And um – oh I'm really going on and on now . . . so you know, the dating world

### 3i) Domains

Person – spirituality, affective

Environment – social

### 3i) Focal Meaning

Novel social environments can distort Chris's sense of self and induce apprehension regarding being perceived by others as an aberration.

### 3j) Meaning Unit

. . .but then I remember, 'cause I have a son now who's [age], when he was born I would've been, I guess [age]. I was so worried about picking him up. . .

Anyway, I was just concerned with picking him up. Because an artificial arm is hard and, you know, it doesn't feel – I wouldn't want to pick up a little baby let alone anything with – a person – with my left arm. So I remember being so worried about, for one, picking him up, how am I going to hold his head and do everything. And I certainly adapted to all of that but . . . I did, I tried a couple of times with my arm on and I'm like 'no this isn't working'. So never wore my arm at all looking after my son or picking him up. But say if I put right hand, which is my normal hand, say under his armpit if he was standing, my left arm is short just below my elbow, so when I would go to pick him up one of his arms would go up higher than the other, if that makes sense. So then you start thinking well is he going to have one arm that's a little, you know, crazy because I'm always picking him up that way. So anyway, that was something I had to adapt and figure out on my own. But I remember being worried about changing and picking him up and putting on clothes, how am I going to do that with one hand? But certainly I did it. Yea, having a kid was a bit of a concern. And then you wonder too, because I was just born this way, my mom never took anything, just kind of freak nature happened. So then, you know, you always think, well I wonder if my kid will miss a limb? Which would have been fine but, yea.

3j) Domains

Person – affective

Environment – physical

3j) Focal Meaning

Parenthood introduces new disquietude pertaining to potential physical challenges caused by an upper limb absence or use of a prosthesis.

3k) Meaning Unit

What else comes to mind... I find sometimes that missing a limb, if I'm in a short-sleeved shirt so it certainly stands out, people asking if they can help. Like in the grocery store and I'm picking something up and holding a basket. I might hold the basket a little differently than most people. But people coming up to me asking if they can help – which is very nice that they're doing that – it's a bit of a pet peeve of mine. Like you know, if I needed help I would ask for help, but it's fine. It can be a little bit of a pain in my side.

3k) Domains

Person – affective

Environment – social

3k) Focal Meaning

Although extended with good intention, unsolicited offers of assistance generate feelings of vexation in Chris.

3l) Meaning Unit



Cutting – oh my goodness – you know what’s tough missing a limb? And back to dating, or even meeting people for the first time going out to supper, cutting your food, cutting meat. Like I will totally, totally try to avoid ordering or getting anything where I can’t cut it with a fork. And yes I know you can get special utensils but, you know in all honesty, you know – haul out my special utensil in my purse at a meal. And even more or less now, not that I have to, but if I can avoid using a knife to cut something I will. I have to hold it awkwardly in my left hand, kind of weave it in between the passive hand fingers and sometimes it flies out and anyway. Yea, so restaurants, try to avoid anything where you have to use a knife. Crazy. Yea, things like that. . .

Or you know, to sports bras for running. Pretty much have to avoid any – like some of them are pretty complicated and I have to make sure that they’re simple – like even just a bra, like do up in the front and then I turn it around to the back. Some sports bras you have to have them on first and then do up the clasp in the back and I can’t do that. So I certainly have to really think when buying items like that. Am I going to be able to do this up? And if I’m not then I’m not buying it.

31) Domains

Person – physical

Occupation – self-care

Environment – social

31) Focal Meaning

Premeditated modifications to mundane self-care activities enable Chris to circumvent both physical barriers and unwanted attention.

### **Situated Structural Description for Chris.**

In adulthood, Chris perceives elements of having CLD that were not considered throughout adolescence. For example, an upper limb absence exacerbates physical challenges presented by daily self-care activities that are necessary for professionals, often requiring Chris to seek assistance. Furthermore, as an adult, Chris's prosthesis introduces novel impediments to occupations and is intermittently deemed bothersome and removed. This is demonstrated when caring for infants, as parenthood instills new disquietude regarding potential challenges caused by an upper limb absence or use of a prosthesis. Finally, the risk of injury to Chris's unaffected arm is increasingly considered with age. Chris resents the potential reliance on others and contemplates what future adjustments will be necessary.

Chris's dynamic childhood instilled traits of ambition, perseverance, and resourcefulness that are highlighted through the completion of physically strenuous leisure activities. Although extended with good intention, unsolicited offers of assistance generate feelings of vexation in Chris. Premeditated modifications to mundane self-care activities enable Chris to circumvent physical barriers and unwanted attention.

Having an upper limb absence is indispensable to Chris's perception of self. However, novel social environments can distort Chris's sense of self and induce apprehension toward being perceived by others as an aberration. Consequently, Chris chooses to wear an artificial limb in social environments to reduce recurrent questions and stares. In contrast, Chris declines to don a prosthesis at home and shares banter with family regarding having an upper limb absence. For Chris, institutional support aids in acceptance but does not alleviate feelings of alienation in social environments.

***Participant 4: Devin***

**Meaning Units, Domains, and Focal Meanings for Devin.**

4a) Meaning Unit

okay. It's been 26 years, so. Well the recent experience would be I'm a new grandmother . . . she's 9 months old, so I have to, I take off my prosthesis to take care of her. Because it's too hard, I'm afraid to hurt her if I have the prosthesis. And I could feel her more without it . . . But um, yea, I raised my two kids with the amputation. When I was amputated 26 years ago I had a 3 month old and a 15 month old, so that was... it's like it's on different years, different levels of the way I carried myself with or without the prosthesis. So, yeah. Everyday use, I use it every day, except now with my little grandbaby.

4a) Domains

Person – physical, affective

4a) Focal Meaning

Due to trepidation, Devin's prosthesis emerges as a physical barrier to providing care to infants.

4b) Meaning Unit

But apart from that I wear my prosthesis every day. It's just part of me now. It's just, people don't even notice that I'm an amputee because I carry it so well.

4b) Domains

Person – spirituality

4b) Focal Meaning

Integral to Devin's body image, embodiment of the prosthesis is demonstrated.

4c) Meaning Unit

It's a myo[electric] yea . . . Yes, so that, really now, I feel like I couldn't live without it.

Just to help me zip up things and uh, everyday things you do with your two hands I can do with my myo[electric], so.

4c) Domains

Person – physical

Occupation – self-care

4c) Focal Meaning

Devin considers prostheses essential to performing occupations.

4d) Meaning Unit

. . . I lost my limb in December, and by May I had my prosthesis. But it was, uh, still then it wasn't processed . . .

To adjust and in the beginning, I didn't want it, I didn't accept it. It was such an emotional trauma. Now it doesn't seem, like looking back it was a trauma, but now it doesn't seem like, you know it's everyday life for me. This is the way I am now . . . Yea, it's just, it's a whole process really. This is what life gave me and you know, you just deal with it and do the best you can. That's all we can do.

4d) Domains

Person – affective

4d) Focal Meaning

Replete with affective adversities, the journey to acceptance for Devin has been extensive and arduous.

4e) Meaning Unit

Plus, in the beginning, I had such a traumatic 2 years, right up to the time I lost my hand. You know, I had cancer with this also. But before that I had lost my mom to cancer. So I watched her go through that, and then I had my two kids right 'bam bam' right one behind the other. And then I got cancer myself and then at the end of cancer I lost my arm. So it's like a, it's like a whole chapter right there.

Yes, it was a very long period of stress but when I lost my arm, that's when I started to get better. Physically. So, after that, it was a process of getting used to being an amputee and taking care of my two kids. And, you know, everyday life. . .

Being an amputee has been challenging, but like I said, it was a ending to a turbulent 2 years before starting with the loss of my Mom, witnessing her go through cancer and succumb to it. The week after her loss, I got pregnant with my son, when he was 10 months old, I got pregnant with my daughter, all the while I was feeling ill myself, but just thought I had gone through so much in a short period of time, I told myself I was just tired. When my daughter was 3 months, I found a lump...a biopsy was done, it was Hodgkin's stage 4, thank goodness the doctor only told me the stage after I was healed, it would've been heavier to know that. While having lifesaving chemo, I developed a sort if skin infection on my left arm, a sort of gangrene. My last chemo was right before Christmas, and on the 26th of December 1994, my arm turned black with what felt like

intolerable pain. From [Hospital Name], I was transferred to [Hospital Name] where my arm was amputated the next day. So now I was finally cancer free, but I was a new amputee. On to healing and adjusting to life as a new mom and a new amputee. There was a lot of learning of how to navigate life, getting used to a prosthesis, and also healings from the passing of my mom. I felt for years that her loss was more painful than losing my arm, she was 50, I was 25.

4e) Domains

Person – affective, physical

4e) Focal Meaning

Devin's suffering due to limb loss was compounded by additional physical and affective hardships. Paradoxically, amputation terminated an extended duration of affliction caused by a malady while simultaneously commencing a difficult process of adjustment.

4f) Meaning Unit

Yea, so the acceptance throughout the years changed, up until now, which is, I'm ok.

You know, it's really fine now. I'm totally okay with it.

Anything that helped with the adjustment... really, it's all work from inside. There's nothing really that can help you adjust except your own mind, your own thoughts about it. So it – therapy, therapy worked. Not just because of my arm, but just because of life itself. It's just, it's a whole, it's all intertwined with everything. So accepting your own self and your own body throughout the years makes everything easier.

I'm surrounded by great friends and great family also. So they helped me along the way also. So, you know, I'm well-loved. Yes, strong support network, yep . . .

Now 26 years later, I'm [age], it all seems like it was all part of my journey, like I said, I'm surrounded by wonderful family and a circle of friends that don't see me or define me as an amputee, I'm just Devin, it's all in the thought process, always putting a positive spin on things.

4f) Domains

Person – spirituality, cognitive, affective

Environment – social, institutional

4f) Focal Meaning

Adaptation to new existence emanates from cognitive and affective growth, augmented by encouragement from loved ones.

4g) Meaning Unit

In everyday life, I'm so used to it now there's really no challenge. The only challenge I would say is, I'm still not 100% with how people perceive me. So it's more of a, I can't say, I'm about 95% there, I'd say. But I still wear, in certain places I'll still wear a long sleeve or a three-quarter sleeve, just to cover the arm partly. If I go to the grocery store, I'm still not 100% there. But I am, if I can go to the beach and take off my arm and go to the beach and swim. I have no problem with that. But it's just certain areas of where I go, I'm still not 100%. I still have work to do.

4g) Domains

Person – affective

Environment – social

4g) Focal Meaning

Otherwise demonstrating acceptance and adjustment, the reactions of peers persist as a challenge to Devin's affect.

#### 4h) Meaning Unit

What I wish I had when I was newly amputated would of been someone who had gone through it themselves, I did get introduced to a young woman who had loss her arm, but it was new to her too and I felt that we were both dealing with it in a different way. I think I needed someone who had some years of experience. But then again, it's a journey that I had to navigate myself, a learning process for sure. [Clinician team member] knows I'm always available to connect with new amputees, to give them what I felt I needed then.

#### 4h) Domains

Occupation – productivity

Environment – social, institutional

#### 4h) Focal Meaning

Upon losing a limb, Devin desired, but was unable to find, comradeship and guidance from others who had lived with an upper limb loss for a while. Consequently, Devin now elects to offer such moral support to those who seek it.

### **Situated Structural Description for Devin.**

Devin's suffering due to limb loss was compounded by additional physical and affective hardships. Paradoxically, amputation terminated an extended duration of affliction caused by a malady while simultaneously commencing a difficult process of



adjustment. Replete with affective adversities, the journey to acceptance for Devin has been extensive and arduous. For Devin, adaptation to new existence emanates from cognitive and affective growth, augmented by encouragement from loved ones. Demonstrating acceptance and adjustment, the reactions of peers persist as the only challenge to Devin's affect.

Devin considers prostheses essential to performing occupations. Furthermore, a prosthesis is integral to Devin's body image, demonstrating embodiment of the device. However, due to trepidation, Devin's prosthesis emerges as a physical barrier when providing care to infants.

Finally, upon losing a limb, Devin desired, but was unable to find, comradeship and guidance from others who had lived with an upper limb loss for a while. Consequently, Devin now elects to offer such moral support to those who seek it.

### ***Participant 5: Elliot***

#### **Meaning Units, Domains, and Focal Meanings for Elliot.**

##### 5a) Meaning Unit

So at 22 years old, actually my 22<sup>nd</sup> birthday, I got my hand caught in a conveyor belt . . . but at the end of the day, really it's just my carelessness and basically had my hand where it shouldn't have been. So I got wounded, I was caught for 10 seconds or so, but it totally ripped it off.

I was about 21 days in the hospital and was out a little early because my mother was a nurse at the time, so she was able to basically change my bandages every day . . . and whatnot.

5a) Domains

Person – physical

5a) Focal Meaning

Inattention while working with serious equipment precipitated the loss of Elliot's upper limb.

5b) Meaning Unit

But then, I was in line to be fitted with a myoelectric prosthesis from UNB. Because my doctor that I had . . . because I was only 22, he wondered about prosthetics for me. That I could take with a grain of salt, but either way, the myo experience wasn't great for me. I had a lot of trouble with the [myoelectric] elbow. At one time the electrodes actually burned holes in my skin because it short-circuited, and the back bit burnt into my electrodes. And of course, with minimal feeling in the stump, I didn't know that I was getting burnt. And we had a lot of trouble with the [myoelectric] elbow, sometimes I think I would have just rather gone with a passive prosthesis with cables and hooks. But it is what it is.

That being said, at a young age and I was very self-conscious of how my prosthetic looked, so a hook and cables might have made that worse, I don't know.

5b) Domains

Environment – physical

5b) Focal Meaning

Desirability of a prosthesis entails a balance between functionality and appearance.

5c) Meaning Unit

Yea, the cosmetics were really an issue for me. I had very little self-esteem at that time. You know I was a victim of sexual abuse as a child so my whole world was already askew and then throw this in on top of it. The only thing I felt I had going for me before I got hurt was my physique, because I was well built, y'know, blah blah blah. So yea, it really took its toll on me . . .

I just, I wanted that other arm to be there. I didn't like the image of myself without it . . .

5c) Domains

Person – spirituality, cognitive, physical

5c) Focal Meaning

Losing an upper limb disrupted Elliot's body image and confidence.

5d) Meaning Unit

There wasn't really anything in the healthcare system at that time set up to help me. I did reach out to a psychologist that worked for the [Hospital Name], he kind of helped me a little. He said you know try and build some humour around it, take it in stride, sort of . . . So it was difficult, I turned to the liquor. Like again, because of my childhood . . . tried to drink the pain away and hide in the bottle. But only went on for a little while. I think at 26 I ended up in AA. And I am sober for 5 years, I did my 12 steps several times. I was on a path of self-destruction. I wasn't necessarily a full-blown true alcoholic, but I was starting to drink like one and certainly had behavioural issues that needed to be dealt with. Just very angry all the time.

So I come out of the other side of that, I found a real good therapist only just a year ago that helped me with my abuse issues and also I had to start antianxiety meds about, I don't know, probably 6 years ago . . . and it's helped to take the edge off a lot.

Principal Investigator: You said that there weren't really any resources offered to you from hospital staff or anything back then?

No, nothing.

Principal Investigator: None, wow. And so you had to take it upon yourself to reach out to that psychologist?

Yep. And then many other times after that. I've probably been through 70 hours of therapy since I was probably 23. I went the first time . . . and then I didn't go again for, I don't know, probably 5 or 6 years. And then every so often I'd reach out because I needed help. I needed help to cope. And so when I finally found this gentleman last year . . . he helped me tremendously . . . my quality of life is certainly better let's say. My mind's a lot quieter . . . I'm back in control of my life again, I feel.

5d) Domains

Person – affective, cognitive

Environment – institutional

5d) Focal Meaning

With no support offered by the health care system, Elliot sought mechanisms to cope, intermittently seeking aid when despondent. The eventual procurement of effective care greatly ameliorated Elliot's cognitive and affective well-being.

5e) Meaning Unit

. . . but it was difficult because the thing with losing a limb, after you've had one, you wake up every day and it never goes away. They can attribute it to loss of a loved one, I've heard that different times, but, you lose a loved one and there is mornings that you wake up and look in a mirror and you don't think of that loved one necessarily. Like the pain fades with time. With a limb loss, it's there every second of every day. So it makes it more difficult in that way. I did have a hard time with it, I'll be honest with ya.

5e) Domains

Person – cognitive, physical

5e) Focal Meaning

The absence of a limb is a relentless reminder of what has been lost.

5f) Meaning Unit

I mean I'm [age] now, so I've got almost 34 years, I've got 33 and a half years now that I've been handicapped. I can look back – I can tell you things now that I couldn't – that I was experiencing through my life that I didn't realize at the time, right? I can go without my prosthetic now for days and days and days and days and go everywhere and do everything and it really doesn't bother me. Whereas one time I wouldn't be caught dead outside of the house without it, right? . . . but now I'm really ok with it. So there's a big change that way, I've relaxed a lot, because I am older. I mean I'm married; I've got a 20-year-old and a 17-year-old. So, you know, your life changes, right? You grow up and your mindset changes – and none of us are the same person that we were this time last year.

5f) Domains

Person – cognitive, physical

5f) Focal Meaning

The passing of time elevates acceptance and adjustment.

5g) Meaning Unit

With me, my whole life I grew up in my beloved garage. So I did everything myself mechanic-wise. Worked on my own vehicles, motorcycles, snowmobiles, the whole 9 yards. I was always doing complex . . . maneuvers when I was 15 years old. And after losing a limb, that ended. And I tried to do stuff, and I did accomplish a lot, don't get me wrong, I was so tenacious and stubborn that I did do things . . . but I got away from that about 10, yea 15 years ago, 'cause it just was such a source of aggravation. Because I knew how and always could but then now I can't nearly as easy and it just – I thought you know what I'm just beating myself up. So I walked away from that.

5g) Domains

Person – affective

Occupation – leisure

5g) Focal Meaning

Ensuing limb loss, leisure occupations that once were considered undemanding now provoked feelings of exasperation, inducing Elliot to relinquish such passions.

5h) Meaning Unit

So, silver lining to the dark cloud of losing my arm traumatically is that Workers' Compensation said they'd retrain me. I first thought that they'd just come to the house

and get me to sign off and give me a hundred dollars and say go away. Haha kind of – you know what I mean? But anyway, [Workers' Compensation] came to the house at my parents' and he said, "We'll retrain you", and I said, "In what?" And he said, "Anything you want". So I – when I first graduated high school I went to community college and I enrolled in pre-technology because I didn't have my level two math and sciences. So I enrolled in pre-tech and then I was going to take civil engineering technology, because I love the idea of the outside/inside job. And I failed. Both years I tried pre-tech and I just I wasn't interested in being there. Mind you I did graduate on the honour roll in high school, but I just didn't grab the book at community college. So I failed and then that's when I went to work. So I mentioned to him about civil again and he said, "Sure, we'll pay you your 80-whatever, 80% of your wage", and they paid my tuition and the whole 9 yards. So I did graduate 3 years later. I went to school September of '87 and June '90 I graduated with a civil engineering technology diploma . . .

Yea, so amazingly I got through that, 'cause I was drinking quite a bit at the time. But I did do it and passed everything and got a job with [Organization Name]. And I've been here now since 90s so, what am I, 30 years, this year.

Yea it was really, like I say it's definitely a silver lining. Because I know I talk to [Clinician Team] . . . well they were telling me this winter, just, I don't know how we got on the subject but they just kind of offered up, they said, "Well most people with your injury never work again". And I felt pretty good about that. The fact that I went back to school and ended up with a much, much better future really. Because now I have a good job and pension and good rate of pay. I could've went back in construction and you know, just worked . . . moving trucks or whatever. And that would've been pretty

much a dead-end job, right? So I did end up getting a good career out of going back to school, so that worked out well. Yea I was tenacious I guess, and I never thought a whole lot of it until they said that. But most people, even at [that age] never work again, right? And I thought wow that's something to be proud of actually, that I could do that for myself . . .

. . . Because I got hurt on the job, they contacted me. An automatic thing, that worked really well. And it's funny, when I graduated community college I thought, well maybe now I can go to university – but I never thought I was university material, I didn't think I was smart enough. And after I graduated community college, 'cause it's an extremely hard course, I took the highway municipal option and it's the hardest one of all the disciplines in the college. And I thought, hey, I can do anything now. He said, “Unfortunately, the compensation board considers you retrained, so they can't retrain you again”. So I said no problem, I got a job at [Organization Name]. Yea, I wouldn't have gone too much further but hey I got a great career out of it I have a great job and I'm not complaining one bit . . .

Yep, and [Job Organization Name] asked me to do this – there's this under bridge platform that we use to inspect the big bridges . . . and they trained me to also go on that platform. They said, “Would you like to do your own bridges?”, because someone else has done them from our team before. And I said, “Sure if there's a way that I can do it”. Yea they set up all the training . . . I have a couple of special precautions that I have to take, I have to have a self-retracting lanyard hooked in my harness at all times that I'm going up and down the ladder of the machine to get underneath the structure, because you have to get underneath and stuff . . . Yep it's a good gig.



5h) Domains

Occupation – productivity

Environment – institutional

5h) Focal Meaning

Elliot feels fortunate that losing a limb while at work created the opportunity to obtain a formal education and proud of the subsequent career accomplishments.

5i) Meaning Unit

Now as far as life goes, I mean I try and not do too much because my arm is wearing out of course. And my shoulder and stuff. But I still grab a shovel sometimes and I'll shovel for 5 or 10 minutes, you know, until I start to get tired. I don't overdo it like I used to. I don't try and lift things anymore. I used to carry washers and dryers up and down stairs with people if I was helping them move or moving myself or whatever, I don't bother with any of that. I hurt my back a few times, so I try to stay away from any heavy lifting and yea.

5i) Domains

Person – physical

Occupation – self-care

5i) Focal Meaning

With age, Elliot grows increasingly wary of further harm and abstains from completing laborious self-care and productivity occupations.

5j) Meaning Unit

I drive all the time for work and . . . I have an office and all of that and I've had ergonomic assessment that set me up so . . . that I'm sitting with proper posture and proper chair and all that which is great . . . it's really stuff to pay attention to because I don't need a repetitive strain or injury . . . So in that way too, [Job Organization Name] has been very forthcoming with paying for my ergonomic assessment and whole 9 yards. They say it's worth all that cost that they have people that do that.

5j) Domains

Person – physical

Environment – institutional

5j) Focal Meaning

Elliot's employers implement precautionary modifications to prevent physical stress.

5k) Meaning Unit

So I don't know what else I could tell you really. That pretty well does it. There's still things I get a little frustrated at but I take it in stride a lot better than I used to. But yea it'd be nice if – I don't know what there is today for people that are hurt in a traumatic accident. You don't hear tell very much around here of people losing an upper limb in an accident, but it's something that should have mechanisms in place. Ok this happened well it could trigger this person or that person to go in and talk to these people. And do follow-up because, when I first got hurt, I was in denial. And I'm not sure exactly why. In a way it was good because I just put forward like a friggin' bull. But yea, I was in some denial. So it'd be nice to have a follow-up. You know, if somebody said they go talk to somebody for a session or 2. Then in 6 months have a follow-up. Get that person

to call again. And then in 6 months do it again. And stay at it. For years really. It should really be set up that way for people . . .

5k) Domains

Environment – institutional

5k) Focal Meaning

Elliot emphasizes the importance of long-term institutional support, notably, from peers, for the cognitive well-being of individuals experiencing upper limb loss.

### **Situated Structural Description for Elliot.**

Inattention while working with serious equipment precipitated the loss of Elliot's upper limb. Losing an upper limb disrupted Elliot's body image and confidence; the physical absence of a limb is a relentless reminder of what has been lost. With no support offered by the health care system, Elliot succumbed to detrimental coping mechanisms, intermittently seeking aid when despondent. The eventual procurement of effective care greatly ameliorated Elliot's cognitive and affective well-being. Additionally, Elliot indicates that the passing of time elevates acceptance and adjustment. Presently, Elliot emphasizes the importance of long-term institutional support, notably, from peers, for the cognitive well-being of individuals experiencing upper limb loss.

Elliot feels fortunate that losing a limb while at work created the opportunity to obtain a formal education and consequent enhanced career opportunities. However, ensuing limb loss, leisure occupations that once were considered undemanding now provoked feelings of exasperation, inducing Elliot to relinquish such passions.

With age, Elliot grows increasingly wary of further harm and abstains from completing laborious self-care and productivity occupations. As well, Elliot's employers implement precautionary modifications to prevent physical stress. Finally, for Elliot, desirability of a prosthesis entails a balance between functionality and appearance.

### ***General Structural Description***

From the five situated structural descriptions, a final passage was composed. The general structural description, or core finding, is:

Accepting oneself as a person with ULLD is marked by cognitive well-being and indicates a shift in spirituality, or perception of self. The environment influences acceptance, with the capacity to bolster the well-being of individuals. In contrast, the stereotypes entrenched in society's perceptions present challenges to spirituality and cognitive well-being. Smashing through stereotypes, however, imparts a high sense of accomplishment and pride. Peer support is desired amongst persons with ULLD but is found wanting.

Although ULLD renders certain occupations increasingly difficult, individuals demonstrate that much is achievable through modification and determination. The prosthesis is meaningful to adults with ULLD and is viewed as either part of the person, part of the environment, or a combination of both. Finally, aging introduces new concerns for some individuals with ULLD.

### ***Essences***

The general structural description is composed of eight themes, or essences, and is presented in the language of the theoretical framework (CMOP-E). These essences

were revealed by in-depth analysis-synthesis of the data descriptions and application of the CMOP-E. The following section discusses in detail each of the eight essences and illustrates that the higher level of discourse is based on the participants' own words.

**Essence 1: Accepting Oneself as a Person with ULLD is Marked by Cognitive Well-Being and Indicates a Shift in Spirituality.** Participants' acceptance of life with ULLD is illustrated through cognitive well-being. Participants are content with having ULLD and for some this is reflected by the lack of everyday contemplation of the subject, "*Living with the absence of my left arm is not something that I think of every day. For me personally I go about my day thinking I have 2 arms some days*" (Alex).

For others, this peace of mind is exhibited through spirituality, or from where one draws meaning:

*It's made me a better person in lots of ways . . . There are even times where I've said, in some ways it's been a blessing that I do have a prosthetic or don't have a hand, just because I appreciate life a lot more. (Blake)*

Thus, one's outlook on life can be positively shaped by the absence of an upper limb. Optimistic perspectives such as Blake's emanate from the individual's spirituality and are indicative of cognitive well-being and acceptance.

Spirituality also refers to one's perception of self. In such context, cognitive well-being and acceptance are displayed when ULLD has been incorporated into an individual's self-identity. The following meaning unit exemplifies this:

*. . . I've said this probably – not a million times – but quite a few times, I would not, I would not want to have two arms . . . right now, if I had the chance to go back and to have two arms, or if all of a sudden I could have two, I wouldn't want it because it's not me. Yea, it's just not me . . . I wouldn't want two arms, no way. (Chris)*

However, cognitive well-being and acceptance of ULLD do not occur instantly and can take years to achieve. For some, peace of mind and acceptance arise from the passing of time:

*I can go without my prosthetic now for days and days and days and days and go everywhere and do everything and it really doesn't bother me. Whereas one time I wouldn't be caught dead outside of the house without it, right? . . . but now I'm really ok with it. So, there's a big change that way, I've relaxed a lot, because I am older. I mean I'm married; I've got a 20-year-old and a 17-year-old. So, you know, your life changes, right? You grow up and your mindset changes – and none of us are the same person that we were this time last year. (Elliot)*

Over the years, Elliot experienced cognitive growth and a shift in spirituality that led to acceptance. Similarly, Devin also emphasized the importance of cognitive growth over time for acceptance:

*The acceptance throughout the years changed, up until now, which is, I'm ok. You know, it's really fine now. I'm totally okay with it . . . it's all work from inside. There's nothing really that can help you adjust except your own mind, your own thoughts about it . . . in the beginning I didn't want it, I didn't accept it. It was such an emotional trauma. Now . . . you know it's everyday life for me.*

*This is the way I am now. So yea . . . it's a whole process really. This is what life gave me and you know, you just deal with it and do the best you can. That's all we can do.* (**Devin**)

Thus, although the journey to acceptance can be long and challenging, cognitive well-being and shifts in spirituality demonstrate acceptance of life with ULLD.

**Essence 2: The Environment Influences Acceptance, with the Capacity to Bolster the Well-Being of Individuals.** As depicted by the CMOP-E (Figure 1), the environment is the domain within which the person exists (Polatajko et al., 2007). Accordingly, in the present study, the environment was found capable of having a direct, positive impact on the person, ultimately influencing acceptance. Many participants identified various social environments that have had beneficial effects. Reflecting on childhood, one participant revealed that “. . . [I] was really fortunate enough to grow up in an active family” (**Chris**). Encouraged by siblings and parents, Chris demonstrated acceptance and attributed a current active lifestyle to the social support provided by family from a young age.

Another participant highlighted the significant role that social environments play in the journey to acceptance, “I’m surrounded by great friends and great family also. So they helped me along the way. So, you know, I’m well-loved . . . Yes, strong support network” (**Devin**). For Devin, the presence of friends and family to help navigate life with ULLD was essential. This illustrates how support provided by loved ones can facilitate well-being and acceptance.

The importance of social involvement with groups outside of one's close family and friends was also highlighted:

*Playing hockey has been a blessing, my parents got me into hockey, I was at 3 or 4 years of age. So, just being involved in sports is a great – you know it's involvement, it's getting out there, it's getting involved in the community and socializing. So that's been good. You know I could see where some kids, as they're growing up, by not having a limb they may shy away and it's not good for your mental health. But anyways, I was able to overcome that, without even knowing. (Blake)*

Blake exemplifies that participation in various group activities contributes to overall well-being and acceptance. This further highlights the positive impact that social environments can have on individuals with ULLD.

In addition to social environments, however, physical environments also directly influence the well-being of an individual. For some, certain physical environments can produce feelings of empowerment and contentment:

*When I feel my uttermost "invincible self" I like to call it, is when I am at the gym . . . This is my place that I feel comfortable, resilient and courageous. A place that I know I can do ANYTHING and I never have the thought coming to mind that I have an absent limb. (Alex)*

This meaning unit demonstrates that the physical environment of the person is capable of arousing feelings of acceptance and heightening overall well-being.

Finally, institutional environments can also directly influence well-being and acceptance:



*. . . I found a real good therapist only just a year ago that . . . helped me tremendously . . . my quality of life is certainly better let's say. My mind's a lot quieter . . . I'm back in control of my life again, I feel. (Elliot)*

As exemplified by Elliot, therapy, an example of an institutional environment, produces considerable positive effects for individuals.

Together, these meaning units illustrate that the environment, whether it be social, physical, or institutional, directly influences the person. Specifically, the environment has the capacity to improve the overall well-being and acceptance of individuals with ULLD. These findings are congruent with the representation of the person existing within the environment found in the CMOP-E (Figure 1).

**Essence 3: The Stereotypes Entrenched in Society's Perceptions Present Challenges to Spirituality and Cognitive Well-Being.** In contrast to Essence 2, the environment can also be a source of negativity. Specifically, the cognitive well-being of individuals with ULLD can be challenged due to social stereotypes and stigmas that are present in one's social environment:

*. . . as an adult and say meeting someone for the first time, I was really concerned. Why? I don't know, I don't think I would be now but say 15 years ago I was certainly concerned about my arm and being a bit of – you know what? A bit of a freak haha if that's the right thing to say. (Chris)*

For some, the perceptions of others remain the greatest barrier to acceptance:

*The only challenge I would say is, I'm still not 100% with how people perceive me . . . in certain places I'll still wear a long sleeve or a three-quarter sleeve, just to cover the arm partly . . . I still have work to do. (Devin)*

This meaning unit demonstrates that the stereotypes that are present in others' perceptions can disturb one's cognitive well-being and acceptance.

Such stereotypes can also affect the spirituality and distort the self-identity of individuals with ULLD:

*It took me a while to truly understand and accept myself as disabled, because that is what the general population sees, I just don't see myself that way. Of course, I realize it more when I'm in public and people are staring at me, I wonder "What is it they're staring at?!" and I realize "Oh yeah, I'm missing an arm!!". (Alex)*

Due solely to the perceptions of others, the label of "disabled" has been accepted and Alex's self-image has been altered. This exemplifies how stereotypes can influence and disrupt an individual's spirituality, or perception of self.

Finally, the existence of these stereotypes is evident as early as childhood. The following meaning units illustrate that individuals with ULLD experience difficulties due to stigma from a young age:

*As a result of not having my right hand, I would say that I have dealt with adversity. When you're young and you're a kid there's always kids that are curious, right? Or they'll ask questions or, you know, they'll look or stare.*

**(Blake)**

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*When I was a kid, I don't know, kids can be pretty mean, some kids can, and ask a lot of questions. (Chris)*

**Essence 4: Smashing Through Stereotypes Imparts a High Sense of Accomplishment and Pride.** Although social stereotypes are challenging for individuals with ULLD, defying these stereotypes instills feelings of self-confidence and self-worth. For some, these euphoric feelings can be attained by completing arduous physical tasks:

*When I feel my uttermost "invincible self" I like to call it, is when I am at the gym. I have realized I can do things there that EVERYONE can do there, plus more!! I see myself lifting heavier weights than some guys! (Alex)*

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*I've always liked to run so I decided, you know, you can do anything. So I took up . . . triathlons. (Chris)*

For others, occupations that are not based on physical ability can also impart such feelings. One participant describes surpassing expectations regarding educational and career advancements:

*I talk to [clinician team] . . . they said, "Well most people with your injury never work again". And I felt pretty good about that. The fact that I went back to school and ended up with a much, much better future really . . . Yea I was tenacious I guess, and I never thought a whole lot of it until they said that. But most people, even at 22 never work again, right? And I thought wow that's something to be proud of actually, that I could do that for myself. (Elliot)*

Finally, not adhering to stereotypes also has a positive effect on others in society. Breaking from the mold of what is expected can aid in decreasing the stereotypes that are present in society's perceptions of individuals with ULLD:

*I consider myself that I've been successful in life . . . there's even lots of adults that have had questions and been curious. But in some ways, I've inspired them because of what I've done and what I've accomplished throughout my life.*

**(Blake)**

**Essence 5: Peer Support is Desired Amongst Persons with ULLD but is Found Wanting.** The beneficial effects of social support have been previously discussed under Essence 2. However, one component of social support that was found to be particularly important was peer support, or support from individuals who have lived with ULLD for a while. Each of the two participants with an acquired limb loss discussed the unmet desire for support from others with an upper limb loss:

*What I wish I had when I was newly amputated would have been someone who had gone through it themselves. I did get introduced to a young woman who had lost her arm, but it was new to her too and I felt that we were both dealing with it in a different way. I think I needed someone who had some years of experience.*

**(Devin)**

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*You don't hear tell very much around here of people losing an upper limb in an accident, but it's something that should have mechanisms in place. Ok this happened well it could trigger this person or that person to go in and talk to*

*these people. And do follow-up because, when I first got hurt, I was in denial . . . So it'd be nice to have a follow-up. You know, if somebody said they go talk to somebody for a session or 2. Then in 6 months have a follow-up. Get that person to call again. And then in 6 months do it again. And stay at it. For years really. It should really be set up that way for people. (Elliot)*

One participant with CLD did have access to a level of peer support as a child; however, this participant indicated that additional peer support would assist in decreasing feelings of alienation:

*I was a part of the Champs program with the War Amps . . . so I would often see other amputees, so I knew it was normal but I also knew, you know, I was the only one in my school, the only one in my community . . . (Chris)*

Together, these meaning units demonstrate both the strong desire and the current inadequacy surrounding peer support for persons with ULLD. The potential positive impact that such support could render is highlighted. Additionally, the need for institutional aid to implement peer support is expressed.

**Essence 6: Although ULLD Renders Certain Occupations Increasingly Difficult, Individuals Demonstrate that Much is Achievable Through Modification and Determination.** Although achievable, certain everyday self-care tasks are more challenging due to ULLD:

*The only time I would say I notice my disability is when I subconsciously try to do things with 2 hands and end up dropping items I am trying to hold, or perhaps pushing a heavy grocery cart, maybe even tying my shoes, putting on a watch, or*

*when I need to ask someone to zip my coat up for me. I can still manage to do all of these things; they are simple to the general public – yet considered difficult tasks for me personally. (Alex)*

Furthermore, leisure occupations that once were considered effortless can be a source of frustration ensuing limb loss:

*My whole life I grew up in my beloved garage . . . I was always doing complex . . . maneuvers when I was 15 years old. And after losing a limb, that ended. And I tried to do stuff, and I did accomplish a lot, don't get me wrong, I was so tenacious and stubborn that I did do things . . . but I got away from that about 10, yea 15 years ago, 'cause it just was such a source of aggravation. Because I knew how and always could but then now I can't nearly as easy and it just – I thought you know what I'm just beating myself up. So I walked away from that. (Elliot)*

However, despite relinquishing leisure occupations due to novel feelings of exasperation, Elliot displayed qualities of resolution and determination by relearning how to perform such tasks with an upper limb absence. Blake also demonstrated these characteristics:

*Through life I've been able to accomplish – there's nothing that I can't do physically. I've always been able to figure it out one way or another. Like I said I played hockey my whole life, I played sports in high school, I played soccer, I played football. Growing up I had a snowmobile and bicycles. So, I've been able to adapt. I've always been a firm believer that if there's a will there's a way. (Blake)*

The above meaning unit also illustrates the resourcefulness of some persons with ULLD. This quality is further exhibited through the modifications that individuals make to complete occupations:

*I've just always adapted; I just do things differently . . . Grew up on a farm . . . you know I could do everything everyone else was doing no matter what. Took up cross-country skiing at a young age . . . but did that differently than everyone else . . . So long story short, I've always had to adapt. (Chris)*

**Essence 7: The Prosthesis is Meaningful to Adults with ULLD and is Viewed as Either Part of the Person, Part of the Environment, or a Combination of Both.** Perceptions of prostheses are subjective, varying between individuals who wear a device. For some, the prosthesis is incorporated into the schema of one's own body:

*It's just an extension of my body, right? It's no different than you know, you put your glasses on or you put a pair of boots on . . . I don't really think about it. When I go home in the evenings, I take my arm off if I know I'm in for the night, just to give my arm a little bit of a breather, like a rest . . . But you know there's times where I'll get home and for whatever reason I'll put my arm back on and I won't even know that I have it on. So it's not that it's a burden. It's like, at this point in my life, it's a part of me. (Blake)*

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*I wear my prosthesis every day. It's just part of me now . . . people don't even notice that I'm an amputee because I carry it so well. (Devin)*

These meaning units exemplify how some individuals with ULLD embody the prosthesis.

Others, however, view the prosthesis as part of the environment, rather than part of the person:

*I've always worn an arm . . . it's been very rare where I've gone anywhere without wearing an arm. I guess part of that is just I'm getting, it's bad to say but, you know, so tired of explaining or just the looks that, you know, you certainly get from people . . . Well it's funny, at home I never ever wear my arm at all but when I'm out in public I do. (Chris)*

For Chris, the prosthesis is a tool (part of the environment) utilized in social settings to reduce recurrent questions and stares. In contrast, when at home, Chris chooses not to wear a prosthesis, further demonstrating that the device has not been embodied.

Issues with prostheses further highlight how some individuals view the prosthesis as part of the environment and not part of the person:

*. . . the myo[electric] experience wasn't great for me. I had a lot of trouble . . . At one time the electrodes actually burned holes in my skin because it short-circuited, and the back bit burnt into my electrodes. And of course, with minimal feeling in the stump, I didn't know that I was getting burnt . . . sometimes I think I would have just rather gone with a passive prosthesis with cables and hooks. But it is what it is . . . That being said, at a young age and I was very self-conscious of how my prosthetic looked, so a hook and cables might have made that worse, I don't know. (Elliot)*



For some individuals, however, the prosthesis coexists as both part of the environment and part of the person:

*When I feel my uttermost "invincible self" I like to call it, is when I am at the gym. I have realized I can do things there that EVERYONE can do there, plus more!! I see myself lifting heavier weights than some guys! My recreational device gives me the opportunity to lift heavy weights, do pull ups, jump rope, deadlift, squat, push-ups, what have you. This is my place that I feel comfortable, resilient and courageous. A place that I know I can do ANYTHING and I never have the thought coming to mind that I have an absent limb. (Alex)*

Realization of Alex's supreme self occurs when wearing a prosthesis, suggesting embodiment of the device. Simultaneously, however, Alex recognizes the prosthesis as part of the environment that enables completion of complex occupations.

**Essence 8: Aging Introduces New Concerns for Some Individuals with ULLD.** Participants discussed concerns regarding having ULLD that are novel in adulthood. For example, the risk and subsequent consequences of injury to an upper limb are increasingly considered with age:

*. . . I'm starting to get worried – what if I do something to my right arm? Or I think, my right arm has done everything for 44 years. Just the added stress and wear and tear it's taken . . . am I going to have to be more dependent, and that'd be the absolute – because I am not – I don't like to depend on anyone. Am I going to have to ask for help more? Because I find I'm doing that a little bit more now. I really don't want to but with some things I am. (Chris)*

To reduce the risk of injury, some participants now take precautionary measures and avoid certain activities:

*Now as far as life goes, I mean I try and not do too much because my arm is wearing out of course. And my shoulder and stuff. But I still grab a shovel sometimes and I'll shovel for 5 or 10 minutes, you know, until I start to get tired. I don't overdo it like I used to. (Elliot)*

Caring for young children also introduces new worries for adults with ULLD. Concerns surrounding wearing a prosthesis while caring for an infant were highlighted in discussions with participants:

*I'm a new grandmother . . . she's 9 months old, so I have to – I take off my prosthesis to take care of her. Because it's too hard, I'm afraid to hurt her if I have the prosthesis. And I could feel her more without it . . . (Devin)*

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*I was just concerned with picking him [infant son] up. Because an artificial arm is hard . . . I tried a couple of times with my arm on and I'm like 'no this isn't working'. So never wore my arm at all looking after my son or picking him up. But . . . my left arm is short just below my elbow, so when I would go to pick him up one of his arms would go up higher than the other, if that makes sense. So then you start thinking well is he going to have one arm that's a little, you know, crazy because I'm always picking him up that way. So anyway, that was something I had to adapt and figure out on my own (Chris)*

### *Summary*

This chapter provided a comprehensive account of this study's findings. The meaning units, domains, focal meanings, and situated structural descriptions for each participant were presented. The general structural description then described the meaning of everyday life for adults with ULLD. This composite passage was composed of eight themes, or essences. Each essence was then discussed in detail using the participants' own words to illustrate congruency among the increasing levels of abstraction. The next chapter (5) will involve discussion of and implications for the research findings.

## Chapter 5

### Discussion and Implications

#### *Overview*

The purpose of this descriptive phenomenological study was to describe the essence, or meaning, of everyday life for adults with ULLD. Findings revealed that the everyday life of those with ULLD is a multifaceted experience that both challenges and rewards the individual. This chapter will contextualize the findings in relation to previous literature and discuss the implications of these findings for future education, research, practices, policies, and use of the CMOP-E. As well, study limitations will be considered.

#### *Synthesis of Findings to Literature*

The purpose of this study was to describe the essence, or meaning, of everyday life for adults with ULLD. As such, within the *Literature Review* section of this thesis, research that is relevant to this topic was discussed. Eight studies were found to have investigated some aspect of the essence of everyday life with a limb absence. Below is a table summarizing these eight studies in relation to the present study.

**Table 4: Summary of Literature that has Investigated the Essence of Everyday Life with a Limb Absence and Comparison of the Literature to the Present Study.**

<b>Study</b>	<b>Methodology</b>	<b>Purpose</b>	<b>Participants</b>	<b>Themes/ Essences</b>	<b>Similarities</b>	<b>Differences</b>
(Amorelli et al., 2019)	Qualitative phenomenology	To shape the final content of Amputees Unanimous by identifying personal beliefs and opinions of healthcare professionals and amputees.	Five focus groups, four with amputees and one with healthcare providers.	Three themes: accepting limb loss, peer inspiration, and regaining prior level of function.	Similar themes regarding the importance of peer support.	This study focused only on amputation and included individuals with either an upper or a lower limb absence.
(Day et al., 2018)	Focus groups and inductive thematic analysis	To provide an understanding of the everyday experiences of individuals with a limb amputation.	21 participants with a lower limb amputation, 1 participant with a lower limb CLD.	Four themes: pain, organization and planning, the embodied experience after amputation, and interactions with others.	Similar themes regarding the significant influence that interactions with others can have on one's experiences.	This study focused only on lower limb amputations.
(Grech & Debono, 2014)	Interpretive Phenomenology	Explore the lived experiences of Maltese individuals with a lower or upper limb amputation.	Three participants had a lower limb amputation and one participant had an upper limb amputation.	Three core themes: an emotional reaction, a different life, and social connections and support.	Similar themes of shifts in spirituality, or how participants view their own lives. As well, similar themes regarding both environmental and peer support.	This study focused only on the experiences of Maltese individuals with an amputation.

<b>Study</b>	<b>Methodology</b>	<b>Purpose</b>	<b>Participants</b>	<b>Themes/Essences</b>	<b>Similarities</b>	<b>Differences</b>
(Ligthelm & Wright, 2014)	Qualitative Phenomenology	Explore the lived experiences of individuals with an amputation of an upper limb to provide an evidence base to support nursing interventions.	Eight participants with an upper limb amputation, living in South Africa.	Seven themes: initial reaction post amputation, support from family, support facilitated adaptation, amputation had financial implications, external response to disability, recurrent physical problems, and acceptance is a process.	Similar themes regarding the influence of environmental support, the challenges presented by society's perceptions, and acceptance as a process.	This study focused only on the experience of individuals with an amputation living in South Africa.
(Liu et al., 2010)	Phenomenology	Describe and understand the lived experience of people with lower extremity amputation.	22 people with lower limb amputation.	Four themes: 'lost in the dark woods', 'emotional collapse', 'difficulty in passing through the shadow' and 'igniting a gleam of hope'.	Similar themes regarding the challenges that social stereotypes present, acceptance in relation to cognitive well-being and spirituality, and the importance of peer support.	This study focused only on lower limb amputation.
(Livingstone et al., 2011)	Grounded theory	To allow amputees to describe their experiences of amputation and to generate grounded theory that will lead health professionals towards a better understanding of the realities of post-amputation life.	Five participants with diabetes-related amputation.	Three categories: 'imposed powerlessness', 'adaptive functionality', and 'endurance'.	Similar themes regarding acceptance as a process marked by cognitive well-being.	This study focused only on diabetes-related lower limb amputation.

<b>Study</b>	<b>Methodology</b>	<b>Purpose</b>	<b>Participants</b>	<b>Themes/Essences</b>	<b>Similarities</b>	<b>Differences</b>
(Möhler & Schnepf, 2010)	Grounded theory	Examine how people with a lower-limb amputation caused by vascular diseases experience and manage their every-day life.	Nine participants with lower limb amputations due to vascular disease.	Three main findings: As a result of an amputation, people must cope with severe loss. To manage their daily activities again, amputees need to regain their mobility. Regained mobility also enables them to perform activities of individual importance within their disability.	Similar themes regarding acceptance.	This study focused only on vascular disease-related lower limb amputation.
(Norlyk et al., 2013)	Reflective Lifeworld Research Phenomenology	Explore the lived experience of losing a leg as described by the patients post-discharge.	12 Danish patients.	Six themes: Home as a confined space, Maintenance of symmetry and dignity in social relations, Reconstitution of bodily confidence, Hope and willpower as driving forces, Establishment of a meaningful role in life, and Dependence on care and rehabilitation initiatives.	Similar themes regarding environmental support.	This study focused only on lower limb amputation.

Each theme, or essence, from this study's findings will now be synthesized to the literature in greater detail. For ease of reading, the title of each essence will be presented in italics.

*Essence 1: Accepting oneself as a person with ULLD is marked by cognitive well-being and indicates a shift in spirituality.*

In the present study, participants demonstrated that acceptance of life with ULLD is marked by cognitive well-being and a shift in spirituality, or from where one draws meaning. Similar findings have been presented in the literature previously. Participants in a study by Grech & Debono (2014) reported that amputation had a positive impact on the way in which they viewed life; participants described an increased appreciation for day-to-day life. Another study highlighted that "Acceptance is only achieved when feelings around the loss of a limb are dealt with." (Ligthelm & Wright, 2014, p. 103). This literature supports the assertion that acceptance of ULLD is accompanied by cognitive well-being and a shift in spirituality.

Providing further evidence to support this essence, one study noted that, subsequent to amputation, ". . . some participants began to re-evaluate the meaning and value of their life." (Liu et al., 2010, p. 2156). However, the authors also revealed that, despite some participants displaying a shift in spirituality, most participants had yet to accept the loss of a limb (Liu et al., 2010). This heterogeneity could be due to the short period of time since amputation (within two months prior to being interviewed) for participants in this study (Liu et al., 2010). Indeed, data from the literature, including this thesis, demonstrate that attaining acceptance and cognitive well-being is a process



that requires time (Hamill et al., 2010; Ligthelm & Wright, 2014; Livingstone et al., 2011).

*Essence 2: The environment influences acceptance, with the capacity to bolster the well-being of individuals.*

The significance of environmental support regarding the absence of a limb is well-reported in the literature. In the present study, the beneficial effects that certain social environments can have on one's well-being were discussed by three of the five participants: Blake, Chris, and Devin. This theme is congruent with findings in the literature, as previous studies have shown that social support aids in psychosocial well-being and acceptance (Dadkhah, Valizadeh, Mohammadi, & Hassankhani, 2013; Grech & Debono, 2014; Senra et al., 2012; Stutts et al., 2015). Further corroborating this finding, past research has also demonstrated that perceived lack of social support is correlated with higher levels of depression (Rybarczyk, Nyenhuis, Nicholas, Cash, & Kaiser, 1995).

One participant in the present study, Elliot, emphasized the powerful influence that institutional support can have on acceptance and well-being. Results from previous studies align with this finding (Murray & Forshaw, 2013). For example, one study found that physiotherapy was an impactful form of institutional support (Norlyk et al., 2013). However, this study by Norlyk et al. (2013) also highlighted that, although participants felt they received adequate practical support from institutional services, psychosocial support was scarce. Thus, the literature reflects findings from the present study. Elliot disclosed that "there wasn't really anything in the healthcare system at that time set up to

help” and that it took many years of reaching out to find a therapist who helped with acceptance and improved well-being. In another study, only three of eight participants were referred to health care professionals other than prosthetists (e.g. psychologists) subsequent to amputation (Ligthelm & Wright, 2014). Finally, despite many not receiving any therapy themselves, there was consensus among participants from another study that counselling should be mandatory pre- and post-amputation (P Gallagher & Maclachlan, 2001). These findings further illustrate that, despite the demonstrable positive effects that institutional support can have on acceptance and well-being, such care is often found wanting. Notably, these results highlight the need for psychological support to be incorporated into the provision of care for persons with ULLD.

One participant in this study, Alex, discussed the positive impact that the physical environment can have on well-being. For Alex, the gymnasium is a physical environment that bolsters acceptance and well-being. In contrast, a study consisting of participants with a lower limb absence found that sports centres presented a challenging physical environment that was not reflective of the needs these individuals (Bragaru et al., 2013). Similarly, previous literature focuses on the various barriers, rather than facilitators, that a person’s physical environment can present to well-being (Day et al., 2018; Ephraim, MacKenzie, Wegener, Dillingham, & Pezzin, 2006; Pamela Gallagher, O’Donovan, Doyle, & Desmond, 2011; Sousa, Corredeira, & Pereira, 2009).

Thus, the person’s environment, whether it is social, institutional, or physical, has the potential to facilitate acceptance and increase well-being. However, despite these findings, such environmental support is often found to be inadequate. Importantly, psychological support should be provided for all persons with ULLD.

*Essence 3: The stereotypes entrenched in society's perceptions present challenges to spirituality and cognitive well-being.*

In the present research, four of the five participants described challenges they faced due to stereotypes that are embedded in society's perceptions of persons with ULLD. This theme is recurrent among the literature. Many individuals with a limb absence, including participants of the current study, reported being negatively affected by others' stares (Ligthelm & Wright, 2014; Sousa et al., 2009; Stutts et al., 2015). Corroborating these findings, a quantitative study demonstrated that perceived social stigma was significantly correlated to level of depression (Rybarczyk et al., 1995).

To avoid judgement from others, some individuals, such as Devin from the present study, attempted to conceal physical differences (Murray, 2009b). For others, worry of stigmatization led to self-isolation (Liu et al., 2010; Sousa et al., 2009). Finally, in accordance with findings from the present study, the literature demonstrates that stereotypes surrounding ULLD are present in society's perceptions from childhood (de Jong, Reinders-Messelink, Janssen, et al., 2012; Franzblau et al., 2015).

Stigma in the workplace is a common theme presented in the literature (Ligthelm & Wright, 2014; Snyder, Carmichael, Blackwell, Cleveland, & Thornton, 2010; Stutts et al., 2015). The present study, however, yielded no findings similar to this. In contrast, participants Blake, Chris, and Elliot each indicated overall career satisfaction. For example, Elliot's place of work provided ergonomic assessments to prevent physical stress and offered Elliot opportunities to complete complex tasks that required additional precautions. This finding diverges from a previous study wherein participants reported that assumptions about one's capability negatively affected the work they were offered

(Stutts et al., 2015). In another study, responses on the matter varied; some participants described receiving support from their work, whereas others disclosed that they received none (Valizadeh, Dadkhah, Mohammadi, & Hassankhani, 2014).

Stigma surrounding disability remains one of the least studied stigmas (e.g. in comparison to racial and ethnic stigmas) (Bogart, Rosa, & Slepian, 2019). However, the evidence provided by this thesis and previous literature illustrates the negative effects that stereotypes can have for persons with a limb absence as well as the expansive presence of stigma amongst society.

*Essence 4: Smashing through stereotypes imparts a high sense of accomplishment and pride.*

As discussed above, past research has thoroughly demonstrated that stereotypes have detrimental effects on the well-being of persons with a limb absence. However, findings from the present study also reveal that defying stereotypes imparts feelings of accomplishment and pride for persons with ULLD. Two participants from this study, Blake and Elliot, described how educational and career-related successes produced such positive effects. For two other participants, Alex and Chris, completion of strenuous physical activity generated the same rewarding feelings. This sentiment is echoed in the literature, as one study concluded that “sport and physical activity participation is an involvement that can reaffirm ability rather than disability and serve as a means to affirm one’s bodily competence” (Sousa et al., 2009, p. 254). Thus, surpassing expectations and breaking through stereotypes contributes to the well-being of individuals with ULLD.

*Essence 5: Peer support is desired amongst persons with ULLD but is found wanting.*

Peer support refers to a supportive relationship between persons who have experienced the same phenomenon (Mental Health Commission of Canada, 2020). Previous research illustrates the numerous positive effects that peer support can have for individuals with a limb absence. Peer support offers an environment that puts individuals at ease, encourages open communication, and provides a deeper level of understanding of one's experiences (Grech & Debono, 2014; Hamill et al., 2010; Liu et al., 2010; Valizadeh et al., 2014). A recurrent theme of hope is evident in the literature, as peer support shows new amputees the realms of what is possible (Amorelli et al., 2019; P Gallagher & Maclachlan, 2001; Liu et al., 2010). Furthermore, peer support reduces self-isolation and emotional stress (Grech & Debono, 2014; Liu et al., 2010). One study found that many amputees consider offering support to peers rewarding, as it provides an opportunity to share personal success stories and inspire others (Amorelli et al., 2019). This is consistent with the findings of the present study, as Devin now elects to offer moral support to new amputees and Blake to children with CLD.

Previous research that considers peer support includes a sample of individuals who experienced amputation, rather than persons with CLD (Amorelli et al., 2019; P Gallagher & Maclachlan, 2001; Grech & Debono, 2014; Hamill et al., 2010; Liu et al., 2010). In the present study, three participants, Chris, Devin, and Elliot, discussed sentiments surrounding peer support. Chris, who has CLD, observed that obtaining peer support as a child aided in acceptance and feelings of normalcy, but indicated that additional peer support would assist in decreasing feelings of alienation. Devin and Elliot, the two participants in this study with an acquired limb loss, described desiring

peer support following amputation, but receiving none. Thus, these findings suggest that peer support is of significance to individuals with an acquired limb loss as well as those with CLD. However, congruent with the literature, these results illustrate that desire for peer support is more commonly discussed among persons with an acquired limb loss than persons with CLD. This difference may be due in part to the fact that, in Canada, children with CLD have access to peer support through programs provided by The War Amps.

Findings from the present research diverge from the literature, as the studies mentioned above show that many persons with an acquired limb loss had access to peer support following amputation. Indeed, in one study conducted in the U.S., only one of the 17 participants reported not having any peer support, though disclosed a desire for such a relationship (Amorelli et al., 2019). In another study, also from the U.S., 86.7% of participants received peer support after amputation (Stutts et al., 2015).

Thus, evidence from this thesis as well as previous studies suggests that persons with a limb absence desire peer support. Furthermore, peer support is shown to have numerous benefits that bolster the well-being for these individuals. Despite these findings, however, results demonstrate that access to peer support for persons with a limb absence varies across locations.

*Essence 6: Although ULLD renders certain occupations increasingly difficult, individuals demonstrate that much is achievable through modification and determination.*

Participants from this research displayed traits of tenacity and resourcefulness when performing activities made more difficult by ULLD. Similarly, participants from a previous study who had undergone upper limb amputation reported that they were still able to complete leisure and productivity occupations; however, modifications were necessary (Saradjian et al., 2008). In contrast, a quantitative study demonstrated that participation in leisure activities decreased following amputation (Couture, Caron, & Desrosiers, 2010). This decrease was due to both external and personal constraints (e.g. affective constraints) (Couture et al., 2010). Thus, although persons with ULLD exhibit attributes of determination and resourcefulness, external and personal factors can hinder the completion of occupations.

*Essence 7: The prosthesis is meaningful to adults with ULLD and is viewed as either part of the person, part of the environment, or a combination of both.*

Traditionally in the literature, the prosthesis has been viewed as a tool, or part of the environment; the primarily quantitative nature of limb absence research may explain this perspective. However, this viewpoint is changing. The idea of the prosthesis having been incorporated into the schema of one's own body has been introduced (Fraser, 1984), and the phenomenon of embodiment has been explored (Murray, 2004).

Findings from the present research support both the phenomenon of embodiment as well as the view of the prosthesis as part of the environment. Blake and Devin demonstrated clear embodiment of the prosthesis, Chris and Elliot considered the prosthesis as part of the environment, and for Alex, the prosthesis coexisted as both part of the person and part of the environment. Previous studies have produced similar

findings, wherein some participants of the study viewed the prosthesis as part of the person, and other participants viewed the prosthesis as part of the environment (Chini & Boemer, 2007; Lundberg et al., 2011; Murray, 2004; Sousa et al., 2009; Widehammar et al., 2018). Thus, for individuals with ULLD, the prosthesis can exist as part of the person, part of the environment, or a combination of both. This highlights the versatility and subjective nature of prostheses.

A systematic review by Chadwell et al. (2020) has called for more studies that investigate embodiment of the prosthesis. Findings from the present study contribute to this growing body of literature and aid in understanding the experiences of persons with ULLD who use a prosthesis.

*Essence 8: Aging introduces new concerns for some individuals with ULLD.*

In the present research, three of five participants discussed novel concerns that were introduced with age. For instance, two participants, Chris and Devin, highlighted worries surrounding wearing a prosthesis while caring for an infant. Previous literature pertaining to parenthood and limb absences focuses on the experiences of parents of a child with CLD, rather than the experiences of parents who themselves have a limb absence (Andrews et al., 2009; Kerr & McIntosh, 2000; Oliver, Dixon, & Murray, 2020). However, findings from a study that examined the benefits of sensory-enabled prostheses alluded to this concern in parents. The authors described that for one participant, the sensory stimulation information “enabled them to perform activities [pick up a small child] that they otherwise may have avoided due to concerns about squeezing too hard or inadvertently hurting others” (Graczyk, Gill, Tyler, & Resnik,



2019, p. 9). This finding is congruent with the current research and suggests that persons with ULLD experience disquietude surrounding caring for infants.

Participants from the present study also explained that risk of injury to an upper limb was increasingly considered with age; to the PI's knowledge, this finding is unexplored in the literature. Thus, aging introduces novel concerns for adults with ULLD; however, additional research on this topic is advised.

### ***Implications***

**Implications for Education.** The findings from this research contribute to the body of literature that describes the essence of everyday life for persons with ULLD. Sharing this knowledge with health care professionals will offer a better understanding of the lived experiences of individuals with ULLD. Health care providers who commonly work with this population, such as occupational therapists, physiotherapists, and prosthetists, should be aware of the factors that influence the quality of life for persons with ULLD and the concerns that these individuals share. The findings from this study can educate professionals on such barriers and facilitators to well-being. This knowledge will aid in ensuring that pertinent and empathetic care is being delivered and the needs and wants of persons with ULLD are being met.

The findings from this research should also be utilized to educate graduate students who are conducting research in this area on the essence of everyday life for adults with an ULLD. Doing so would be especially useful for students performing quantitative research, as it will provide these researchers with a more holistic understanding of the population being studied. The findings from this study will also aid

researchers in setting aside any preconceived notions that may exist regarding persons with ULLD.

**Implications for Future Research.** The present study provides important, novel information regarding life with ULLD. However, findings from this study also reveal that additional research is warranted. For example, findings from this thesis demonstrate that aging introduces new concerns for persons with ULLD. This topic, however, is relatively unexplored in the literature. Thus, to ensure pertinent care that enhances the quality of life for adults with ULLD, future research should investigate these concerns.

The present study also provides evidence corroborating the view of the prosthesis as not only part of the environment (i.e. a tool), but as part of the person as well. Thus, findings from this study suggest that future research should take into consideration the potential for participants, or the target demographic, to embody the prosthesis. Additionally, future research that examines the barriers and facilitators to embodiment is recommended.

Finally, additional qualitative studies that investigate the experiences of persons with ULLD are suggested. To gain a thorough understanding of life with ULLD, the perspectives of more individuals who have experienced the phenomenon must be shared. In this way, future qualitative research in this area will further expand the current understanding of the essence of everyday life for individuals with ULLD.

**Implications for the Provision of Care.** To ensure relevant and effective health care practices, the findings from this research should be applied to the provision of care for individuals with ULLD. For example, the unmet desire for peer support among

persons with ULLD was highlighted in this thesis. To address this shortcoming in the provision of care, a database of volunteers who are willing to provide such support should be produced. This database could be implemented globally, as findings from this research demonstrate that access to peer support varies by location. Global use would increase access to peer support for those who live rurally or in smaller communities, as individuals could connect virtually.

The present study also emphasizes the need for institutional support that focuses on the psychological well-being of persons post-amputation. Hospital staff should provide individuals who have experienced amputation with a referral to a therapist. This will aid in ensuring that persons who have undergone amputation have access to care that supports psychological well-being.

The findings from this study also highlight that the risk of injury to an upper limb is increasingly considered with age for persons with ULLD. As such, resources that address this concern should be provided by health care practitioners. For example, a list of exercises that minimize the risk of injury to an upper limb (e.g. strength and flexibility exercises) could be offered. As well, ergonomic assessments should be conducted to minimize the risk of repetitive strains at work.

**Implications for Policy.** This research demonstrates the harmful impact that stereotypes have on one's well-being. As such, policy that aims to address and reduce the stereotypes regarding ULLD is necessary. For example, educational campaigns that relay information regarding ULLD to the public could aid in increasing awareness and decreasing stigma. As well, workplace policies that target stereotyping and

discrimination are encouraged. Finally, education on the harmful effects of stereotypes and how to avoid stereotyping should be included in elementary school curriculums.

**Implications for the Atlantic Clinic for Upper Limb Prosthetics.** As the participants of this study were recruited from the Atlantic Clinic for Upper Limb Prosthetics, the data and results from this research can be of direct value to the clinic. Review of these findings could aid the clinic in identifying gaps in services offered. For example, the clinic could implement a referral system for services that are not offered at the clinic (e.g. psychological support). As well, the clinic could create a peer mentoring program. Currently, of their own volition, clients may offer to be put in touch with others who desire peer support. However, a formal peer mentoring referral system could produce more effective and efficient support. The clinic could also offer a formal opportunity for clients to provide feedback regarding the provision of care at the clinic as well as any other potential comments and concerns. Finally, as discussed previously, the findings from this study can serve as an important educational tool for health care providers and researchers at the clinic.

**Implications for the CMOP-E.** Results from this study demonstrate that each domain of the CMOP-E (the person, occupation, and environment) is of importance to persons with ULLD. As such, this research supports the holistic approach to care that is enacted when health care practitioners utilize the CMOP-E. Furthermore, this research

demonstrates the versatility of the CMOP-E and its potential for use across health care practices and research.

### ***Study Limitations***

Due to exceptional circumstances caused by the COVID-19 pandemic, in-person recruitment, as was originally planned, was not feasible. Instead, potential participants were contacted by means of email. This necessary modification potentially led to a lower response rate and consequently fewer perspectives shared than what was possible.

A second limitation in this study is that each participant was from one specific region of Atlantic Canada; this is representative of the clientele at the Atlantic Clinic for Upper Limb Prosthetics. Individuals from other regions may have shared additional perspectives. Furthermore, as each participant was a client of this clinic, they had access to a level of specialized care that not all individuals with ULLD have.

Finally, self-selection bias may be present in this study, as persons who chose to take part in this research may have been more accepting of life with ULLD than those who chose not to participate. Of the five participants in this study, three were adults with CLD and two were adults with upwards of 26 years since time of limb loss. Substantial time with a limb absence had passed for each participant, influencing their acceptance of life with ULLD. In contrast, a more recent experience with limb loss or a negative overall experience regarding life with ULLD may have discouraged other individuals from participating.

### *Summary*

This chapter synthesized the findings from this study to the relevant previous literature. As well, the implications of this research regarding future education, research, provision of care, policy, and use of the CMOP-E were discussed. Importantly, the findings from this study provide valuable insight to the lived experiences of persons with ULLD. Furthermore, these findings have the potential to positively influence the overall quality of life for persons with ULLD.

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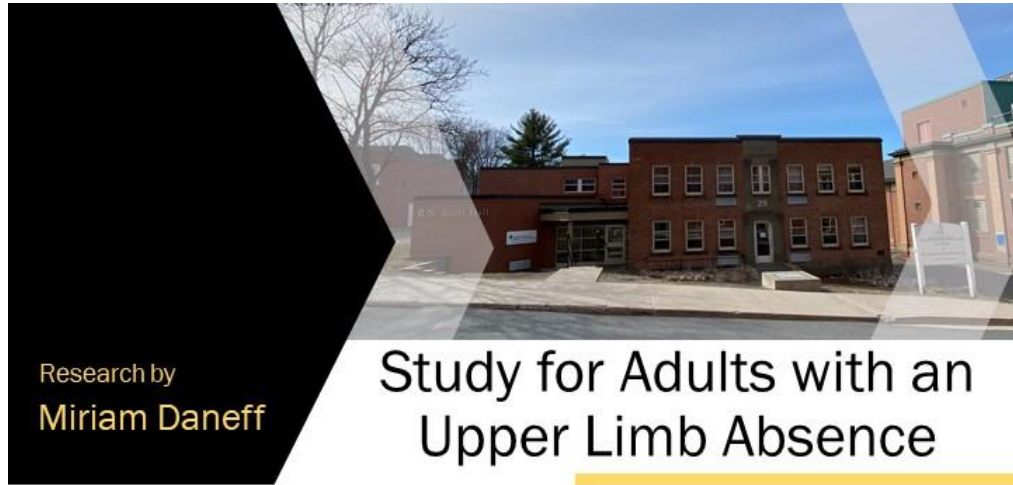
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# Appendix A

## Study Flyer



### About the study

- The goal of this study is to describe the meaning of everyday life for adults with an upper limb absence
- This study is supported by the Atlantic Clinic for Upper Limb Prosthetics



### Participation in the study

- You are eligible to participate if you are over the age of 18, understand English, and have one upper limb absence
- Participants will be asked to describe what it is like for them to live with an upper limb absence
- You can participate by email, phone, or video chat at a time convenient for you



### About the researcher

- I am currently completing my Masters of Applied Health Services Research at UNBF and am proudly from Fredericton, NB
- For more information regarding the study, please contact me at [miriam.daneff@unb.ca](mailto:miriam.daneff@unb.ca) or 1-506-261-6922

### Supervisors

Dr. Edmund Biden, Wendy Hill\*, and Dr. Catherine Aquino-Russell

\*No member of your clinician team will be aware as to whether you have participated in this study

## Appendix B

### Written Section Provided by PI for the Email to Potential Participants

Hi there,

My name is Miriam Daneff and I'm a master's student at the University of New Brunswick. I am conducting a study called "The Experiences of Adults with an Upper Limb Absence" and am currently seeking volunteers to participate in my study.

Participation in this study will require one written/typed response **or** one interview at a time convenient for you (via phone or video chat). Participants will be asked to describe what it is like for them to live with an upper limb absence. There is no length requirement for responses. Interviews will be recorded and later written out by me.

This study has been approved by the UNB Research Ethics Board and is supported by the Atlantic Clinic for Upper Limb Prosthetics.

Attached to this email is an Informed Consent Form. Participants will be asked to provide consent through one of the following methods: (1) provide an electronic signature on the document, (2) print and sign the form, and send back a copy or photo of the signed form, (3) if you choose to submit a written/typed response, this will be considered assumed consent.

A flyer for the study is also attached to this email.

If you are interested in participating, please contact me at [miriam.daneff@unb.ca](mailto:miriam.daneff@unb.ca) or 1-506-261-6922.

Best,  
Miriam



## Appendix C

### Informed Consent Form

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#### **Research Consent Form**

University of New Brunswick

Institute of Biomedical Engineering

Fredericton, N.B.

**Project Title:** The Experiences of Adults with an Upper Limb Absence

**Principal Investigator:** Miriam Daneff

**Supervisors:** Dr. Edmund Biden, Wendy Hill, Dr. Catherine Aquino-Russell

This project has been reviewed by the Research Ethics Board of the University of New Brunswick and is on file as REB 2020-028.

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#### **PURPOSE**

In this study, we explore experiences of people with an upper limb absence. I would like to invite you to participate in this research. Our short-term goal is to describe everyday life for people with an upper limb absence. This will help us understand challenges faced by those living with an absence. It will aid in improving their quality of life.

## **STUDY CONTACTS**

If you have any questions about the research, please contact me, Miriam Daneff, [miriam.daneff@unb.ca](mailto:miriam.daneff@unb.ca), or my supervisor, Dr. Edmund Biden, [biden@unb.ca](mailto:biden@unb.ca), 1-506-458-7762.

## **RATIONALE**

Much research has studied the physical aspects of limb absence. Also, most research focuses on lower limb loss. Research must explore the viewpoints of people with an upper limb absence.

## **PROCEDURES**

Your participation will require one in-person interview or one written/typed response. The question will be the same for either. “Please describe what it is like for you to live with an upper limb absence.” A written response has no length limit. An interview will take place in the Atlantic Clinic for Upper Limb Prosthetics. Following the question, I may ask open-ended questions or prompts. You do not have to answer all questions. In-person interviews will be recorded and later written out by me. The estimated time to complete an interview is <60 minutes.

## **COSTS**

There is no cost to you for participating in the study. Please contact me if you feel there has been an unreasonable cost to participate.

## **RISKS AND DISCOMFORTS**

In this study, you will be asked to talk about living with a limb absence. Speaking about this topic may be emotional. If you feel discomfort or at risk, you can take a break or stop the interview at any time. Your participation is voluntary. You may stop at any time before or during your visit with no penalties or judgement.

## **BENEFITS**

You may not directly benefit from being a part of this study. However, this study will provide useful information about the experiences of people living with a limb absence.

## **PRIVACY AND CONFIDENTIALITY**

All personal information will be kept secure. It will never be shared outside of the research team. This includes items such as your name and contact information. Your clinician team will not be aware as to whether you have participated in this study.

A code name will be used instead of your real name. The “master list” linking personal information to the code name will not be shared. It will be kept by me in a locked file on a locked computer. Paper files will be kept in a locked cabinet in a locked office. This will include consent forms and written responses. Responses sent by email will be edited to remove all identifiable information. The data will be saved, and the email permanently deleted. Data will be kept secure on a locked computer.

Non-personal information will be used and shared with others for research and teaching purposes only. For example, with supervisors, researchers, or UNB Research Ethics Board members. All audio recordings and personal information linking you to your data will be destroyed after 7 years following the study.

### **PUBLICATION OF RESULTS**

The results of this study may be published in a journal, shared at a conference, or used for teaching purposes. Your personal information will not be used in any publication or shared materials.

You may request a copy of any material made public from the study. For example, published journal papers or conference abstracts. To request this information please contact me.

### **REQUEST FOR MORE INFORMATION**

You may ask questions about the study at any time. My contact information is listed on this consent form should you have any concerns about the study. A copy of this consent form will be given to you to keep.

If you want to speak to someone not directly involved in the study about any concerns regarding the study, contact the UNB Research Ethics Board at 1-506-453-5189. For example, you can contact them about your rights as a research participant or your

participation in the study. You can also contact them if you feel under any pressure to enrol or continue to participate in this study.

**REFUSAL OR WITHDRAWAL OF PARTICIPATION**

Participation in this study is voluntary. You do not need to sign the consent form. If you do not sign the consent form, you cannot participate in the researcher. You can drop out of the study at any time, without any penalties or judgment.

**CONSENT TO PARTICIPATE IN RESEARCH AND AUTHORIZATION TO USE INDIVIDUAL’S PROVIDED HEALTH INFORMATION FOR RESEARCH**

I confirm that the purpose of the research, the study procedures, the possible risks and potential benefits that I may experience have been explained to me. All my questions have been answered. I have read this consent form. My signature below indicates I am willing to participate in this research study. I understand that I will receive a signed copy of this consent.

**NAME** (Please print):

**SIGNATURE:**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Participant

Date/Time

I have explained the purpose of the research, the study procedures, the possible risks and discomforts, and potential benefits. I have answered any questions regarding the research study to the best of my ability.

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Investigator/Individual Obtaining Consent

Date/Time

## Curriculum Vitae

**Candidate's full name:** Miriam Alex Daneff

**Universities attended (with dates and degrees obtained):**

University of New Brunswick | Master of Applied Health Services Research | FEB 2021

Carleton University | BSc Combined Honours in Neuroscience | APR 2017

**Publications:**

Daneff, M., & Jadavji, N. (2019). The role of synaptic plasticity in the pathophysiology of cocaine addiction. *The Journal of Young Investigators*.

**Conference Presentations:**

Daneff, M. (presenter), Biden, E., Hill, W., & Aquino-Russell, C. (2021, April 22-24). *The Experiences of Adults with an Upper Limb Loss/Difference* [Abstract presentation]. Association of Children's Prosthetic-Orthotic Clinics.