

Quality of Life Experiences of Adults who have Undergone an Amputation

by

Walter King  
B.Com., University of Victoria, 2003

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of the Requirements for the Degree of

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**Supervisory Committee**

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Dr. Jillian Roberts, Department of Educational Psychology and Leadership Studies  
**Supervisor**

Dr. Donna McGhie-Richmond, Department of Educational Psychology and Leadership  
Studies  
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## **Abstract**

### **Supervisory Committee**

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The present study used phenomenology to inquire about the quality of life experiences of six adults who had undergone an amputation. This study also explored how the adults perceive their lives. All participants resided in Western Canada and had undergone an upper limb amputation several years prior to the study. Each participant was interviewed twice. Some of the interview questions were from Roberts and Cairns' (1999) adaptation of Keith and Schalock's (1994) QOL model. Interviews were conducted, transcribed, and thematically analyzed. Results indicated that some participants experienced a change whereas others reported stability in quality of life. The data analysis revealed specific categories, clusters, and themes of participants' quality of life experiences. Quality of life categories related to empowerment, satisfaction and well-being, and the social realm. Participants described their lives as being significantly changed as a result of an amputation. The data analysis also revealed specific categories, clusters, and themes of participants' perceptions of their lives. Psychological attributes and health care were two categories. The present study offers implications for several groups of people.

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## **Chapter 1: Introduction**

Every year, thousands of people in Canada and the United States of America undergo a limb amputation (British Columbia Podiatric Medical Association; Dawes, Iqbal, Steinmetz, & Mayo, 2010; Ziegler-Graham, MacKenzie, Ephraim, Trivison, & Brookmeyer, 2008); yet, research that explores their quality of life is limited (Desmond & Gallagher, 2010; Østlie, Magnus, Skjeldal, Garfelt, & Tambs, 2011). The present study helps to augment this limited research. In this chapter, a brief overview outlines the frequency of and reasons for amputations. A concise summary of the research literature follows that explores possible impacts experienced by individuals who have undergone an upper limb amputation. The research study's problem, purpose, and questions are then introduced. The chapter concludes with sections containing definitions of terms and limitations of the study.

### **Overview**

At present, no published data indicates the annual number of worldwide amputations (Sinha & Van Den Heuvel, 2011). The published data does, however, indicate that amputations occur frequently. The British Columbia Podiatric Medical Association reports that over 1,000 amputations occur annually in British Columbia, Canada. A significant number of amputations occur in Quebec, Canada; 10,834 people underwent 15,992 amputations between January 1, 1996 and December 31, 2004 (Dawes et al., 2010). In addition, 1.6 million individuals in the United States of America were estimated to be living without a limb in 2005 (Ziegler-Graham et al., 2008). Ziegler-Graham et al. (2008) noted that as a result of an increase in diabetes and in the population of older adults, the incidence of amputations in the United States of America is

anticipated to rise and that by 2050, approximately 3.6 million people will be living without a limb. In general, amputations of lower limbs occur in significantly greater numbers than amputations of upper limbs (Kejlaa, 1992; Rybarczyk & Behel, 2008).

People undergo or choose to have an amputation for many reasons. Studies have consistently demonstrated that medical conditions, such as vascular issues, are a significant factor affecting amputation rates in many Western countries (Dawes et al., 2010; Pernot, Winnubst, Cluitmans, & Witte, 2000; Rommers, Vos, Groothoff, Schuiling, & Eisma, 1997). Diabetes is a specific medical condition that affects amputation rates. In a study by Johannesson et al. (2009), individuals with diabetes had a significantly elevated rate of amputation when compared to individuals without diabetes. Amputations also result from military combat or other types of violence (Desmond & Gallagher, 2010), “terrorism and natural calamities” (Sinha & Van Den Heuvel, 2011, p. 883), and “traumatic accidents” (Sinha & Van Den Heuvel, 2011, p. 883).

### **Impacts of Upper Limb Amputation**

Researchers have examined several impacts (e.g., difficulties or constraints) possibly experienced by some people who have undergone an upper limb amputation (Gallagher, O’Donovan, Doyle, & Desmond, 2011). Datta, Selvarajah, and Davey (2004), Jones and Davidson (1995), and Kejlaa (1992) inquired how individuals function in areas such as employment after having an upper limb amputation. In other studies, researchers have focused on pain (Desmond & MacLachlan, 2010; Hanley et al., 2009; Kooijman, Dijkstra, Geertzen, Elzinga, & van der Schans, 2000) and psychosocial difficulties such as depression and anxiety (Desmond, 2007).

## **Statement of the Problem**

The previously mentioned studies exploring impacts are important because they have advanced research, theory, and practice in the field of upper limb amputation. Research exploring *quality of life* (QOL) is also needed to provide a comprehensive understanding of the experiences of people with an upper limb amputation. Østlie, Magnus, et al. (2011) indicated that a limited number of researchers have explored the QOL experiences of individuals who have undergone an amputation of an upper limb. The paucity of research in this area is compounded by the fact that there is no universal definition of QOL. In their respective articles focusing on lower limb amputations, Desmond and Gallagher (2010) and Zidarov, Swaine, and Gauthier-Gagnon (2009) highlighted this lack of universal QOL definition within the field of amputation. Furthermore, Hambleton, Keeling, and McKenzie (2009) noted that some researchers from various fields have not explicitly defined QOL in their studies. The absence of a consensual QOL definition or model makes it difficult for researchers to inform theory and practice in a cohesive and manageable fashion. As a result, comparing, generalizing, or discussing multiple research studies that explore QOL may be challenging.

## **Purposes of the Study and Research Questions**

The primary purpose of this research study is to utilize a phenomenological inquiry to better describe and understand the essence of QOL experiences of people who have undergone an upper limb amputation in Western Canada. Acknowledging the problem arising from a lack of a single definition of QOL within the amputation research field, a specific QOL model was used to create the interview questions. In alignment with the research study's purpose, the primary research question is as follows: "*What are the*

*quality of life experiences of adults who have undergone an amputation of an upper limb?*” This research question involves identifying changes in QOL from participants’ perspectives. The secondary purpose is to better understand how participants perceive their life after an amputation. The secondary research question is thus: “*How do participants perceive their lives after an upper limb amputation?*”

### **Definition of Terms**

Many medical terms are used in this study. To ensure consistency and interpretation by all readers, medical terms are defined with some exact phrases from dictionaries.

Amputation: “The removal of a limb, part of a limb, or any other portion of the body” (“Amputation,” 2008) typically by surgery.

Upper limb: “Part of the body that includes the arm, forearm, and hand” (“Upper limb,” 2007).

Lower limb: “Region of the body containing three functional segments: the thigh, the lower leg (knee, tibia, and fibula), and the foot” (“Lower limb,” 2007).

Prosthesis: A device attached to the body “in replacement for a limb, organ, or other body part” (“Prosthesis,” 2007).

### **The Researcher**

I strived to bracket my interests and values in this research study to exclusively focus on participant responses. I acknowledge that my preferences and values influenced my interest to undertake this study. Research concerning quality of life and amputations is of particular interest to me. My review of the literature revealed that there was a

minimal number of studies pertaining to the quality of life of individuals with an upper limb amputation.

Two of my values are learning and attentive listening. I am grateful to have had the opportunity to learn more about the lives of people who have undergone an amputation. By participating in interviews, I was most interested to learn more about their insights and perspectives. I have considerable employment and educational experiences in attentive listening as well as two years of volunteering at an agency that operated a Crisis and Information phone line. My interest in attentive listening naturally led me to engage in a research study where I could conduct interviews.

Communicating with others has been a central component of my current employment which primarily focusses on supporting adult students. Since 2004, I have been an employee at a community college. In my position, I provide a variety of supports for adult students registered with the College's Disability Resource Centre. These experiences helped to hone my knowledge and communication skills which I will utilize throughout this research study. I chose qualitative research, in part, because it provided an opportunity to engage in extensive communication, both verbal (e.g., interviews) and written (e.g., rich descriptions of participant responses).

The American Psychological Association's (APA) publication manual provides a suggestion, that when referring to participants, to, "put the person first," followed by a descriptive phrase" (VandenBos, 2010, p. 72). Examples could include a *person* who has undergone an amputation or an adult who has an amputated limb. This recommendation is consistent with my own preference and values that people's uniqueness and individuality be respected. The APA also notes: "it may be cumbersome to repeat phrases

such as “person with \_\_\_\_\_” (VandenBos, 2010, p. 72). Throughout this thesis, I have used language that ensures the person is central; in alignment with a significant portion of the literature and in order to be parsimonious, however, I also use the term “amputee” in place of “a person who has undergone an amputation”.

### **Delimitations**

A researchers’ employment of a specific methodology or form of inquiry can impact all aspects of the research process and dynamics. I acknowledge the following possible limitations or restrictions:

- In concert with the phenomenological method’s tradition of having a small number of subjects, the study was limited to six participants.
- The study was limited to the participants’ geographical residence.
- The study was limited to the characteristics (e.g., demographics, prosthetic utilization rates) of participants.
- The study was limited to upper limb amputees who voluntarily completed a consent form and participated in two interviews.
- The study was limited to the date range of the interviews.
- The study was limited to the initial and probing questions asked during the interviews.

As a result of these limitations noted above, the results of the present study are not intended to be generalizable to the population of all adult upper limb amputees.

### **Summary**

This chapter provided an overview of several key areas. Important research has been conducted on possible impacts related to individuals with an upper limb amputation.



Few research studies have explored the QOL experiences of individuals with an upper limb amputation. Consequently, research, theory, and practice, within the field of upper limb amputation have been limited.

Chapter two will explore the literature with a specific focus on QOL, relating to upper limb amputees. Chapter three will highlight the research study's methodology. The results will be presented in chapter four. Chapter five will present a discussion of several areas including an analysis of the results in relation to the research questions, limitations, and implications.

## **Chapter 2: Review of the Literature**

As a minimal amount of research has been conducted in relation to the present study's research questions, the aim of this review of the literature is to provide an exploratory and organized summary of the literature primarily relating to upper limb amputees. The first section outlines the need for research studies that comprise people who have undergone an upper limb amputation. Possible impacts (e.g., challenges and difficulties) experienced by some individuals as a result of an upper limb amputation are referred to in the subsequent section. A section relating to prostheses is also provided. A brief overview explores how individuals may respond to these impacts. QOL (QOL) is then defined and situated within the literature. Justification is provided for recommending the use of a specific QOL model developed by Keith and Schalock (1994) and modified by Roberts and Cairns (1999). An overview of the literature is presented with reference to amputees' QOL. The final section outlines the need for further research and the utilization of phenomenology to explore the QOL experiences of individuals who have undergone an upper limb amputation.

To ensure clarity regarding the several research studies referred to in this thesis, I will use the term 'participants' when referring to the present study (e.g., the six adults whom I interviewed). For other research studies, I will use the terms *subjects* or *respondents*.

### **Need for Upper Limb Amputee Research**

Research investigating lower limb amputees and upper limb amputees are of equal importance. In conjunction with the present study's research questions, this review will primarily focus on studies with samples consisting of upper limb amputees.

As more studies have been conducted with lower limb amputees than with upper limb amputees, research and analysis regarding lower limb amputations will also be referred to at various times throughout this review of the literature.

Researchers have outlined unique circumstances experienced by upper limb amputees. One manner in which researchers have highlighted these distinct circumstances is to demonstrate how the experiences of upper limb amputees may differ from the experiences of lower limb amputees. Østlie, Magnus, et al. (2011) indicated some of the ways these experiences may differ. These researchers stated that upper limb amputees, at the time of their amputation, are typically younger and have fewer health issues than lower limb amputees. One reason for these differences is that lower limb amputations are performed more often with older people with vascular complications. Østlie, Magnus, et al. noted that upper limb amputations often result from a specific “traumatic injury” (2011, p. 1595). In the United States and the United Kingdom, lower limb amputations comprise up to 90% of the total number of amputations (Rybarczyk & Behel, 2008). Kejlaa (1992) noted that 97% of all amputations in Denmark were of a lower limb. Steinbach (1978) indicated how the prevalence of war can have an influence on a country’s ratio of upper to lower limb amputations.

Many researchers stress the importance of the arms and hands. Rybarczyk and Behel (2008) write that “arm and hand amputations appear to entail qualitatively different experiences than lower limb amputations for several reasons” (p. 26). These researchers highlight the vast importance of the arm and hand for activities such as cooking and holding and for non-verbal communication such as “gesturing and physical contact” (p. 26). In accordance with these differences, Østlie, Magnus, et al. (2011) state:

Given the unique nature and functions of the hand and the upper limb, the mental and psychosocial effects of losing an upper limb is likely to be different from those of lower limb loss. . . . Pooled knowledge on both groups or knowledge on lower limb amputees alone may not be applicable to upper limb amputees. The need for further information is evident (p. 1595).

Similarly, Desmond (2007) indicated that “there are obvious differences in terms of functional implications, visibility/concealability of the amputation and/or prosthesis, and in the characteristic circumstances surrounding upper and lower limb amputations” (p. 16). Hanley et al. (2009) and Saradjian, Thompson, and Datta (2008) have also written about potential differences between people with upper limb amputations and those with lower limb amputations.

### **Possible Impacts**

Researchers have identified impacts that people who have undergone an upper limb amputation may experience in their lives. Some of the impacts highlighted in the literature relate to activity limitations, pain, psychosocial difficulties, body image, and employment. Each of these areas will now be described.

In a study in Australia conducted by Davidson (2002), subjects responded to two questionnaires that probed several areas. One of these areas included possible activity limitations. The results of the study revealed that the respondents had the highest levels of dissatisfaction with certain activities: ““using a knife and fork,”” ““peeling vegetables,”” and ““tying shoelaces”” (Davidson, 2002, p. 66). In a study by Jones and Davidson (1995), 16 respondents noted various sports they had played before their amputation. Fourteen of them responded that their amputation ““had caused them to cease

these sports” (Jones & Davidson, 1995, p. 441). The latter study revealed other activities that respondents indicated were not impacted by their amputations.

Contemporary researchers continue to examine potential activity limitations experienced by individuals with upper limb amputations. In a study by Gallagher et al. (2011), the following are percentages of respondents with a prosthesis who reported “some participation restriction (mild, moderate, severe or extreme)” (p. 282) with the following activities: “employment or job seeking (91.7%), family life (41.2%), and leisure/cultural activities (41.2%)” (p. 280).

Researchers have investigated pain experienced by upper limb amputees. In a study by Hanley et al. (2009), the following percentages represent the respondents (104 in total) who experienced specific kinds of pain: phantom limb pain (79%); residual limb pain (71%); some other type of pain, such as in the back (52%) or neck (43%). Hanley et al. noted that both chronic and residual pain is common for many individuals after an upper limb amputation. These researchers discovered that respondents’ QOL was negatively correlated with their pain. Desmond and MacLachlan (2010) also conducted research investigating phantom and residual limb pain for upper limb amputees. Although respondents experienced phantom and residual limb pain, their most common response indicated that the pain was “discomforting” in contrast to descriptions such as “horrible” or “excruciating” (Desmond & MacLachlan, 2010, p. 281).

Psychosocial impacts for upper limb amputees are outlined in the literature. In a research study conducted by Cheung, Alvaro, and Colotla (2003), upper limb amputees (compared to lower limb amputees) had higher rates of depression and post-traumatic stress syndrome. Furthermore, in Desmond’s (2007) study, upper limb amputees

completed the *Hospital Anxiety and Depression Scale* (HADS-D). 28.3% of upper limb amputees had responses indicative of depression.

Paterson and Burke's (1995) article included a case study of an upper limb amputee and some of the psychosocial impacts he experienced. This study involved a case report of a constable whose both arms were amputated when his vehicle was attacked by rockets. The constable shared his feelings including that he does not like it when other people assume that his cognitive capacity has been adversely affected because he has two amputated limbs. The constable provided an example of a time when he was in a restaurant and his cognitive capacity was assumed to be low by a restaurant server. The server seemed to think the constable was not able to answer a simple question. Instead of directly talking to the constable, the server asked the constable's wife if sugar was needed. The constable explained this situation: "Yes, the "does he take sugar?" scenario happened to me. When my wife was asked the question, I interjected with "No, he does not!" (Paterson & Burke, 1995, p. 778). The constable explained his "dislike" (p. 778) when these types of instances occurred.

The constable described that during his time in hospital, his relationship with his spouse was, at times, adversely affected. He also talked about sadness after his time in hospital: "In the 6 months or so following discharge, I did get frustrated on occasions and cried. The short bouts of self-pity worked as a safety valve, after which things did not look as bad as I had previously thought" (Paterson & Burke, 1995, p. 778). The constable described his development: "As time passed, proficiency with my prosthesis improved as did my independence and fitness, and, ultimately, my self-esteem" (Paterson & Burke, 1995, p. 778). After his amputation, he returned to university and completed his studies.

Desmond and MacLachlan (2006a) conducted a study investigating both pain and psychosocial issues for 582 male subjects consisting of both upper limb and lower limb amputees. Most subjects were veterans of the Second World War. The *Hospital Anxiety and Depression scale* was used to gauge respondents' level of depression and anxiety. The authors noted that “in contrast with previous studies, the current findings reveal associations between postamputation pain and affective distress” (Desmond & MacLachlan, 2006a, p. 365). Since 32% of respondents “met the criterion for possible clinical depression and 34% (198/582) met the criterion for possible clinical anxiety” (Desmond & MacLachlan, 2006a, p. 365), the authors state that the high level of depression and anxiety among amputees is a concern. Desmond and MacLachlan state that those who experience psychological distress may find it advantageous to seek support from health specialists.

Body image is another area that has been explored by researchers. Gallagher, Horgan, Franchignoni, Giordano, and MacLachlan (2007) investigated the *Amputee Body Image Scale (ABIS)* for individuals with a lower limb amputation. A summary of actual components from the ABIS instrument provides a perspective into what constitutes body image. Below are some of the verbatim statements that comprise the ABIS instrument:

- Because I am an amputee, I feel more anxious about my physical appearance in social situations than when I am alone.
- It concerns me that the loss of my limb impairs my body's functional capabilities in various activities of daily living.
- Because I am amputee, I feel anxious about my physical appearance on a daily basis.

- When I am walking, people notice my limp.

(Gallagher et al., 2007, p. 214).

These statements help to gauge the image that an amputee has of their own body and his or her corresponding comfort or anxiety.

Rybarczyk and Behel (2008) provide insights relating to body image and amputation. The authors write about the relationship between body image and self-concept. In Sardjian et al.'s (2008) study, the authors wrote that male upper limb amputees "were highly invested in portraying a "normal" appearance that served to maintain a "normal" identity and offset a self-image as disfigured and disabled" (p. 881). The feelings and perceptions about one's body image can have significant implications. Having referred to research studies, Rybarczyk and Behel write: "A poor body image following amputation is correlated with a range of negative outcomes, including increased depression and decreased life satisfaction, quality of life, activity levels, and overall psychological adjustment" (p. 30). Clearly, how an individual perceives himself or herself and his or her body can have significant implications on a range of psychosocial issues and QOL.

Additional points about both body image and prostheses are made by Rybarczyk and Behel (2008). First, the prosthesis is viewed by some as an "extension of the body" (p. 30). Individuals may have a challenging time adjusting if they are content with their prosthesis. Second, upper limb amputees may experience unique challenges with body image due to the important roles of arms and hands. Third, how an individual views his or her body may be impacted if he or she has experienced prejudice and stigmatization



from others. Finally, the authors cite both research and theory as to why older adults may be less prone to concerns about body image.

The return to work has been another area outlined by researchers. In contrast to the results of Kejlaa's (1992) study, Datta et al. (2004) and Jones and Davidson (1995) did not report a comparatively high unemployment rates among individuals with an upper limb amputation; although in their studies, the majority of respondents reported having to change occupations. Paterson and Burke (1995) highlight the need for employers to be cognizant of employees' psychosocial challenges after an upper limb amputation. Burger (2010) reviewed literature concerning amputees' return to their employment. Burger reported that the length of time to return to work is an individualized process, possibly ranging from a few days to a couple years. The return to work is complex and may depend on many factors. Burger believes these stakeholders should not be operating in isolation but rather they need to cooperate and communicate with each other to best support the return to work for an individual who has undergone an amputation.

The previously outlined challenges are meant to expose a select range of possible impacts that have surfaced in the literature with regard to upper limb amputee. Several researchers referred to in this section acknowledged potential limitations with respect to their studies. The review of possible impacts noted in this section is not intended to provide the impression that all individuals may experience impacts after their amputation. Some individuals may experience minimal or no change.

## **Prosthesis**

An active area in research investigating amputees is an individual's functionality or satisfaction with his or her prosthesis. Although a comprehensive review of prosthesis functionality and satisfaction is beyond the scope of the purposes of the current research study, several key points will be briefly stated. Variation exists as to amputees' usage rates as well as their level of satisfaction with their prosthesis (Davidson, 2002).

Davidson argues: "For any prosthesis to be accepted and used by an amputee, it must be comfortable, functional, and reasonable cosmetic" (2002, p. 62). Prosthesis utilization may typically require a period of adjustment (Saradjian et al., 2008).

Research focuses on how a prosthesis relates to an amputee's rehabilitation. A study conducted by Østlie, Lesjø, et al. (2011) demonstrates that people who have never worn a prosthesis typically did not see a need to use one; Biddiss and Chau (2007) also note the importance of need. "Dissatisfaction of comfort, function, and control" (Østlie, Lesjø, et al. 2011, p. 7) was cited by as major reasons for those who did wear a prosthesis but ultimately discontinued use. Regarding prostheses for upper limb amputees, researchers have addressed other areas: quality of life (for a review of instruments see Desmond & Gallagher, 2010; Gallagher & Desmond, 2007); focus on improvements (Østlie, Lesjø, et al., 2011); training and rehabilitation opportunities (Biddis & Chau, 2007); and outcomes (Wright, 2009).

## **Responses**

In addition to their investigations of any impacts potentially experienced by amputees, researchers have examined areas termed as *adjustment* and *coping*. Desmond and Gallagher (2008) made many statements pertaining to adjustment and amputation.

First, they indicate that adjustment has not been explicitly defined by researchers. Second, research has historically conceptualized adjustment to be the lack of psychological problems, such as the avoidance of depression. Third, some researchers have focused on indicators of satisfaction to be associated with adjustment. Desmond and Gallagher conclude by stating that a comprehensive description of adjustment is not possible if a researcher exclusively focuses on positive indicators (e.g., satisfaction) or challenges (e.g., depression). Rather, to ensure a comprehensive portrayal of adjustment, both positive indicators and challenges need to be considered in tandem (Desmond & Gallagher).

Researchers have investigated coping strategies. Desmond (2007) and Desmond and Gallagher (2008) summarized the limited research regarding coping and amputation. Desmond and Gallagher (2010) note that a single definition of coping does not exist in the literature. They cite a definition of coping proposed by Lazarus (1991): “cognitive and behavioral efforts to manage specific external or internal demands (and conflicts between them) that are appraised as taxing the resources of a person” (p. 12). One major finding relates to a person’s utilization of coping strategies. In Desmond’s (2007) study, upper limb amputees completed the *Coping Strategy Indicator*—an instrument developed by Amirkhan (1990). A key finding from Desmond’s research study is that an individual’s employment of particular coping strategies predicted his or her psychosocial adjustment and depression. Specifically, upper limb amputees who employed strategies that aimed to respond to problems (e.g., dealing directly with the stressor) had scores associated with higher adjustment and lower depression. These results are consistent with findings from a research study involving lower limb amputees conducted by Desmond

and MacLachlan (2006b). In this study, lower limb amputees who employed a coping style associated with avoidance (e.g., withdrawal) were significantly associated with higher levels of anxiety and depression and they had a negative correlation to adjustment.

Saradjian et al. (2008) employed a phenomenological study, consisting of 11 male upper limb amputees. In their study, the data analysis revealed themes related to respondents' adjustment: "acceptance & support of others", "social interactions", "leisure activities", "occupational role", and "cognitive adaptation" (Saradjian et al, 2008, p. 875). Family and friends were key to providing this acceptance and support. Positive adjustment was aided by positivity and a willingness to interact with life, and embrace novel experiences. Positivity consisted of life in general and constructively dealing with problems. Most respondents were able to make changes to their activities as well as their work roles and tasks.

### **Quality of Life**

**Background.** A thorough literature search on QOL yields literally *thousands* of articles and citations. Walters (2009) provided some key historical highlights regarding QOL. First, Walters noted the term has existed for several decades and has significantly developed since its inclusion in the literature. Some researchers have employed the term *quality of life* whereas other researchers have employed the term *health related quality of life*, to emphasize the focus on examining aspects related to health. The term, quality of life, is well situated in the literature and as such, it is used in the present research study.

Researchers have not concurred upon a single definition of QOL (Dijkers, 2003). In fact, Schalock (2000) noted that researchers have defined QOL in more than 100 different ways. Nevertheless, a review of the literature yields perspectives and insights

into its definition. First, subjectivity is a key component of the definition although researchers have also highlighted objective indicators (Dijkers, 2003; Schallock, 2000). Second, QOL is a multidimensional concept (Kuijer & De Ridder, 2003; Zidarov et al., 2009). Schallock made three more statements regarding its definition: it cannot be summarized as “a single “thing,” of which the person may have a considerable amount, some amount, or none” (p. 118); satisfaction is a central component; and it is fluid and subject to changes across an individual’s life.

Methodology and measurement have been important areas in QOL research. Researchers have employed methodological diversity to investigate QOL. Although this diversity exists, more studies have used quantitative methodology in comparison to qualitative methodology (Hambleton et al., 2009). When conducting studies involving quantitative methodology, researchers have opted to use either general or condition specific instrument (Walters, 2009; Zidarov et al., 2009). Differences exist between these two types of instruments. A general instrument, such as the *SF-36*, is designed to be used with all populations without reference to a particular illness or health condition. In contrast, a condition specific instrument is designed for individuals representing a specific population. For example, there are condition specific instruments to measure QOL for individuals with heart failure (Garin et al., 2009) and diabetes (Speight, Reaney, & Barnard, 2009). Desmond and Gallagher (2010) identified four condition specific instruments relating to QOL and prosthetics of lower limb amputees: *Trinity Amputation and Prosthesis Experience Scales*, *Prosthesis Evaluation Questionnaire*, *Orthotics and Prosthetics Users’ Survey*, and *Questionnaire for Persons with a Transfemoral Amputation*.

Some authors do not provide a definition of QOL in their research studies. For many years, this definitional imprecision has adversely affected both the amputation and non-amputation related fields. In a review of 75 research articles, Gill and Feinstein (1994) noted that quality of life was defined by researchers in only 11 of the articles. Furthermore, researchers in academic disciplines may differ on their perceptions and approaches towards QOL. Differences even exist among researchers in the social sciences. Specifically, in a review article Hambleton et al. (2009) indicated that there are QOL definitional differences between psychology and sociology. Most importantly for the present study, Desmond and Gallagher (2010) indicate that a lack of definitions continues to plague the literature related to amputations: “This failure to make [QOL definitions] explicit has contributed to a lack of conceptual and terminological clarity in the field” (p. 3788).

Investigating the QOL of amputees can be a complex endeavour. Desmond and Gallagher (2010) substantiate this:

In attempting to summarize literature on QOL post-amputation difficulties arise due, in particular, to differing inclusion criteria and heterogeneity within and between samples in terms of amputation related variables (e.g., amputation aetiology, level of amputation, access to prosthetic restoration and rehabilitation, and time since amputation) and demographic variables (e.g., age, sex and socioeconomic status (p. 3794).

In this statement, the authors outline several variables and the corresponding complexities of a literature review of amputees and QOL. Compounding this complexity is that some

research studies address QOL with a specific focus on an individual's prosthesis (see Gallagher & Desmond, 2007).

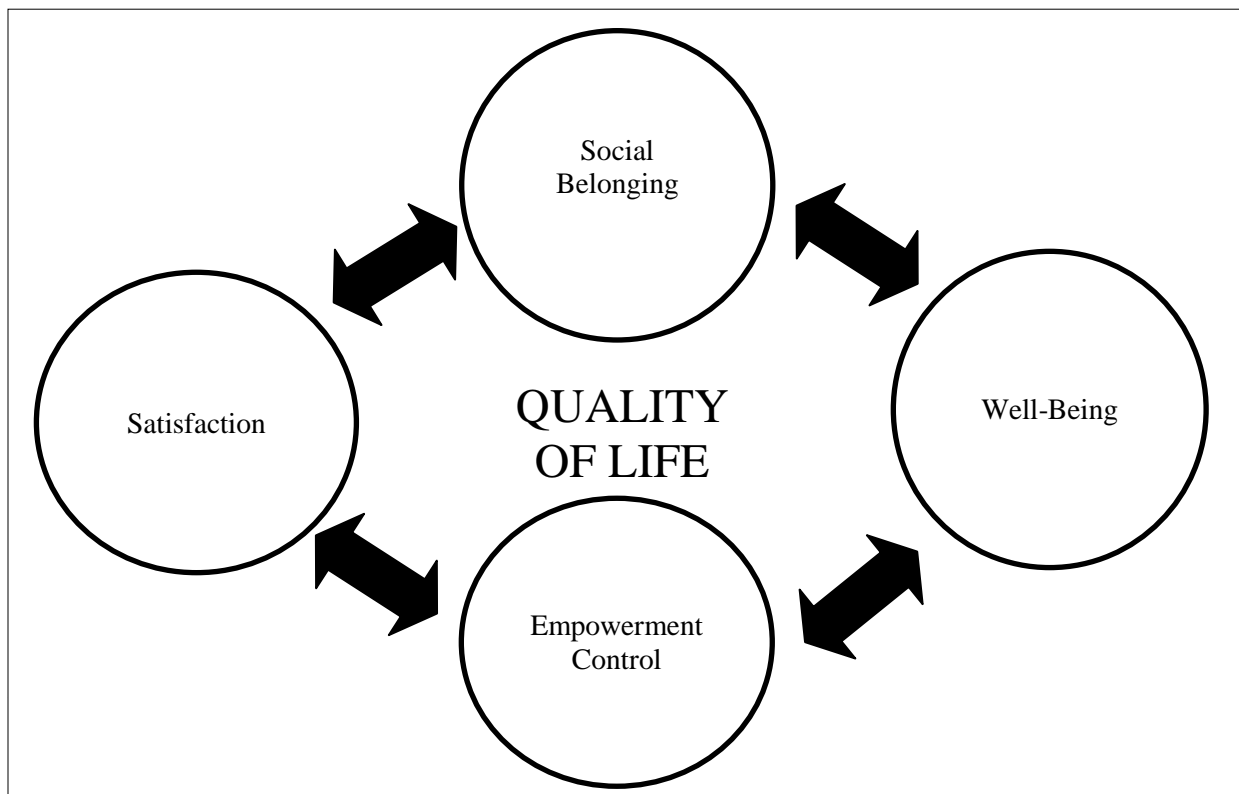
**QOL model.** Keith and Schalock (1994) identified four factors associated with QOL. Below are general descriptions of these factors.

- *Satisfaction:* Opinions and feelings regarding contentment with his or her present situation
- *Well-being:* General perceptions about one's overall life
- *Social belonging:* Association and engagement with events and activities, social connections, and relationship involvement with other people
- *Empowerment/Control:* A sense of having control with respect to decisions in life and being able to choose among options

Each factor was comprised of ten items on a questionnaire designed by Keith and Schalock (1992, 1994).

A QOL model derived by Keith and Schalock (1994) and modified by Roberts and Cairns (1999) was used to develop the interview questions. Figure 1 provides an illustration of this QOL model.

Figure 1 - Quality of Life Model



*Figure 1.* Roberts and Cairns' (1999) pictorial representation of Keith and Schalock's (1999) QOL model.

Figure 1 illustrates the four components of QOL and the arrows illustrate the reciprocal influence. Roberts and Cairns write: "Our understanding of quality of life focuses on general feelings of satisfaction, well-being, social belonging and empowerment. ...Quality of life is not solely dependent on one area, but relies on a fluid and transactional interplay of each individual area" (1999, p. 33). The use of the word 'general feelings', 'fluid', and 'transactional interplay' signify that the QOL components are not rigidly categorized. This QOL model has been instrumental to understand people's experiences in other research studies (see Roberts, Hayashi, Anderson, Martin,



& Maxwell, 2003; Roberts, MacMath, et al., 2006; Roberts, Massie, Mortimer, & Maxwell, 2005; Roberts, Morden, et al., 2006).

**Adult amputation-related research results.** In a review of how individuals adjust to their lower limb amputation, Horgan and MacLachlan (2004) specifically requested additional research exploring QOL: “While much research has focused on negative outcomes associated with amputations, we call for research that broadly addresses patient’s quality of life (positive and negative), from within a psychosocial perspective” (p. 846). Research inquiring about QOL for lower limb amputees is much more extensive than research focusing on upper limb amputation. As Østlie et al. (2011) contend, “literature specifically addressing upper limb amputee and quality of life is scarce” (p. 1595). Compounding the scarcity of this research with upper limb amputees is that there have been few studies that focus on psychosocial issues. Desmond (2007) used the term “dearth” (p. 15) to describe the amount of research that has examined psychosocial adaptation with upper limb amputees. Although amputees’ QOL has received limited attention in the literature, more researchers are focusing on this field, especially with regards to studies investigating individuals with a lower limb amputation (Desmond & Gallagher, 2010).

A review of the literature by Desmond and Gallagher (2010) conveys that amputees’ QOL may be affected by several areas. Demet, Martinet, Guillemin, Paysant, and André (2003) highlighted some of these variables. To measure respondents’ QOL, the researchers used the *Nottingham Health Profile* (NHP) as the generic instrument. Results indicated that for most or all areas of the areas that were measured, men, upper limb amputees, and individuals who had an amputation at a younger age reported a

higher QOL than women, lower limb amputees, and people who had an amputation at an older age. In comparison to lower limb amputees' QOL, "people with upper limb amputation had a better HRQL than those with lower limb amputations, mostly from physical disability, pain and energy level scores" (Demet et al., 2004, p. 485). Specifically upper limb amputees reported lower levels of physical disability and pain as well as higher levels of energy.

A recent study by Østlie, Magnus, et al. (2011) investigated *life satisfaction*—a component more specific than QOL. Investigating individuals residing in Norway, Østlie et al. (2011a) compared life satisfaction of 224 upper limb amputees and 318 people who represented the control group. To measure life satisfaction, the researchers used the *Satisfaction With Life Scale* (SWLS). Diener, Emmons, Larsen, and Griffin (1985) developed the SWLS, which concentrates on satisfaction, thereby not assessing "related constructs such as positive affect or loneliness" (p. 71). When compared to the control group, upper limb amputees had a significantly lower level of life satisfaction (Østlie, Magnus, et al., 2011).

As previously noted, more research has been conducted with lower limb amputees than with upper limb amputees. Specific research studies investigating lower limb amputees will now be discussed. These studies are referred to with the acknowledgment that a comprehensive literature review of lower limb amputees' QOL is beyond the scope of the present study's research questions.

Asano, Rushton, Miller, and Deathe (2008) used a generic condition assessment, termed *Visual Analogue Scale* (VAS), to research 295 men and 120 women with a lower limb amputation in Ontario, Canada. The mean age of subjects was 61.9 years.

Researchers indicated “seven significant factors (depression, perceived prosthetic mobility, social support, comorbidity, prosthesis problems, age and social activity participation) as predictors of subjects’ perceived QOL” (Asano et al., 2008, p. 231).

Using a generic assessment, *Subjective Quality of Life Profile (SQLP)*, Zidarov et al. (2009) researched 19 individuals (14 men and 5 women) who had a lower limb amputation in Quebec, Canada. The mean age of respondents was 53.4 years. One result from this study was that relationship between QOL and body image.

Sinha and Van Den Heuvel (2011) conducted a review of 26 research studies that explored the QOL of lower limb amputees. Key findings from this review were variables associated with lower levels of QOL (authors as cited by Sinha and Van Den Heuvel are also noted): feelings of vulnerability (Behel, Rybarczyk, Elliot, Nicholas, & Nyenhuis, 2002); pain (van der Schans, Geertzen, Schoppen, & Dijkstra, 2002); and prosthesis or mobility problems (Hagberg & Branemark, 2001).

The results from the previously mentioned research studies must be interpreted with caution especially with regards to making any type of generalizations to the amputee population. Sinha and Van Den Heuvel (2011) noted at least three limitations with the 26 research studies referred to in their review. First, they wrote that researchers noted that many of the studies did not provide background information about the respondents. Second, response rates in the majority of the studies were less than 80%. Third, some of the studies did not investigate variables that may have potentially confounded with a respondent’s QOL.

In their review of the 26 studies, Sinha and Van Den Heuvel (2011) noted a majority of the researchers used generic assessments to measure QOL. They indicated

that “amputee specific standardized and validated QoL instruments” (Sinha & Van Den Heuvel, 2011, p. 897) are needed.

### **Need for Future Research**

Additional QOL research has the potential to be advantageous to several groups of individuals. Amputees may find the research to be useful as a means to relate with their own QOL. Family members and friends may utilize the research to positively affect their relationships with people who have undergone an amputation. Health care practitioners, such as physicians and prosthetists, may discover the research helps them to develop a better understanding of the experiences of individuals who have undergone an amputation.

In terms of health care practice, additional advantages exist for measuring QOL. Some medical researchers have a tendency to focus exclusively on a single area: “Many measures link QoL to functional capacity, assuming if a person is unable to achieve full physical capacity their QoL is poorer” (Asano et al., 2008, p. 232). Walters noted the historical tendency to focus on one area: “Medicine and health care have traditionally tended to focus on symptom relief as the main outcome measure...and using QOL instruments may reveal other issues that are equally or more important to patients than just symptom relief” (p. 10). The latter quotation highlights the need for a comprehensive approach to QOL inquiries. As previously noted, QOL is complex and cannot be attributed to a single item (Schalock, 2000). Focusing on a single issue or impact—such as physical capacities or relief—may result in a limited understanding of an individual’s multi-faceted and unique circumstances. To develop a comprehensive understanding of

amputees' QOL experiences, additional research is required (Horgan & MacLachlan, 2004).

The present study addresses researchers' concerns about the limited amount of research that focuses on QOL for upper limb amputees. Furthermore, researchers have been advocating for additional studies employing a qualitative methodology. Specifically, Sinha and Van Den Heuvel (2011) recommend additional qualitative studies exploring amputees' QOL. Horgan and MacLachlan (2004) have sought an increased qualitative approach to studying adjustment to amputation. Furthermore, researchers have encouraged the utilization of phenomenology to inquire about experiences of individuals who use prostheses (see Murray, 2010). Phenomenology has been employed in specific research studies with upper limb amputees, such as the study employed by Saradjian et al. (2008).

### **Summary**

This chapter outlined unique circumstances experienced by upper limb amputees. An overview was presented of possible impacts experienced by upper limb amputees. Responses to these impacts were explored with a specific reference to coping and adjustment. Quality of life was introduced accompanied with an illustration of Roberts and Cairns' (1999) pictorial representation of Keith and Schalock's (1994) model. Research findings were presented relating to the quality of life experiences of individuals who have an amputated limb. The chapter concluded with the need for additional research.

## **Chapter 3: Methodology**

### **General Approach**

Qualitative research seeks to develop a greater understanding of a phenomenon and meaning of experiences (Anderson & Arsenault, 1998). In the present study, the phenomenon is the lived experiences of adults who have undergone an upper limb amputation. To best understand these lived experiences relative to the concept of QOL, an approach is needed where participants are able to both consider their experiences and freely express themselves. This consideration and expression can be fostered when the interviewer asks open-ended questions, thereby permitting opportunities for the expression of ideas and feelings. Furthermore, Marshall and Rossman (2011) articulate that qualitative research is conducted in natural settings as opposed to in labs and is “grounded in the lived experiences of people” (p. 2). Qualitative methodology is an optimal choice for the present research study.

Qualitative researchers tend to possess certain views. Creswell (2007, 2009) indicated that these views relate to both the research process and the role of the researcher. With respect to the research process, one philosophical perspective of qualitative research is that the focus of the study is on the participant’s (and not the researcher’s) experiences, ideas, and viewpoints. Another view is that participant responses are not static. Rather, they are subject to cultural and social norms, interactions, and influences. Third, the research process is not static and as such, it is emergent and subject to changes.

Creswell (2007) further contends that qualitative researchers possess views about their own role. They accept that researchers cannot completely isolate their own

experiences from their interpretation. They need to be open and reflexive while outlining any potential biases. As opposed to having preconceived hypotheses and theories, researchers are in a position to learn from participants.

### **Research Design**

Phenomenology is the method of inquiry for the present research study. Many researchers, such as Caelli (2001) and Creswell (2007), have written about the philosophical elements of phenomenology. Creswell indicated that phenomenological inquiry “describes the meaning for several individuals of their lived experiences of a concept or phenomenon” (p. 57). In an analytical review of the literature, Norlyk and Harder (2010) outlined variations of how, in several studies, researchers have employed phenomenology. Despite these variations, Creswell (2007) demonstrates that phenomenological research contains common features. Creswell outlines several of these features. First, the sample is “people who have all experienced the phenomenon” (p. 61). Second, participants may have different perspectives or viewpoints about the phenomenon. One major task of the researcher is to review the expressed experiences of the participants as conveyed through interviews and documented in transcripts. The researcher then describes (as opposed to explains) the participant’s lived experiences. To bring meaning to these experiences, the researcher, in concert with the participant, reviews, analyzes, and describes the data.

Moustakas (1994) writes: “The phenomenological interview involves an informal, interactive process and utilizes open-ended comments and questions” (p. 114). Open-ended questions foster the opportunity for participants to use language to express themselves and their experiences. In terms of discussing their experiences, participants

might “perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others” (Patton, 2002, p. 104). Researchers hear directly from participants as to how they experienced the phenomenon.

Researchers are advised to acknowledge the philosophical aspects of phenomenology (Creswell, 2007; Norlyk & Harder, 2010). In response to the need to discuss the philosophical elements, I employed descriptive (eidetic) phenomenology for reasons outlined by Lopez and Willis (2004). The first reason is that in descriptive phenomenology, the focus is on the description of participants’ experiences. Second, the emphasis is “that experiences as perceived by human consciousness has value and should be an object of scientific study” (Lopez & Willis, 2004, p. 727). The primary purpose of the present study is to develop a better understanding of upper limb amputees’ QOL experiences. Hence, I chose to employ descriptive phenomenology as its philosophical assumptions align with the present study’s primary and secondary research question.

### **Entering Assumptions**

Researchers have an important role when they employ phenomenological research. In order to describe a participant’s experiences, researchers need to put aside their own experiences and judgments; this process is known as “bracketing” (Creswell, 2007, p. 59) or “the epoche process” (Moustakas, 1994, p.22). Although qualitative researchers employ bracketing and epoche, their role extends beyond that of an individual who only collects data. Rather, qualitative researchers need to make decisions such as what questions to ask during the interview, whether to use prompts, and the how to ensure rigour. I identify the following assumptions:

- Participants will be honest with their responses.



- Participants are able to express their conscious experiences.
- Since participants have voluntarily accepted to engage in this study, they—as compared to individuals who did not want to be interviewed—may be more comfortable being interviewed and sharing their experiences.
- Participants may choose to describe their experiences in a variety of ways such as, but not limited to areas such as beliefs, judgments, perceptions, and values.

### **Reflexivity**

Horsburg (2003) wrote that as researchers reflect on their role and involvement, they cannot be completely isolated from the research process. In accordance with the importance for researchers to be reflective and to engage in bracketing, I used a journal to document my thoughts relating to the present research study. Ryan-Nicholls and Will (2009) stated that researchers can outline their interest in their area of study. I completed two entries before the interview process, including outlining my interest in the study. I completed four entries during and two entries after the interviews. These entries are provided in the subsequent chapter on results.

### **Sampling and Recruitment**

The present study employed both criterion and convenience sampling. Participants in the present research study satisfy a criterion that they have all experienced a phenomenon of undergoing an upper limb amputation. A member of Dr. Roberts' research team assisted with the process of presenting names of individuals with an upper limb amputation. I phoned all seven of the people. I read a script to potential participants over the telephone to inquire if they would be interested in being interviewed for a study exploring the QOL experiences of individuals who had undergone an amputation. The

script is contained in Appendix A. The script communicated that each participant would be interviewed twice, one interview in-person and a second over the telephone.

Five individuals agreed to participate, one declined, and another indicated availability in the future. At a later date, the same member of Dr. Roberts' research team provided me with two more names of individuals. I repeated the process above (e.g., phoning and reading a telephone script to potential participants). Both of these people agreed to participate. If the potential participant was interested, a mutually convenient time was arranged for the first interview. The location of the interview was determined by the participant. When meeting in-person, I thanked the participant and asked if he or she would sign two copies of a consent form (see Appendix B). One signed consent form was retained by the participant. The other signed consent form was kept by me and is now stored in a locked filing cabinet.

### **Participants**

Six individuals with an age range of 45-82, living in Western Canada participated in this study. There were one female and five males. The majority was born in Canada. All individuals had undergone an upper limb (arm or hand) amputation several years prior to being interviewed.

### **Interview Guide**

The questionnaire used during the interview is provided in Appendix C. The questions were open-ended to provide an opportunity for participants to comprehensively share and describe their experiences. Participants were provided with as much time as possible to answer each question. Some follow up questions (i.e., probes) were asked to

develop a comprehensive understanding of their experiences. If a participant asked for clarification to a question, I rephrased the question with slightly different wording.

### **Data Collection Procedures**

Data collection spanned a five month period in 2011. The in-person interview took place at a location of the participant's choice. All interviews took place at either the participant's residence or at the University of Victoria. Each participant was asked to sign two consent forms and I reminded them that the interview would be audiotaped, participation was voluntary, and that he or she could withdraw at any time. I thanked participants at the conclusion of the interview. Participants were informed that the interview would be transcribed and sent to them. I informed participants that a telephone interview would be scheduled as an opportunity to provide additional feedback and insights.

I conducted and transcribed all interviews. The interviews were then analyzed for significant statements. A copy of the transcription and an accompanying letter (Appendix D) was mailed to participants. So as to ensure identifiable information was not in the transcript, the responses to the initial background questions (e.g., beginning with age and ending with health concerns) were not included in the mailed transcript to participants.

In the transcripts, specific statements were highlighted, with themes noted in the right hand margin of the transcription. The second interview occurred at least one week after each participant received the transcription and analysis. Depending on the particular participant, the telephone and in-person interviews occurred within two to five months of one another. I phoned the participant for the second interview. During the second interview on the telephone, participants were first asked to comment on the accuracy of

the transcription and analysis. Second, participants were asked if they would like to provide any additional insights. I asked occasional questions for clarification. Thus, I conducted twelve interviews in total (six in-person and six over the telephone).

### **Data Analysis**

Once the first interview was complete, I followed a procedure created by Colaizzi (1978) and altered by Roberts and Cairns (1999, p. 36): a) “gathering a sense of each transcript’s meaning through repeatedly listening to the interview tapes;” b) “extracting significant statements from each paragraph;” and c) “formulating statements of meaning and/or themes from these extracted statements” (Roberts & Cairns, 1999, p. 36). A word or phrase was used to represent the central meaning of a participant’s statement. Each participant received his or her transcript, which consisted of a verbatim copy of the typed interview and highlighted statements accompanied by the corresponding word or phrase.

Some key points surfaced during the second interviews. First, all participants agreed on the accuracy of the transcript with the minor exception consisting of a few words. Specifically, two participants brought to my attention a few words associated with a sentence. Although I listened to the tape several times, it was difficult to transcribe three particular phrases (of 3-5 words each) with one hundred percent accuracy. Second, participants agreed with the accuracy of the analysis (e.g., word or phrase assigned to a specific statement). During the second interview, participants provided additional clarification and insights.

A word or phrase was classified as a theme if it was assigned to two or more participants. The theme name was either the name given to the word or phrase assigned to participant statements or confirmed during the second interview. Once a specific theme

was identified twice, subsequent identifications were not made on the transcript. Similar themes were organized into clusters. Similar clusters were then organized into categories. The purpose of this data analysis is to provide a descriptive and overall meaning and essence of the QOL experiences of adults with an upper limb amputation.

### **Rigour**

Researchers have a vital role in the process and need to make interpretations about what they “see, hear, and understand” (Creswell, 2007, p. 39). I strove to ensure rigour and credibility in the present study. First, I clearly outlined methods and procedures. Second, I had consultations and collaborations with my Supervisory Committee members. Third, participants had a chance to review and comment on the accuracy of the transcription and interpretations. Finally, I employed methodologies (e.g., phenomenology) in a manner consistent with other researchers.

### **Ethical Considerations**

Ethical areas were adhered to throughout the study. Ethical approval was provided from the University of Victoria (Appendix E). Participants were informed both verbally and in writing of the research objectives and purpose. To reduce any inconvenience, interviews took place at the participant’s choice of location. Participants indicated consent on the telephone as well as in person with their signing of the consent form. Participants were reminded that their participation was completely voluntary and that at any time during the study, they were free to withdraw without any consequences. To ensure anonymity of participants, pseudonyms were used in the results section. Protection of data is of utmost importance in a research study. Data is stored in a locked filing

cabinet. All paper data and audiotapes will be destroyed (i.e., shredded and burned respectively) five years after the study.

### **Summary**

Chapter three outlined the general approach and research design used to address the research questions. The sampling process and the interview guides were both described. The procedures for data collection and data analysis were provided. Ethical considerations were documented.

## Chapter 4: Results

This chapter is divided into several sections. In the first section, the participants' characteristics are briefly described. The second section, entitled "Essential structure of experience", outlines the main results of the study. Results related to the primary research question are presented in the next section. The final section reports results in relation to the secondary research question.

I report the results using both pseudonyms and also the term participant(s). To ensure rich descriptions of their experiences, participants' quotations are frequently employed throughout this chapter. On occasion, participants would laugh while responding and this was denoted as a "chuckle" in the transcripts.

The data analysis of participant responses revealed both similarities and differences. In order to report these similarities, I needed to make a decision as to the precise definition of the plural form of the word participant. For the duration of this thesis, the word 'participants' is defined as *two or more participants*. This definition of participants ensures clarity for all readers.

### Participant Profile

For the purposes of participants' anonymity, pseudonyms are employed. *Suzanna* is the female pseudonym. The five male pseudonyms are: *Mark, Adam, John, Robert, and Anton*. Participants resided in Western Canada, had a variety of employment statuses, and their age ranges were between 48-82 (+/- five years). The data does not reveal an exact length of time since an amputation; an approximation is a range between 15-60 years (+/- five years). All participants reported using a prosthetic device. Amputations

consisted of the following: below elbow (three); below wrist (two); arm, unknown if below or above elbow (one).

### **Essential Structure of Experience**

In regards to the primary research question, this study explored participants' QOL experiences. Some participants said QOL remained the same, others indicated an increase in a specific area, and one noted a decrease. Participants provided at least one reason for this stability or change. Three main categories related to QOL emerged from the data analysis of participant responses: empowerment, satisfaction and well-being, and social realm. Each category included clusters and themes.

**Empowerment.** Participants expressed agency as they directly influenced main aspects of their lives. They discussed that decision-making was performed frequently and without difficulty. Participants held the belief that they exerted control in their everyday lives. By either adjusting their approach or the length of time needed, participants engaged with and often finished tasks. As a result of having an amputated upper limb, participants stated they experienced some limitations in activities. One participant said that empowerment may be affected in subsequent years as she gets older. Another participant felt his own empowerment was very limited in the areas of employment and technology usage.

**Satisfaction and well-being.** Many participants indicated moderately high levels with respect to these two QOL areas. Relationships with family, significant others, and friends fostered satisfaction and well-being. Participants experienced positive affect with respect to several areas: achievement, gratefulness, happiness, positivity, and recognition. Three actions seemed to foster satisfaction and well-being: acting humorous,



participating in activities, and being employed. As a result of their amputations, participants shared a variety of challenges, which sometimes led to feelings of frustration. Three participants stated how the death of a loved one (either a spouse or a father) affected their satisfaction and well-being. Finances and physical health were discussed as influences that either contributed to or were related to an individuals' satisfaction and well-being.

**Social realm.** Family, a significant person, and friends contributed to participants' social belonging. In two key areas (physical appearance and perceptions) participants shared their thoughts relating to the social realm. Participants mentioned that they were content with their physical appearance while simultaneously stating that their appearance was different from other people. Participants expressed their opinions as to what they believed were perceptions held by other people. Social engagement was enhanced by their sociability and participation in activities. Many participants shared their experiences regarding some of the responses they received from other people. Three participants reported they felt discomfort and annoyance when they were stared at by other people.

In regards to the secondary research question, the data analysis of participants' descriptions revealed references to health care and psychological attributes. Health care included references to pre-amputation, hospital experiences, and rehabilitation. Categories representing psychological attributes were adjustment, motivation, and resiliency.

### **Primary Research Question**

Results are now presented in two areas in relation to the study's primary research question. First, I report whether participants expressed stability or changes in QOL after an upper limb amputation. Second, I present the categories, clusters, and themes of participant QOL experiences derived from data analysis.

**QOL stability or changes.** Each participant provided insight into how his or her QOL was influenced by undergoing an amputation.

Mark indicated his amputation affected how active he had been: "Well, it's slowed me down with all my sports. So my quality of life has gone down because I used to be quite active. I used to get out like seven nights a week playing sports, doing something. Nowadays, I just hardly ever go out anymore." Mark commented that he thinks most people who are active would likely experience a reduction in QOL after an amputation.

Adam did not specifically indicate a change to his QOL. Adam said, "I don't know if the quality's changed" and two issues were central to his responses. First, he immediately spoke of all the activities that he is no longer able to do, such as playing sports and gripping items:

I can't throw a ball. There's lots of things that I can't do that I used to be able to do. .... there's just so much I used to do. ... Like I can't climb on rocks or anything now because I can't, you know, get a grip or anything like that.

Second, he expressed his determination:

There's things that are awkward to carry now because you don't have the fingers so it makes it a little more awkward to carry things but the determination is still there; that never went away.

He referred to activities when discussing his QOL. Since being discharged from the hospital after his amputation, he said that "things have improved a great deal"; this remark indicates improvements Adam has experienced in his life. He reflected on these improvements and his personal development and said, "I've come a long way."

Suzanna commented that her QOL improved in a specific way and provided a rationale for this change. When asked if there were any changes to her QOL, she responded:

Oh, I think the quality is, one way has improved because of your more conscious of what you think, what you have and your valuables more. But I still before I had my amputation I felt quite fine with myself too. You know it wasn't like that I ever felt I wasn't doing very well. Always felt I could do just about anything I wanted to and I did. Socially, it [amputation] didn't make any, much difference.

The first part of this quotation illustrates that Suzanna's QOL has improved in at least in one specific area; whereas the second part indicates that she felt fine before and after her amputation. Any analysis that reports that Suzanna's QOL increased needs to take into account her self-assessment prior to her amputation.

After initially responding with "I don't know" to describe changes to his QOL, John elaborated: "I mean, you can say that it got better just because of the changes that I made personally, you know, all hingeing around maturing or growing or whatever you want to call it." John provided a specific reason as to why he has seen an improvement in

his QOL. His remark about developing as a person after his amputation (e.g., through maturity) was shared by other participants, including Suzanna.

Robert conveyed that his QOL has been stable:

My quality of life never really changed. I, I simply have an arm missing that I compensate for with a prosthesis so really there's no change in life. I still enjoy everything that I ever did. So, that's the way I can answer it.

Robert's comment suggests the importance he attaches to enjoying life as well as the compensatory function of his prosthesis.

Anton expressed several insights when asked about any changes to his QOL.

First, he shared that his amputation was something that he never had expected—not once in “hundreds” of years. Second, he explained that his amputation slowed his pace a few years after his amputation. Third, he remarked that he cannot change the situation.

Fourth, he conveyed his acceptance of his situation and that he is more careful in life so as not to injure his other arm. Mirroring the beliefs shared by other participants, Anton commented that how a person responds to an amputation is a unique and individualized process: “Maybe someone else it's a different idea, different all together, you know ...”

His comment suggests an awareness that other people may respond differently to a similar set of circumstances.

**Categorical, cluster, and thematic structures.** Three categories emerged from the data analysis of QOL experiences: empowerment, satisfaction and well-being, and social realm. Each category was comprised of a minimum of two clusters. These clusters were associated with at least two themes. Table 1 illustrates the clusters within each of

the categories. The categories, clusters, and themes, are not separate or distinct. Rather, they likely reciprocally influence and interact with each other.

Table 1

*Categories and Clusters for QOL Experiences*

Categories		
Empowerment	Satisfaction and well-being	Social Realm
Clusters within each Category		
Agency	Actions	Belonging
Changes	Challenges	Cognition
	Contextual areas	Engagement
	Positive affect	Responses
	Relationships	

***Empowerment.*** In the present study, empowerment contained two clusters: agency and changes. Agency included three themes: control, decision making, and task adjustment. Activity limitations and empowerment descriptions constituted the changes cluster. The clusters and themes related to empowerment are outlined in Table 2.

Table 2

*Clusters and Themes for the Empowerment Category*

Clusters	
Agency	Changes
Themes within each cluster	
Control	Activity limitations
Decision making	Empowerment descriptions
Task adjustment	

*Agency.* Participants remarked that they are in control of their lives. Suzanna said that people should control their own lives: “So I believe we should all exercise our own will. That doesn’t mean the will shouldn’t be disciplined and educated.” Three participants stated that their control needs to be balanced. For example, Anton said, “I like to be in control but to the certain point I would say, you know, you have to back off. You can’t be in constantly in control of something or somebody, you know.” This comment conveys a desire to be in control while acknowledging the limits. Another participant volunteered that his spouse has just as much control and influence within the home.

Participants described their decision making as “normal”, thereby emphasizing it as a regular occurrence. For example, Mark stated, “It’s just normal like everybody else’s is. I mean I control my own decisions like everybody else.” John reflected on his decision making: “My decisions on a day-to-day basis, like just, you know, work, what I’m doing at work, what my kids are involved. You know, just normal everyday stuff. Yeah.”

John's and Mark's comments indicate that decision-making was a typical occurrence and considered to be ordinary and regular.

Participants referred to the thinking involved in their decision making. For instance, when referring to his decision making, Robert said, "I always think for a moment. What's the outcome? Is it going to be good or is it going to be the other side? ... Now if the answer comes up good, then I carry on with that ..." This remark suggests that Robert is purposeful with his decisions and conveyed that he adheres to a certain path after making a decision. Suzanna's descriptions conveyed her sense of resolve. She indicated that she will "stick" with decisions she has made.

During the interviews, participants spoke of an ability to have control and a capacity to complete tasks. They referred to many everyday tasks that required engagement; some participants often remarked that these tasks were a challenge as well. In the second interview, Mark spoke about cooking food and getting dressed. Like Mark, Suzanna mentioned cooking and how she had to make adjustments with respect to cutting and peeling vegetables as well as using kitchen utensils (e.g., can openers). Adam talked about picking up items off the ground.

Participants derived new ways to complete a task and they provided some details with respect to task adjustment. First, when approaching a task, participants indicated they engaged themselves in a cognitive process. For example, to describe how they complete a task, participants used the words "figure out." Second, participants said that completing tasks required a different approach, even if it required more cognition and time. Third, participants expressed a sense of agency with the task adjustment. Adam's

and Anton's quotations support these three points. Adam said, "I've got to figure out, use more brains than my hands." Anton remarked:

Your brain function differently at the time because if I cannot pick up two cups at the same time, you know, you try to figure it out how you will do it, you know.

You'll find a way. It is a way, always.

Anton's comment reveals his focus on cognition before approaching a task. The latter part of the quotation—"you'll find a way. It is a way, always"—emphasizes a sense of agency. Some tasks that may have been routine before the amputation are now ones that can still be completed but require additional cognition.

Mark stated that this task adjustment can be "challenging" and that "people don't realize how hard it is with one hand." This comment conveys his belief that task adjustment was not automatic or seamless—rather, at times, it could be challenging. Mark stated that he enjoys challenges. Suzanna mentioned that the task adjustments could have been a challenge for some individuals in a similar situation. She remarked that the perception of a challenge is largely dependent on an individual's previous life experiences. These comments convey that participants possessed a sense of agency while adjusting their approach to certain tasks. Completing these tasks required forethought, effort, and time. Participants were quite confident in their abilities and did not assume that all their tasks would require more time. For example, Suzanna discussed some tasks that she could do very efficiently.

Participants did not always complete their tasks individually. Rather, they were open and willing to request assistance from other people. Adam conveyed that he grapples with a task and when needed, he can ask for help from someone in the vicinity.



John's experience signifies the balance of many participants' desire to independently engage with a task, but to seek help when necessary:

You, you feel good because you accomplished it and you got it done. You didn't have to ask anybody for help. Or, or whatever you know. Not that that's the best way to go sometimes. Sometimes, you need help, you know.

The data analysis revealed a trend that participants often tried to engage in a task independently and then if necessary, they would ask for help. Robert said, "Go see someone who will help you. There's no shame in going to see someone to help you. But you've got to do it ...". Anton talked about how some people want to be independent. Further, he stressed the importance, if necessary of going to see a medical professional and that "they can help you if you accept their help. But if you don't they cannot help." The data analysis demonstrates a consensus among participants of their belief that other amputees, when necessary, may need to accept assistance from other people.

*Changes.* Participants experienced a change in their ability to engage in certain activities. A reduction or elimination of certain sports was the most common of all the activity limitations indicated by participants. In fact, half of all participants specifically noted that, as a result of their amputation, they are unable to play sports they had previously enjoyed. Adam revealed changes in activities that he has experienced as a result of his amputation. He indicated that certain activities associated with sports (e.g., throwing a baseball and climbing rocks) are not possible for him anymore. Mark conveyed a reduction in his ability to play certain sports. He first listed several sports that he used to play and then said the following: "That's all gone now. I can't, I can't do those

with one hand.” Robert spoke of two sports—boxing and hockey—that he is no longer able to play as a result of having undergone his amputation.

With the exception of sports, the data analysis revealed that participants’ empowerment did not significantly change as a direct result of an amputation. For example, Mark shared that “an amputation didn’t affect it [decision making and control] other than to do something that involves my amputation then obviously I can’t do it. Like volleyball and stuff like that but I still make normal decisions like everyone else.” This comment suggests that Mark’s empowerment was affected in certain activities because of having an amputated limb.

The data analysis of Robert’s responses did not indicate that his amputation changed his empowerment. He does provide some insights. For example, Robert mentioned that his empowerment was much higher in his previous job which he had been doing both before and after his amputation. He described his empowerment as “very limited” as a result of areas—technology and his current job—that were not directly related to his amputation.

***Satisfaction and well-being.*** According to Keith and Schalock (1994), satisfaction is an individual’s opinions and feelings regarding contentment with his or her present situation and well-being is the general perceptions about one’s overall life. These definitions show a difference between these two constructs. Although they are listed together in the present study, the constructs are not identical; participants’ responses to these constructs showed some variety. However, these constructs are listed together in the present research study due to the strong overlap of themes that emerged within the two categories. Additionally, responses from five of six participants to questions regarding

satisfaction and well-being were consistently similar in their evaluation. Mark was the one participant who indicated a considerable difference in his evaluation of satisfaction (described as “right now, not very satisfied”) and well-being (described as “on average, it’s okay”). Clusters and themes for satisfaction and well-being are included in Table 3.

Table 3

*Clusters and Themes for the Satisfaction and Well-being Category*

Clusters				
Actions	Challenges	Contextual areas	Positive affect	Relationships
Themes within each cluster				
Activities	Death (Spouse/Father)	Finances	Achievement	Family/Significant other
Humour	Frustration	Physical health	Gratefulness	Friends
Employment			Happiness	
			Positivity	
			Recognition	

*Actions.* Participants spoke of their enjoyment of several activities such as hobbies, leisure activities, and walks. They engaged in these activities both individually and with family and friends. Acting humorous was discussed by four of the participants. In his second interview, Mark said that humour serves multiple functions. He said that laughter is "good medicine", especially with helping to reduce physical pain. His time in the hospital was improved by sharing humour and jokes with the nurses. Robert and Anton spoke of their efforts to be humorous when talking to children about their amputations or prostheses.

Participants articulated responses regarding their employment. Adam said that “things are going good. ... Been doing a lot more working this year and not as many health problems.” Suzanna directly linked her employment with QOL. When asked about his well-being, John said, “I went back to work right away” to a job that he “enjoys.” Similarly, Robert returned to his employment soon after his amputation to a job that he had “love” for.

*Challenges.* Some participants indicated their satisfaction and well-being was impacted by the death of someone they loved. Specifically, when answering an interview question about well-being, Robert, whose spouse recently passed away, conveyed that he misses her. Adam, when outlining challenges, said his satisfaction was 7/10. In discussing his satisfaction, he spoke of his father’s passing.

Three participants discussed feelings of frustration. In his second interview, Adam noted that some tasks, such as picking up items off the ground and screwing in a nut, can be challenging and lead to frustration. In his second interview, John also said it can be frustrating to do certain tasks but that he can prevail. Participants accompanied their feelings of frustration with statements indicating they could overcome these challenges.

*Contextual areas.* Participants discussed their finances. Adam linked his finances to satisfaction and well-being. When explaining his 7/10 rating for satisfaction, he indicated, “I wish things were going better financially.” When asked, “How satisfied are you with your life?” Suzanna’s first words were, “Oh, I’m very satisfied (chuckle).” She then outlined many reasons for her satisfaction; one of the reasons included finances. She said, “I feel that we’re very fortunate to have what is required to sustain us and we, we have opportunity to have warmth and so on you know” Suzanna spoke of her experiences

with financial hardship when she was younger. The relationship between well-being and finances was complex. For instance, John remarked:

I just think I've grown up a lot personally that if I was presented with that question 15 years ago, it would have been a more materialistic type answer that you would have gotten as opposed to a more; I don't know, a more personal, a more experienced answer that you'd get now.

This comment describes how John's perspectives have changed. Two participants discussed how a prosthesis is expensive and how they receive financial support from the provincial agency responsible for the compensation of workplace accidents. Both participants expressed gratitude for this financial support. Regarding his prosthesis, a participant said that "it costs a lot of money" and that "it's the money for the pieces let alone the technicians that put it all together." This participant had received coverage and spoke about the difficulties that may occur for other people who do not have this financial support and whose prosthetic device is in need of repairs. He said that this provincial agency has "always" helped him. This participant said that a prosthesis can cost thousands of dollars and that there are times when it may need to be fixed. He elaborated: "So I would say, you know, as long as you have some support money-wise, your life will be much easier for you." He said that for those without prosthesis coverage, "it's way harder" and "it's a financial threat, you know." These participants appreciated the financial support they received for both their prosthesis and any necessary maintenance.

Participants spoke about physical health—both their own and that of family members. When asked about their well-being, Anton and Adam commented on their

physical health. Anton remarked that he received positive results from a recent physical exam. Participants' satisfaction and well-being was impacted by concerns of family members' health. For instance, when describing his level of satisfaction, Adam spoke about how he wished there was less sickness in both his and his spouses' families.

Suzanna described high levels of satisfaction but shared that she would be more satisfied if there were fewer people that suffered in the world. She said, "I think my well-being is, is fine, you know, it's good. ... If my children get hurt or something happens to them, I'm not happy about that."

*Positive affect.* Participants experienced positive affect when they demonstrated achievement in their own lives. Participants linked their satisfaction with their efforts to achieve. Suzanna remarked:

But in my own realm, I'm satisfied with what I can do as long as I do the best I can. If I don't do the best I can do, well, then I'm not, I'm very dissatisfied with myself but I think we all have those experiences.

This comment indicates that Suzanna's satisfaction is interwoven with her desire to achieve to the best regardless of circumstances. Anton made a similar comment when he said that high levels of satisfaction are related to his ability to accomplish and achieve tasks. John mentioned that in his employment, "I do the best that I can do with what I've been given ...". These descriptions suggest the importance that participants attach to achievement and its relationship to the QOL components of satisfaction (Suzanna's and Anton's comment) and well-being (John's comment).

With regards to the achievement theme, two important points were derived from data analysis. First, participants felt their day-to-day activities did not generally constitute

an achievement. Adam did not recognize taking care of his lawn (e.g., mowing lawn, weeding) as an achievement. Rather, participants expressed that an achievement was an activity or outcome of a significant nature. Anton summarized both his and other participants' sentiments when he said that achievements were not accomplishments that occur on a daily basis. Rather, he classified achievements as activities—such as writing a book—that could not be completed in a single day. Suzanna felt that academic credentials obtained over the years were noteworthy and could be considered an achievement.

With a variety of responses throughout the interviews, participants expressed their feelings of gratefulness. Two participants spoke of their gratefulness with residing in their present geographical location and two participants spoke of their gratefulness of prosthesis related care. Another participant felt “lucky” that he did not bleed to death during the accident. He was unfortunate and wished that it did not occur, but he accepted the reality.

Participants expressed positivity. They described how they maintained positivity throughout their lives. For Anton, these positive feelings were always present: “I was always positive in my life.” This comment indicates that the positivity existed both before and after his amputation. Participants also talked about happiness. For example, Anton said, “I’m happy as, as I am, you know. It’s no question about, you know. If I’m not happy, I wouldn’t have what I got today, you know.” Anton’s statement reveals surety of his happiness. Suzanna’s happiness was connected to her hope for the best future for all people. In his second interview, Mark indicated that he experiences happiness in life.

Recognition was a theme linked with satisfaction and well-being. Adam expressed feelings of satisfaction when he receives occasional recognition from other

people. Suzanna remarked once the importance to feel useful and to be appreciated by one's spouse. John's well-being is fostered when he is recognized for his employment-related performance.

*Relationships.* Family, significant others, and friends were three themes comprising the relationships cluster. Throughout the interviews, participants spoke of a connection with their families, specifically children and grandchildren. Suzanna expressed love for her children and grandchildren. Suzanna said her children were wonderful and not just because she "made them so"; she provided reasons as to why they are wonderful such as their display of kindness and affection towards her. Robert explained that, as time progresses, he continually becomes closer with his children and grandchildren and that they are the "greatest." These quotations clearly suggest that family is an integral aspect of both Suzanna's and Robert's lives. Other participants discussed their positive family relationships. Two participants discussed temporary obstacles and difficulties with family relationships. These comments demonstrated that the relationships were not always perfect but contained some temporary struggles, all of which in due time, were dealt with and resolved.

Participants talked about their significant other (i.e., spouse or partner). Anton remarked about how nice it was "to have someone constantly beside you" who is patient and accepting. Participants who were widowed spoke very positively and expressed deep love for their late spouses.

Participants shared the importance of their friends. Mark reported that he enjoyed spending time with a particular friend. Robert's relationships with his friends were so strong he compared the relationships to that of a bond shared by siblings. He talked about



seeing his friends on a regular basis and knowing them for decades. Adam commented on his liking to participate with friends in events such as fun competitive activities and certain sports.

A participant with military experience stressed the strong level of attachments with his friends:

If something happen to one, it happen to all. You never backed away from anything. If your friend got in trouble, you were there to help. You were there to support him. It was just a given.

This comment demonstrates the participant's desire to provide assistance to one's friends when necessary. Finally, Anton said that making friends is of high importance and that he participates in activities with them.

***Social realm.*** Four clusters—relationships, cognitions, engagement, and responses—comprise the social realm category. Each of these clusters contains themes.

Table 4 illustrates these clusters and themes.

Table 4

*Clusters and Themes for the Social Realm Category*

Clusters			
Social Relationships	Social Cognitions	Social Engagement	Social Responses
Themes within each cluster			
Family/Significant other	Physical appearance	Sociability	Responses
Friends	Perceptions	Activities	Staring

*Social relationships.* Family was mentioned in responses regarding relationships. When asked to describe his social belonging, John spoke about his children and involvement with activities. Robert remarked on his social belonging through relationships with his children and grandchildren. Additionally, participants commented on their friends. Mark talked about participating in one-to-one activities with two friends. Anton said that he keeps in communication with many friends.

*Social Cognitions.* Participants commented on physical appearance in relation to a social setting. Suzanna spoke about being well-groomed, but that her physical appearance is not a central aspect of her life. If it had been, she felt her adjustment to her amputation would have been different. Anton mentioned, “Yes, I don’t look perfect, you know (chuckle), because I got only one hand but then again, you know, it’s my life. So I have to stay with that. That’s what I think.”

Participants had perceptions regarding how they were thought of by other people. Compared to other participants, Mark expressed the strongest perceptions during the interviews regarding social cognitions:

So, I find in society, kind of looks down on you, I think, being an amputee. Like, you’re not a normal person I guess in their mind. They don’t understand so they don’t, they look at you funny and they kind of treat you weird.

Mark’s comment indicates a feeling that other people, as a result of limited understanding, do not treat amputees equally. Although not a primary concern at present, John, soon after his amputation, was initially concerned about fitting in with other people.

*Social engagement.* Participants frequently remarked that they enjoyed being sociable. Adam said, “Like, people talk to me all the time and I talk to other people. So I

am involved.” This comment describes the frequent discussions Adam has with other individuals. Participants conveyed varying degrees of sociability. For instance, Suzanna mentioned her sociability by indicating that she greets other people. John said that when he is at events with his children, he makes attempts to greet everyone but that having long conversations is not always possible. Anton and Robert spoke at length about their sociability. Anton talked about his desire to be sociable with other people: “I can talk the storm, you know. ...I’m not shy you know. I can talk to the person I never see. It doesn’t matter what he talk about.” Robert said, “I can go up to a perfectly strange person never laid eyes on them before and carry out a conversation.” He likes to talk to people at events. Participants remarked about activities they did with others including walking. A second enjoyed golfing and fishing. A third mentioned camping and finally, another participant talked about attending monthly gatherings with friends.

*Social responses.* Participants articulated how they were treated by other people. John indicated that some people are “blown away” when they realized what he could do with one hand. Anton remarked that sometimes he gets a “lot of respect” from other people.

On some occasions, Anton received a type of disbelief from other individuals; a colleague “couldn’t figure it out” how he was able to function with one hand. A couple times in his life, a person told a participant that they “don’t deal with a person with one hand.” This comment was described by the participant as being “very sad.” Another participant vocalized the difficulties and struggles when dealing with the appropriate officials to acquire financial and legal supports as a result of having an amputated limb.

Staring was a common response experienced by participants and they described the uncomfortable feelings of being looked at by other people. Mark stated:

Being an amputee because people always look at you especially in the summer time, I try to, I won't wear short sleeve shirts because it will show off my prosthetic ... It just felt strange that everybody is always looking at you and staring at you as if you were some alien from another planet, like you're not a human being.

This comment indicates that Mark's selection of clothes and time spent in public was affected by other people staring at him. Adam stated that he would rather have someone ask (as opposed to stare) about his prosthesis. In his second interview, he said, "It bugs me when people stare." Anton shared his thoughts: "If you don't like to look at me, just turn your head the other way, you know." This comment includes an option for people to look away and not stare. John provided some additional context into staring:

I used to really get offended because I thought they're looking at you like you're; well, you are different but you know, you know what I mean, like that's something wrong with you. And I've since discovered that it's more out of curiosity as opposed to malice or whatever you know.

This comment articulates John's perspectives on being stared at by other individuals.

### **Secondary Research Question**

In relation to the study's secondary research question, results are presented in two areas. First, I outline participants' descriptions of their general life stability or changes after an amputation. Second, I report on the categories, clusters, and themes of participants' life experiences derived from the data analysis.

**Life after amputation.** Mark stated that “your whole life changes when you lose a limb.” In our second interview, Mark shared his beliefs that people who have not undergone an amputation may not truly understand what life is like for amputees. Mark made the observation that people would need to have lived in another person’s “shoes” to understand the life of a person who has an amputated limb. Moreover, he expressed that in order for individuals to begin to understand the experiences shared by amputees, they either would need to put a hand behind their back or in a pocket. Mark said that because his prosthesis does not have movement like a wrist, he cannot twist and turn. He said his prosthesis helps but that it cannot be used to do all tasks. Finally, Mark said that he enjoys challenges—now he has to figure out how to do some tasks because a prosthesis does not function like a wrist.

When asked how his amputation changed his life, Adam replied: “Oh, totally.” When referring to his career ambition before his amputation, which he said required two arms and hands, Adam remarked that “there’s not a chance I can do that now.” “Very cold weather” was verbalized as being problematic for him. While talking about life after an amputation, he commented about his prosthesis. He indicated that a prosthesis is useful to open a can or bottle or to pick up items that are hot or magnetized. On other occasions, the prosthesis was not perceived as being beneficial; he said, “sometimes, it’s a hindrance.” Adam remarked that if he is not able to do certain activities using a prosthesis, he can seek assistance from other people. He said that “things are just going good”, including reasons such as his relationship, increased employment, and a reduction in both “prosthesis breakdowns” and health problems.

Suzanna shared how her life has been changed by her amputation: “it’s a discipline (chuckle). I, I may not have been quite as disciplined as I am now. I may not have been quite as appreciative of certain things.” The comment depicts how Suzanna’s discipline and appreciation were influenced as a result of having her amputation. Suzanna then spoke of the strong relationship she had with her spouse and the “marvelous experience” of having a family.

When asked about his life after an amputation, John said, “Things, things are just going good. ...Yeah, so I’m living the dream...So, everything just keeps rolling along.” John talked about his children, employment, and friends. He expressed that, soon after his amputation, he missed having a wrist and that he has developed over the years with maturity. In his second interview, John stated that he “didn’t want to leave an impression that it’s been a piece of cake. Like it’s all rosy. There are challenges.” John shared these challenges which involved both maintaining his prosthesis and responding to tasks that could once be “just taken for granted.”

Robert explained that his amputation helped him developed more tolerance towards people with a disability. He also indicated: “Well from day one, I didn’t really consider myself disabled. I was still capable of doing most all the things I ever did except a few.” When asked, “if anything is worse as a result of having an amputation?” Robert responded:

Nothing is worse than losing a limb. Unless you lose your life or somebody really close to you. Really, what could be worse for what I mentioned? You know, short of something you’re not capable of doing anymore like tying a bootlace. You’re not able to tie a bootlace especially with your hand gone, okay.

This comment, “nothing is worse”, suggests that Robert believes having a limb amputation is a very serious life event. Throughout the interviews, Robert remarked about never once being defeated in life and that he will always do what is necessary for success. Robert then said that acceptance can occur once you get your “head around” the change. He discussed his need to adapt and that he was back at his job only a few weeks after his amputation.

Robert and Anton used the word “accept” when describing their lives after an amputation. Anton said, “After you accept all that thing, you get happier you know.” He said that having an amputation required a “huge adjustment.”

**Categories, clusters, and thematic structures.** During their interviews, participants stated or alluded to several psychological attributes. Three of these attributes relate to adjustment, motivation, and resiliency. Table 5 provides the clusters and themes for the psychological attributes category.

Table 5

*Clusters and Themes for the Psychological Attributes Category*

Psychological attributes		
Adjustment	Motivation	Resiliency
Themes within each cluster		
Adaptation	Determination	Acceptance
Assistance	Perseverance	Influences
Pain	Progression	Optimism
Prosthesis utilization	Self-efficacy	Referencing others
Self		Self-sorrow avoidance

*Adjustment.* Participants often spoke about adapting to the fact that they had undergone an amputation. On some occasions during the interviews, participants provided specific examples of this adaptation. Adam described adapting to a variety of circumstances related to having an amputated limb and using a prosthesis. He learned that his prosthesis becomes damaged if used in a certain way and thus he “kind of learned not to do that because it’s kind of expensive.” Adam’s adaptation was expressed with a comment about approaching tasks differently: “I just used my head and it was just like, just like a, now it’s old hat. ... It’s like an adaptive balance; like, this is the way it is.” For John, his adaptation related to employment as he returned to work within a few weeks after his amputation.

Participants adjusted to the need to seek assistance when necessary. All but one participant either remarked about the importance of seeking assistance when necessary or said that it was fine to do so. Mark did not mention assistance so I am unsure of his views on this theme.

All participants discussed their thoughts relating to experiences with pain. Three participants shared their knowledge of either phantom or residual pain. Mark expressed experiences of pain and felt the average intensity is about four or five out of ten, although it can sometimes reach a seven. Suzanna said she most of the time she is pain-free; she only rarely experiences it. This description varied from Robert who talked about phantom pain and that the “nerve ends are forever there. Okay, they’re always there. You will get these as they refer to phantom pain.”

Participants articulated two additional points about pain. First, the pain was very intense during their hospital stay. Second, the current pain has decreased over the years



and is much less than they experienced during their time in the hospital. Anton's comments provide a summary that embodies participants' experiences:

It is painful on beginning, you know, because you got a phantom pains. And, you know, little things that can be fixed eventually. But the longer you are without hand, you know, without amputation and all that stuff, your body kind of adjust to it, you know slowly. But you will always have that kind of pain, you know.

In summary, some participants experienced pain, which has declined over time. The pain exists but it is not described as being overly intense.

Participants reported using their prostheses for a variety of purposes. They indicated that the prostheses enabled them to continue performing tasks at home and at work. In comparison, other participants did not specifically comment on the process of having to adjust to using a prosthesis.

Participants had a strong sense of self and they described knowing the type of person they were both before and after the amputation. Suzanna said, "I mean I never worried about it. I knew I was an excellent worker and I knew I could cope and I did. That's the long and short of it." This quotation indicates that Suzanna possesses confidence in herself and her specific abilities. John talked about the concept of self: "Just my own self, self-esteem, self-respect or whatever. I didn't want to sit around and mope you know." Robert described his constancy: "That the way I think and I've been like it my lifetime."

**Motivation.** Relating to motivation, four themes emerged from data analysis: determination, progression, perseverance, and self-efficacy. Participants expressed their determination by having a strong resolve or purpose. Adam said that if he puts his mind

to a task, he will either accomplish it or at least make an attempt. Participants indicated their progression with reports of wanting to move through life in a forward fashion. Perseverance was conveyed by participants; they persisted in a plan of action even with difficulties or hardships. Adam said, “Well, it was like trial and error. I would try things and I may screw it up. . . . I’ll try it again, you know. Like, after you do it enough times, you get better at it.” Self-efficacy was expressed as both beliefs that tasks could be completed and beliefs that challenges could be overcome. Participants had a strong self-efficacy and were confident they could accomplish tasks.

***Resiliency.*** Participants’ resiliency was evident through their responses that indicated their ability to adapt to potentially challenging situations. The data analysis of the narratives indicated that participants had come to accept living with an upper limb amputation. They described specific influences that assisted in their ability to respond to potentially challenging circumstances. Participants were influenced by lessons learned in childhood and from their parents. One participant referred to both God and religion and another referred to military experience as a strong influence. Participants indicated that these influences contributed to their sense of optimism. Additionally, participants expressed optimism in their daily lives, especially concerning their own abilities to succeed.

Participants seemed to be aided when they noted serious injuries experienced by other patients in the hospital. Participants felt their health problems were not as severe as these other individuals. John said, “People that I met and, you know, in some cases were worse off than me but still had a positive attitude and, you know, if that doesn’t rub off on you, your, there’s something wrong with you right?” Making references to other

people was raised by five participants. One participant said he knows of other people who chose not to be employed or even to perform daily chores. Another said that he knew some individuals who “gave up.” A third participant said he knew of others who did not accept their challenging circumstances, and as a result they experienced negative consequences in their lives.

The data analysis revealed that five participants said that they made a conscious decision to engage in self-sorrow avoidance. For Mark, this decision was made almost immediately after his amputation as he lay on his hospital bed. During the interview, Mark described avoiding self-sorrow:

It happens all day, all the time to other people and they live with it. So, it’s just, either I choose to feel sorry for the rest of my life or just have to live my life the best I could. And I decided just to do the best I could. There’s no feeling sorry because it’s not going to do any good.

John mirrored Mark’s comments: “No sense sitting around whining about it. Just, you know, ...I just tried to carry on with exactly my life exactly the way it was prior to that.”

Suzanna expressed a resolve to avoid self-sorrow: “I was never afraid, never felt sorry for myself. I have to say that. I’m not bragging or anything but just that is the truth. I, I never did.” Robert and Anton also spoke about the importance of self-sorrow avoidance.

**Health care.** Participants discussed themes related to their health care. Clusters centred on three time periods: pre-amputation and surgery, the hospital stay, and post-amputation. A minimum of three themes was contained within each cluster. Table 6 summarizes the clusters and themes of the health care category.

Table 6  
*Clusters and Themes for the Health Care Category*

Clusters		
Pre-amputation and surgery	Hospital experiences	Post-amputation
Themes within each cluster		
Injured limb	Pain	Rehabilitation
Amputation decision	Medical treatment	Prosthesis orientation
Expectations	Medical team support	Prosthesis maintenance
Amputation	Preferences	

***Pre-amputation and surgery.*** Participants offered a variety of explanations as to how their limb became injured, with accidents being the primary reason. The most common rationale to decide to have an amputation was that it was medically harmful for the injured limb to remain on the body due to the risk of spreading infection. When participants were asked to reflect on the time before their amputation (i.e., pre amputation), they shared their expectations about the surgery, recovery, and rehabilitation. These expectations included a range of responses such as: a) none b) unsure c) realization that changes or limitations might occur and d) discussions of psychological attributes such as acceptance and determination.

One participant had an immediate amputation, whereas the other five had some choice. Descriptions of the amputation from two participants included: “it was like prick. It went really fast” and “it went as good as it could go”.

***Hospital experiences.*** Participants spoke of the intense and at times excruciating pain while they were in the hospital. Adam said:

Well, I was in pain so I couldn't really focus on very much. It was like waking up in a fog and just being in so much intense pain and somebody's telling you that they're going to have to cut off part of your body.

Taking medication to alleviate the pain was discussed. Participants spoke positively about the support they received from their medical team. They specifically discussed the quality care from nurses. A few instances occurred when participants felt quality care was not provided. One instance in which a participant was dissatisfied with the care received was when he, without any notice, was given pain control medication by a nurse. Preferences existed about the type of care received. One of these preferences from participants was that they be treated with respect by medical staff. Participants appreciated transparency from their medical team.

*Post amputation.* Rehabilitation and issues related to their prosthesis were commented on by participants. Rehabilitation involved medical support and treatment. Participants needed to learn how to use a prosthesis to complete various tasks (e.g., picking up an egg without crushing it). Three participants mentioned that they experienced instances when their prosthesis required maintenance or repair.

## **Journal**

Below are entries from my journal which I used throughout the study:

Entries 1-2 were before, entries 3-8 were during, and entries 9-10 were after the interviews.

- Entry #1: I had previously completed ED-D 590, focusing on phenomenology, quality of life, and health psychology. This research study and design appealed to me due to my previous experiences exploring QOL. (February 22, 2011)

- Entry #2: Before this research study, I recall having a conversation with an individual who had one limb. He or she (confidentiality protection) spoke of some challenges experienced as a result of being an amputee. This individual spoke of many positive features in his or her life. Similarly, the review of the literature outlined some potentially challenging issues experienced by individuals with an amputation whereas some individuals did not experience challenges. Hence, I am bracketing these past potential influential experiences so as to only focus on the participants' responses. Indeed, I am in a position to learn from participants.  
(February 25, 2011)
- Entry #3: I feel grateful that this research study uses a specific QOL model. In my previous courses and academic papers, I became aware that the term is defined in several ways. By using a specific model that is grounded in previous research, I, in conjunction with my research team, look forward to comprehensively describing participant experiences. (February 27, 2011)
- Entry #4: Due to limited research with respect to upper limb amputees' QOL, I believe a need exists for additional studies. Hence, this research study is very meaningful. (February 28, 2011)
- Entry #5: At the end of the first interview, one participant asked me for a copy of the thesis when it was completed; I felt encouraged by his interest. (March 20, 2011)
- Entry #6: I found the similarities and variability in participant responses to be interesting. It reinforced for me the uniqueness of an individual's experiences.  
(March 29, 2011)

- Entry #7: I had to exert an effort to bracket some of my own experiences from previous employment. Specifically, my primary employment for the last eight years has been supporting post-secondary students with a disability. Some students and other people in my life have shared with me the hardships of being treated differently and not receiving fair and equitable access. They have expressed how difficult it is when they are treated negatively by others as a result of having a medical condition. Naturally, I felt empathy when a participant shared an experience of a person not interacting with him. (March 30, 2011)
- Entry #8: During all the interviews, participants have been very kind, engaging, and willing to share. I developed a great rapport with each of them and will always feel grateful and appreciative for their volunteer participation in this study. (June 7, 2011)
- Entry #9: I am at the stage in the writing process where my thesis is close to completion (January 25, 2012).
- Entry #10: The journey of conducting this research study has been very positive and my writing and research skills have developed. (February 21, 2012).

Writing these journal entries provided an excellent forum to attend to my thoughts pertaining to the present research study.

### **Summary**

In this chapter, I reported on the results in relation to the research questions. The data analysis revealed there was both stability and change of participants' QOL. The interview narratives and the subsequent data analysis generated an in-depth presentation of participants' QOL experiences. Additionally, participants' perceptions of their lives

changed as a result of undergoing an upper limb amputation. The data analysis of the primary and secondary research questions revealed that specific categories, clusters, and themes represented participants' experiences.



## Chapter 5: Discussion

This chapter contains a discussion and analysis of the current study's results. I present the results in relation to the study's two research questions. In order to develop a comprehensive understanding of six participants, I situate my results within the literature.

### Primary Research Question

As previously stated, the primary research question of this study is, "What are the quality of life experiences of adults who have undergone an amputation of an upper limb?" I will now discuss how participants represented QOL experiences.

**Participants' perspectives on QOL.** For the majority of the participants, an amputation did not negatively affect their QOL. For five of six participants, it either stayed the same or increased. Two participants expressed an improvement in QOL as a result of their increased maturity and discipline. One participant reported a decrease in QOL.

Demet et al.'s (2003) study revealed that upper limb amputees' higher reported QOL (compared to lower limb amputees) was primarily related to their responses pertaining to "physical disability, pain and energy level" (p. 480). In the present study, upper limb amputees did not express major concerns with physical disability and energy level. However, pain was acknowledged as a concern by some participants. A question thus arises: might participants in the present study have evaluated their QOL differently if they experienced much higher levels of pain and physical disability, and accompanied with lower energy levels? This question naturally requires an individualized and personalized response since QOL is multifaceted. Accordingly, researchers, such as

Asano et al. (2008) and Walters (2009), have cautioned against measuring QOL using a single determining item.

In Demet et al.'s (2003) study, being younger when they had their amputation occurred was associated with a higher QOL. In the present study, many participants underwent an amputation at a young age as well. The length of time from the amputation may have had an influence on participants' reported QOL. This statement cannot be verified, however, since the interview guide in the present study did not contain a specific question such as, "Compare your QOL six months after your amputation with the present. Has there been a change?"

**Empowerment.** Participants expressed empowerment as they exhibited agency and control in their lives. If confronted with a new or potentially challenging task, they spent the time, effort, and cognition necessary for completion. They did not choose abandonment if unable to initially complete a task. Rather, they made further attempts or requested assistance. Moreover, their decision making ability was evident. Decisions—including ones made on a daily basis as well as major life changes (e.g., voluntary changes to employment)—were thought out and performed without overt difficulties.

Participant's empowerment was impacted by limitations, most notably sports. Half (i.e., three) of all participants specifically made note of their limited engagement with sports as a result of having an amputated limb. This limitation of playing sports is consistent with the literature. In Gallagher et al. (2011), the sample in the study consisted of residents in Ireland who had previously voluntarily registered on the National Physical and Sensory Disability Database. Gallagher et al. yielded information from a component of the database termed the *Measure of Activity and Participation* (MAP). Results

indicated that 38.5% (5 of the 13 people who used an upper limb prosthesis and responded to the MAP) indicated a level of restriction in sports or physical activities.

**Satisfaction and well-being.** Data analysis of participant responses reveals that having an amputated limb was not related to lower levels of satisfaction and well-being. For example, participants answered a question about both their satisfaction and their well-being, thereby creating a possibility of 12 total responses. None of the responses indicated a low level with respect to well-being; one response described a low level regarding satisfaction. In contrast, in a study conducted by Østlie, Magnus, et al. (2011), upper limb amputees' satisfaction'—when compared to a control group of individuals who had not undergone an amputation—was significantly lower. In Østlie, Magnus, et al.'s study, life satisfaction was influenced by areas such as occupational change and as well as complications arising for the amputation. In comparison, the present study did not demonstrate significant changes in amputation-related complications. These differences may help contribute to the explanation of participant's higher level of satisfaction in the present study than the sample in Østlie, Magnus, et al.'s study.

Participants elaborated on their satisfaction and well-being. Their responses related to these two areas were grounded and embedded with descriptions representing specific clusters and themes. For instance positivity and gratefulness were evident in the data analysis of participants' narratives. Participants appreciated what they had in life. They positively embraced their life in general and they engaged with specific activities. Instrumental to participants' satisfaction and well-being was the fostering of quality relationships and spending time with family, significant others, and friends. These

relationships, described in very positive terms, were accompanied with occasional struggles. Participants expressed their loss at the death of a person they loved.

In the current study, narratives indicated that employment either contributed to or influenced satisfaction and well-being. All participants did not provide extensive elaborations as to their employment, but the responses during the interview were revealing. They enjoyed being recognized for their work and took great care to perform to a high standard. Half of all participants made specific reference to their work-related attention to detail. Employment related issues have also been raised by upper limb amputees in other research studies (Østlie, Magnus, et al., 2011; & Saradjian, et al., 2008).

Regarding whether a change in employment was needed after an amputation, the findings of the present study are slightly less profound than a study conducted by Jones and Davidson (1995). The researchers reported that “fifteen of the 21 amputees who were in the workforce at the time of the amputation needed a change in occupation” (Jones & Davidson, 1995, p. 440). In the present study, three participants either discussed an occupational change or an altering of career plans. The other three participants indicated they did not need to change their occupation after an amputation.

Participants expressed the importance of being humorous and its positive affect on their lives. Two participants remarked that they told jokes when talking about their prosthesis with children. Throughout the interviews, participants sometimes chuckled as they talked about some areas, exhibiting both humour and a sense of ease. Respondents in a study, conducted by Saradjian et al. (2008), also chose to display humour when talking

to other people about their prosthesis. The researchers wrote that the humour seemed to foster amputees' adjustment.

Saradjian et al. (2008) reported how upper limb amputees exhibited a positive attitude. Participants in the present study also conveyed consistent levels of positivity. Whether it was life in general or working through challenging or difficult tasks, pessimism or negativity was not exhibited.

**Social realm.** Family and friends were two themes related to social belonging. Research substantiates the importance of amputees' having social connections. For instance, in a study with lower limb amputees, "social support" (Asano et al., 2008, p. 231) and "social activity participation" predicted respondents' QOL (Asano et al., 2008, p. 231). In the present study, participants openly embraced being sociable with other people. The manner in which participants expressed their sociability was variable, ranging from saying "hello" to starting conversations. Their sociability demonstrates a willingness to connect or engage with other individuals.

Participants were generally treated well by other people; this finding is similar to the results of a study conducted by Hamill, Carson, and Dorahy (2010) who reported that "the majority of participants reported that the response they received from others was overwhelmingly positive" (p. 737). In both the latter and present studies, however, amputees did experience instances when they were not always treated well by others. The data analysis of the narratives of the present study yielded at least one situation that could be interpreted as a participant being subject to discrimination. In the present study, participants generally felt comfortable with their physical appearance in a social setting but their comfort level was affected when they were stared at by other people. They did

not like being the centre of attention. Such feelings are echoed in other research that employed phenomenology such as the studies conducted by Hamill et al. (2010) and Saradjian et al. (2008).

Two themes arising from the social realm category were perceptions and physical appearance. Body image is a specific perception explored by researchers. Low levels of body image have been associated with psychosocial difficulties (Horgan & MacLachlan, 2004; Rybarczyk & Behel, 2008). In the present study, participants whose descriptions conveyed a high body image—when compared to definitions in the literature—reported high adjustment and QOL.

### **Secondary Research Question**

Participants used clear language to indicate that having an amputation yielded changes of varying magnitudes in their lives. Changes involved psychological (e.g., adjustment) or social (e.g., seeking help from others) components. Some changes are evident on a daily basis such as the challenge of carrying heavy items and an inability to tie a shoelace using a prosthesis.

The data analysis revealed that participants often discussed themes relating to psychological attributes. Adjustment was one of these psychological attributes. In the present study, participants conveyed that they had adjusted to their amputation. A series of adaptations were necessary for this adjustment. Some of these adaptations included increasing the time for task completion, learning to properly care for a prosthesis, and changing cognitions when approaching a task.

Coping strategies and styles are referred to in the literature relating to amputations. A central tenet of the coping literature is congruent with the results of the

current study. Specifically, participants employed techniques, such as trying to solve problems as opposed to avoiding them, which are similar to definitions of coping strategies that exist in the literature. Their amputation was not perceived as an event that would be permanently adverse. Rather, participants reported that they exerted control and made attempts to resolve challenges.

Extant literature indicates that adjustment can be facilitated through the use of effective coping strategies. Results from Desmond's (2007) study of 138 male upper limb amputees, who completed a questionnaire, demonstrated that "psychosocial functioning of adults with acquired limb amputations was significantly related to coping strategies" (p. 19). Desmond (2007) and Desmond and Gallagher (2010) emphasize that a coping strategy that focusses on solving problems is related to positive adjustment.

Desmond and Gallagher (2010) stress the need, when assessing adjustment, to examine both positive indicators (e.g., resiliency) and serious emotional challenges (e.g., depression). Respondents in this research study demonstrated adjustment as they shared positive indicators while conveying a lack of emotional challenges. One participant did mention previously seeing a psychiatrist several years prior to the interview. Other research studies have demonstrated that some upper limb amputees experience psychosocial difficulties (Cheung et al., 2003; Desmond, 2007).

Participant responses included utilization of prostheses. The interview guide did not contain specific questions about prostheses so information is not plentiful. In the literature, functional or cosmetic reasons have been referred to as two reasons why upper limb amputees may use a prosthesis (Datta, Selvarajah, & Davey, 2004; Dudkiewicz, Gabriellov, Seiv-ner, & Zelig, 2004). Some participants opted to discuss the usefulness of

their prosthesis. All participants reported using a prosthesis in contrast to other studies with upper limb amputees conducted by Datta, Selvarajah, and Davey (2004) and Østlie, Lesjø, et al. (2011). Three participants shared descriptions of maintaining their prosthesis. Prosthesis maintenance was raised by individuals in Saradjian et al.'s (2008) study.

Participants in the present study identified themselves as determined and motivated. They provided rich descriptions that portrayed adjustment and resiliency. The psychological attributes noted in this study have been well documented within the literature. Indeed, for many years, leading contemporary researchers have focused on these attributes such as Bandura's work on motivation (Bandura & Cervone, 1986) and Zimmerman's study on resiliency (Zimmerman & Arunkumar, 1994).

The data analysis revealed that participants often discussed themes relating to health care. A general path outlined participants' descriptions of their pre- and post-amputation experiences. One participant underwent an instant amputation; five others followed a consultation process of varying length. Participants conveyed that their limb first became injured. An amputation was jointly deemed—by the participant and the medical team—to be the best option due to potentially deleterious consequences (e.g., infection) of opting against surgery. Both before and after the amputation, participants were provided with medical treatment and experienced significant levels of pain. They appreciated and were pleased with the level of support provided by their medical team. For most participants, pain currently remains, but to a much lesser extent and intensity.

### **Summary of Discussion of Research Questions**

Both the primary and secondary research questions have been addressed—results have been analyzed and accompanied with the scarce literature involving upper limb



amputees. An increased understanding exists of participant's QOL experiences. Embedded with this understanding are specific categories, clusters, and themes. Life changes were evident in the data analysis of participants' responses. Finally, psychological attributes and health care represent key pillars of participants' lives.

### **Research Contributions**

Østlie, Magnus et al. (2011b) noted that few research studies investigate the QOL experiences of upper limb amputees. Desmond (2007) reported on the lack of research studies addressing psychosocial issues of upper limb amputees. Paterson and Burke (1995) wrote that "the psychological experience could be considered the most important aspect of major limb injury" (p. 779). The current study augments this limited research by exploring upper limb amputees' experiences.

Most studies investigating amputees have been quantitative in nature while this research study employs a qualitative design. Hence, the present study contributes to the methodological diversity of the field. The studies that utilize a quantitative methodology are certainly valuable and yield specific variables that may impact amputees' QOL as outlined in chapter two of this thesis. The current study expands upon that information by providing an opportunity for participants to respond to open-ended questions.

The present study also responds to researchers' requests for QOL to be defined and situated within a study. Researchers should provide their QOL definition (Gallagher and Desmond, 2007). Accordingly, I defined QOL and used a specific model developed by Keith and Schalock (1994) and modified by Roberts and Cairns (1999). The model was instrumental in the development of the interview guide. The interview guide was an effective way to elicit open-ended responses so a comprehensive understanding of

participants' experiences could be created. Participant responses to the open-ended responses in the present study frequently fell into the QOL components identified by Keith and Schalock (1994). The model is further strengthened as an effective guide to measure and inquire about QOL.

For some individuals, an amputation influenced a directional or general changes to QOL. For others, stability occurred. As a result of this study, a greater understanding now exists of the specific clusters and themes related to the research questions. The present study also increases our understanding of upper limb amputees' psychological attributes and their distinct experiences with health care.

### **Limitations**

Similar to the studies referred to in this thesis, the present study contains limitations. The participant sample size was limited to six individuals. Participants' demographics may not represent the entire population of upper limb amputees. All participants were between the ages of 45 and 82 years old and only one participant was female. As a result of these possible limitations, the results are not meant to be generalizable to the population of all upper limb amputees in Western Canada. Individuals who chose to participate in this research study might have different characteristics than individuals who would not want to be interviewed. Participants in the current study exhibited an openness to share—a trait that may not be necessarily shared by all individuals who have undergone an upper limb amputation.

### **Potential Factors Affecting Results**

Participants conveyed that they received quality medical care. Two participants spoke of the financial support received from the Provincial Agency responsible for their

prosthesis maintenance and repair. A question arises: Might the results have been different if participants did not experience equality and access to medical care, rehabilitation, and support related to their prosthetic device? The Canadian Charter of Rights and Freedoms, formed under the Constitution Act and finalized in 1982, mandates the following:

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability (Department of Justice, Canada, 2012, para. 15).

Furthermore, Health Canada (2012) indicates: “Framed by the *Canada Health Act*, the principles governing our health care system are symbols of the underlying Canadian values of equity and solidarity” (para. 1). This emphasis for equality in Canada may have contributed to participants’ experiences such as their access to health care and how they were treated in employment situations.

In any research study, a potential exists that participant responses may be influenced by the specific questions posed. The open-ended questions in the interview were designed to promote responses. A possibility exists, however, that other categories and clusters may possibly have emerged if different questions were asked.

### **Reflection**

The interview guide and Keith and Schalock’s QOL model contributed to a solid foundation as a means to create questions for this research study. The broad range of interview questions provided a forum for rich descriptions and enhanced understanding. I learned the importance of having alternate questions as noted in the Interview guide. Since two participants asked for clarification on the meaning of empowerment, I was able

to refer to the alternate question noted in the Interview guide. I termed one category as social realm instead of social belonging. I made this decision as the data analysis revealed participants' significant references to the social context.

With limited research in the area, the present study was exploratory. Early in the research project, I thought it may have been advantageous to explore only one specific time period (e.g., pre-amputation, the hospital experience or post-amputation) so as to gain greater depth. I began to realize the value of asking questions ranging from pre-amputation to the present.

### **Implications**

A review of participants' responses and the subsequent data analysis in the present study generates potential implications for several groups of individuals. The implications described in this section are not intended to be definitive.

People's QOL experiences are an individualized and multi-faceted process. For those amputees who aim for an improvement in their QOL, they may find it useful to engage in a reflection of the categories, clusters, and themes from the present study. Completing some tasks using a prosthesis may require a different approach or additional time. Gratefulness and positivity have important implications for amputee's satisfaction and well-being. Amputees may find their social belonging to be positively influenced by maintaining social connections. Being able to accept any changes (e.g., using a prosthesis, altering how one does a task) would seem to be important for a positive adjustment to an amputation. Flexibility and adaptation may be necessary. For instance, if a person is unable to play a specific sport as a result of an amputated limb, he or she could engage in a different sporting activity of his or her choice, such as walking.

Important implications exist for family and friends as well. In the present research study, friends and family were instrumental for participants and fostered their social belonging. Offering love, inclusion, and support to their loved ones is important.

Implications exist for medical professionals such as, but not limited to, nurses, prosthetists, and rehabilitation staff. Ensuring a holistic team—such as a physician, nurse, prosthetist, rehabilitation professional—is involved could have distinct advantages to ensure comprehensive and quality health care. Psychosocial and QOL experiences of amputees need to be considered in tandem with the physical aspects of health care (e.g., surgery). Nurses have a major role caring and supporting people both before and after their amputation. Many patients in the hospital experience high levels of pain both before and after their amputation. Treating and respecting each patient as a unique human being is extremely important to ensure a positive medical experience.

Many areas could influence amputees' experiences with his or her prosthesis such as functionality, comfort, training, and maintenance. For prosthetists, spending the time to respond to and provide support for each person is important. Psychological or functional changes often occur as a result of having an amputated limb. Amputation rehabilitation specialists or counsellors need to attentively and empathically listen to best support amputees.

Several other implications exist. In order to ensure that amputees' return to employment is a positive experience, employers can make any necessary adaptations, provide support, and discuss accommodations. Provincial agencies have a major role. Government can ensure provincial agencies have the financial resources to provide care related to prosthesis or rehabilitation, including any employment assistance. Implications

also exist for members of the public. A friendly hello would be appreciated; whereas, staring, at a person who has an amputated limb, is not welcome.

Areas discussed by participants in this research study—adjustment, prosthesis utilization, pain, and activities—all lend themselves well to specific research studies. Longitudinal studies can provide a more comprehensive understanding of amputees' QOL experiences. Research can explore changes over time. Studies employing both quantitative and qualitative methodology may yield further insights. Additionally, researchers need to ensure there are studies exploring the QOL experiences of individuals with other types of amputations.

Researchers can also find samples of people from other countries and cultures as well. In their investigation of the QOL of people in Brazil who experienced a burn injury, Rossi, Costa, Dantas, & Lopes (2009) explored the socio-cultural dimensions of quality of life. Unique sociocultural issues of QOL may be discovered through research studies that inquire about the upper limb amputees from various countries, ethnicities, and cultures.

### **Final Summary of Participants' Experiences**

Statements in this final summary primarily represent common experiences and are not necessarily shared by all six respondents. To receive the most comprehensive descriptions and understanding, readers of this thesis are encouraged to review the chapter on results and discussions.

This study used a qualitative approach to better understand the lived experiences of individuals who have undergone an amputation of an upper limb. Using a

phenomenological approach, I interviewed each participant on two occasions. Key results have been reported and discussed.

Most participants injured their limb in some type of accident. They went to the hospital where they experienced high levels of physical pain. Participants received medical treatment and underwent an amputation, typically after consultations and discussions of varying lengths with the medical team. Expectations concerning amputation and rehabilitation included a variety of responses such as: being unsure, realizing the possibility of distinct changes, and accepting the situation. After the amputation, a period of rehabilitation and an orientation to a prosthesis typically occurred.

Currently, participants report experiencing a fairly high QOL. Participants' had variable descriptions of stability or changes with respect to their QOL. They experienced agency and exert control in their lives. An analysis of the narratives reveals participants' agency, decision making abilities, and an acknowledgement for their control to be balanced. Empowerment was shared by participants although two individuals were affected by their lack of sports and limited technology use.

Well-being and satisfaction were described as being moderate to high. Several clusters and themes were related to this category including actions, challenges, contextual areas, positive affect, and relationships. In regards to the social realm, family and friends were very important. Participants were sociable and expressed descriptions of contentedness with their physical appearance. They were generally treated well by other people with some exceptions, such as staring. Throughout the interviews, participants expressed psychological attributes. Narratives centred on attributes related to adjustment,

motivation, and resiliency. The health care category revolved around three clusters: pre-amputation, hospital experiences, and post-amputation. Finally, the study provides many implications for both people who have undergone an amputation and for other groups of individuals.



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## Appendix A

### Telephone Script

Page 1 of 2

#### Background:

*Hello! My name is Walter King. I am a member of Dr. Jillian Roberts' research team and a graduate student in a Master of Arts program at the University of Victoria. Jillian Roberts is an Associate Professor at the University of Victoria. We are part of the research team for the study "Health-related quality of life and amputations". I obtained your phone number from my colleagues on that team.*

*I'd like to tell you about another component to the study. The purpose of this phase of the study is to better understand the quality of life experiences of patients who have undergone an amputation. The specific objectives are to: (1) better understand what life is like for individuals after the surgical procedure; and (2) identify changes in quality of life from your perspective. You are being asked to participate in this study because you are in the group of individuals who have had an amputation. We would like to learn from your experience so we can help health professionals' better care for other patients who, in the future, may undergo be faced with the choice of undergoing an amputation. Hearing your thoughts and experiences would be valuable for this study and having a chance to educate others may be of interest to you.*

#### Interview and Respect for Privacy:

*I, Walter, will be the person conducting the interviews. In terms of protecting your anonymity, we cannot promise complete anonymity during the data collection and analysis. In reporting the results, however, a pseudonym or fake name will be used in place of your real name(s). Your name(s), therefore, will never be published. This should, at least partially, protect your anonymity. Further, when data is stored all names will be removed and in their place a code number will be used. Your confidentiality and the confidentiality of the data will be protected by never revealing your identity and by keeping the coded data locked in a file cabinet at all times. The interviews will be arranged at a time convenient to you and the interviewer. Interviews will take place at a location of your convenience.*

#### Interview and Follow-up:

*If you decide to participate, you will be asked questions, and will engage in informal discussion with the interviewer. There is no right or wrong answer. We want to learn about your experiences. Taking part in this study would involve two interviews that would last a minimum of 2 hours and a maximum of 4 hours. The first interview will be tape recorded, and later transcribed. These transcriptions will not include any identifiable information about you. The researchers will use these transcriptions to search for themes of experiences. These themes will be brought back to you at a later time for your review. **Your decision to participate or not to participate in this study and any data that you provide will in no way affect your medical care nor will it jeopardize your relationship with your physician and/or your surgeon.***

Right to Withdraw from Participation:

*There will not be any negative consequences for participants if they choose to withdraw from participation. You can choose to withdraw from participation at any time and the data obtained from your interviews or questionnaires will not be used in final analysis.*

Potential Benefits:

*There are some good reasons to choose to participate. The main reason is that professionals need to learn from your experiences. Research of this type is important because amputations are being performed around the world and there are an increasing number of amputations in Canada and the United States. Given the intense interest in amputations, it is important to investigate how amputations impacts quality of life among these patients. Finally, developing a more comprehensive foundation of knowledge will allow health professionals to better care for patients.*

## Appendix B

### **Human Research Ethics Consent Form**

PAGE 1 OF 2

You are being invited to participate in a study entitled “The Quality of Life Outcomes of Amputation Recipients” that is being conducted by Dr. Jillian Roberts in conjunction with a team from Johns Hopkins University and the University of British Columbia. Dr. Roberts is an Associate Professor in the department of Educational Psychology and Leadership Studies at the University of Victoria and you may contact her if you have further questions by calling 250-721-7759.

The purpose of this study is to better understand the quality of life experiences of patients who have undergone an amputation. The specific objectives are to:

1. Better understand what life is like for you after an amputation; and
2. Identify changes in quality of life from your perspective.

Research of this type is important because a significant amount of amputations are being performed around the world. Given the intense interest in amputations it is important to investigate how amputations impact quality of life among these patients.

You are being asked to participate in this study because you are a member of a group of individuals who has undergone an amputation. We would like to learn from your experience so we can help health professionals’ better care for other patients who, in the future, may undergo the same procedure. Hearing your thoughts and experiences would be valuable for this study.

If you agree to voluntarily participate in this research, your participation will include two interviews. Together these interviews should last a minimum of 2 hours and a maximum of 4 hours. The first interview will be in person and should take 1 to 2 hours. The interview will be arranged at a time convenient for both you and the interviewer. The interview will take place at a suitable location of your choosing. The conversation will be tape-recorded, and later transcribed.

These transcriptions will not include any identifiable information about you or your family. The researchers will use these transcriptions to search for themes of experiences. After they are transcribed and analyzed, a second, follow-up interview will be conducted over the telephone and will last approximately 30 to 60 minutes. During the second interview you will be asked for feedback on the themes and to add any additional information or insights.

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will not be included in the final analysis. Your decision to participate in this study and any data that you provide will in no way affect your medical care. All interviews are confidential.

Pseudonyms will also be used in place of your name(s) in all study reports. Finally, every effort will be made on the part of the researchers to disassociate your words with your identity.

**Human Research Ethics Consent Form Continued**

PAGE 2 OF 2

To make sure that you continue to consent to participate in this research, before each interview you will be reminded that your participation is voluntary and that you can choose to withdraw without any negative consequences.

The person conducting the interviews will be Walter King, a graduate student at the University of Victoria and a member of Dr. Roberts' research team. In terms of protecting your anonymity, we cannot promise complete anonymity during the data collection and analysis. In reporting the results, however, a pseudonym or fake name will be used in place of your real name(s). Your name(s), therefore, will never be published. This should at least partially protect your anonymity. Further, when the data is stored all names will be removed and in their place a code number will be used. Your confidentiality and the confidentiality of the data will be protected by never revealing your identity and by keeping the coded data locked in a file cabinet at all times. Data from this study will be disposed of after five years. The transcribed interviews will be shredded and the audio cassettes will be burned.

It is anticipated that the results of this study will be shared with others in the following ways: the results will be presented and/or published in scholarly meetings and in journals. Other planned uses of this data may include using it in university lectures or professional workshops.

In addition to being able to contact the researcher at the above phone number, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the **Research Ethics Office at the University of Victoria by phone (250-472-4545) or by e-mail (ethics@uvic.ca).**

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

PARTICIPANT SIGNATURE \_\_\_\_\_ DATE \_\_\_\_\_

A COPY OF THIS CONSENT WILL BE LEFT WITH YOU, AND A COPY WILL BE  
TAKEN BY THE RESEARCHER.

## Appendix C

### Interview Guide

Page 1 of 3

Remember that there are no right or wrong answers. I also want to remind you that the interview is being audio-recorded, but that we won't use your name with any of the material.

Do you have any questions before we get started?

#### ***Probing Question Examples:***

- Can you tell me what words or pictures come into your mind when I say [insert topic]?
- Can you explain to me why you think of it in that way?
- Can you give me an example?
- Can you tell me more about that?

#### **Could you please tell me your:**

- Age
- Marital Status
- Gender
- Ethnicity
- Type of amputation
- Do you use a prosthetic device?
- Employment status?
- Any health concerns?

### **1. Pre-amputation**

If you can think back to the time before your amputation, particularly the time when you were deciding whether or not to consider an amputation or possibly some other option.

- a. Tell me a little bit about how you first heard about the possibility that you might need to have an amputation.
  - How did you make the decision to have an amputation?
  
- b. When you thought about a possible amputation, tell me a little bit about what you expected?
 

*(INTERVIEWER: leave open-ended at first, then probe for all items listed below)*

  - What did you expect in terms of recovery from the amputation?
  - What did you expect in terms of your ability to function with your amputation?
  - What did you expect in terms of rehabilitation time and effort?
  - What did you expect in terms of your caregiver's involvement/reaction?
  - Did you have any other expectations or concerns leading up to amputation?



## 2. Screening

Page 2 of 3

- a. Can you talk a little bit about the process that you went through when you were being considered for an amputation?
- b. What did you talk about with the amputation team?

### Interview Guide

- c. Was there anything that you didn't discuss with the team prior to amputation that you wish you had had a chance to discuss?
- d. How prepared did you feel going into the amputation?
- e. Is there a particular conversation that you have already had with the amputation team that stands out?

## 3. Your Hospital Stay

- a. Can you tell me a little bit about your stay in the hospital?
- b. Is there anything in particular that stands out about your hospital stay? (*Probe*)

## 4. Post-amputation

- a. Can you tell me a little bit about how things have been going for you now, following your amputation?
- b. Overall, how has the amputation changed your life?
- c. How satisfied are you with your life?  
Alternate question if above question unclear to participant after repetition: How much do you like your life?
- d. How would you describe your well-being?  
Alternate question if above question unclear to participant after repetition: How would you generally describe or perceive your life?
- e. How would you describe your social belonging?  
Alternate question if above question unclear to participant after repetition: Do you have involvement and connections with other people?
- f. How would you describe your sense of empowerment?  
Alternate question if above question unclear to participant after repetition: How would you describe your sense of control and choice with respect to decisions?

g. What was it like for you to undergo an amputation?

**Page 3 of 3**

h. How would you describe any changes to your quality of life before your amputation versus after your amputation?

### **Interview Guide**

- i. When you think about the amputation overall and where you are now, what things are different from what you expected?
- What (if anything) better?
  - What (if anything) worse?

### **5. Closing**

In closing, is there anything else you would like to add that we didn't discuss?

Turn off audio-recorder. Thanks again, Mr/Ms [insert name]. Do you have any questions? OK, thank you for your time. <b>[END OF INTERVIEW]</b> .
---

## Appendix D

### Letter to Participants

Dear Participant,

Thank you in advance for your time.

Please find attached a transcription of our first interview. I have used this transcription to search for themes of experiences. Peoples' names (and some other information denoted in *italics*) are not included in the transcription so as not to include identifiable information. As such in this transcription, speaker 'A' is myself and speaker 'B' is you.

Please review the transcription and the themes of experiences which are noted with comments in the right hand margin. Please note that once a specific theme was identified twice, subsequent identifications were not made.

A second follow-up interview will be conducted over the telephone. During the telephone interview, you will be asked for feedback on the themes and to add any additional information or insights.

Thank you very much. Approximately one week after you have received this transcript, I will contact you by telephone to arrange a mutually convenient time for our second interview.

Kind regards,

Walter King

## Appendix E

Ethical Approval

University  
of Victoria

**Human Research Ethics Board**  
Office of Research Services  
University of Victoria  
Administrative Services Building B202  
Tel (250) 472-4545 Fax (250) 721-8960  
Email ethics@uvic.ca Web www.research.uvic.ca

## Human Research Ethics Board

### Modification of an Approved Protocol

<u>Principal Investigator</u>	<u>Department/School</u>	<u>Supervisor</u>
<b>Jillian Roberts</b> Faculty	<b>EPLS</b>	
<u>Co-Investigator(s):</u> Alex Anzarut, Primary Leadership Role, UBC Andrew Lee, ASPS Sponsor, University of Pittsburgh Vijay Gorantla, University of Pittsburgh Galen Switzer, University of Pittsburgh Keri Rodriguez, University of Pittsburgh		
<u>Project Title:</u> <b>The Quality of Life Outcomes of Complex Transplant Recipients</b>		
<u>Protocol No.</u> <b>10-172</b>	<u>Date</u> <b>06-Jul-10</b>	
<i>For modifications to an Approved Protocol, your protocol approval period remains the same as your original certificate of approval.</i>		

### Certification

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants.

**This Certificate of Approval is valid for the above term provided there is no change in the protocol. Extensions and/or amendments may be approved with the submission of a "Request for Annual Renewal or Modification" form.**

Dr. Afzal Suleman  
Associate Vice-President, Research

10-172 Roberts, Jillian