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Amputation-Associated Stressors and Dyadic Adjustment

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Amputation-Associated Stressors and Dyadic Adjustment

by

Anila Virani

A THESIS

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Amputation-Associated Stressors and Dyadic Adjustment" submitted by Anila Virani in partial fulfilment of the requirements of the degree of Master of Nursing

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Abstract

The purpose of this quantitative study was to explore the relationship between amputation-related stressors, demographic variables and dyadic adjustment using a correlational study design. A convenience sample of 26 couples, in which one spouse had at least one amputation, were recruited over a four month period from three community-based sites in Calgary, Alberta. The majority of the amputees were male, prosthesis users, with nearly half of the overall sample involved in some kind of sports-related activities. Findings revealed that anxiety ($p<0.01$) was significantly negatively correlated with the amputee's dyadic adjustment. For spouses, amputee depression ($p<0.05$) and pain-related interference ($p<0.05$) were negatively correlated with their dyadic adjustment, whereas the amputee's adaptation to disability ($p<0.05$) was positively associated with dyadic adjustment. Age of spouse ($p<0.05$) and length of relationship ($p<0.05$) were positively related to dyadic adjustment in amputees. It is concluded that amputation-related stressors negatively correlate with the perception of dyadic adjustment; however the significance of stressors is perceived differently in amputees and spouses.

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“For what you have done,
for what you have said...
For what you have helped me with,
thanks seem not enough.
I want only to tell you one simple phrase,
Yet I feel the need to ensure
that the emotion is conveyed.
If I could just say it, and ask you, please,
multiply my thanks by infinity...”

(Anonymous, n.d.).

Dedication

I lovingly dedicate this thesis to my mom, Naseem Virani and my dad, Ahmed Virani, for their unconditional and endless love and support throughout my life. You have been a constant source of strength and inspiration in my life. You have always believed in me. Without your love and affection I would not have achieved this dream of my life.

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To my niece Urooj Amdani, my angel, you have fulfilled my life in a way I never expected. I have never experienced such happiness. I love you very much.

“The happiest moments of my life have been the few which I have passed at home in the bosom of my family” (Thomas Jefferson, n.d.).

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List of Abbreviations

Abbreviation	Definition
AASRA	Alberta Amputee Sports & Recreation Association
ABIS	Amputee Body Image Scale
ADS-R	Adaptation to Disability Scale-Revised
BPI	Brief Pain Inventory
CDA	Canadian Diabetes association
DM	Diabetes Mellitus
HADS	Hospital Anxiety and Depression Scale
HADS-A	Hospital Anxiety and Depression Subscale-Anxiety
HADS-D	Hospital Anxiety and Depression Subscale-Depression
NTR	National Trauma Registry
PSSS	Perceived Social Stigma Scale
RDAS	Revised Dyadic Adjustment Scale

Glossary of Terms

Terms	Definitions
Adaptation to Disability	A dynamic process that describes individuals' experience of coming to terms with a disability and exhibiting a positive attitude towards self and others in relation to their disability. Adaptation to disability is interchangeably used with acceptance of disability in this document.
Altered Body Image	The changes in one's mental image of physique due to limb amputation.
Amputation	Surgical or accidental removal or congenital absence of a limb or part of a limb.
Anxiety	A temporary state of worry or nervousness usually related to a future event or uncertain outcome.
Containment	The subscale of Adaptation to Disability Scale-Revised (ADS-R) that assess amputees' ability to limit their disability to the actual physical impairment. In this phase individuals with a disability focus more on other domains of life, such as social and intellectual, instead of their limitations.

Depression	Five or more symptoms that persists every day for two weeks and negatively affects the previous level of functioning such as activities of daily living, social interactions and work. These symptoms include depressed mood, loss of interest, insomnia or hypersomnia, fatigue, significant weight changes, psychomotor agitation or retardation, suicidal ideation, diminished concentration, and feeling of worthlessness
Dyad	Two heterosexual individuals linked in an intimate relationship.
Dyadic Adjustment	The way a heterosexual couple adapt to each other's interests, values and differences such that it minimizes conflicts, fulfils their expectations and allows them to stay satisfied in a relationship. Dyadic adjustment is interchangeably used with marital adjustment in this document.
Dyadic Consensus	The subscale of the Revised Dyadic Adjustment Scale (RDAS) referring to a couple's ability to agree on important matters such as religion, career, conventionality, major decision, affectional expression and sex relations.

Dyadic Satisfaction	The subscale of RDAS refers to a couple's frequency and intensity of conflicts and the desire to stay together.
Dyadic Cohesion	The subscale of RDAS refers to a couple's ability to participate in positive interactions and compassionate activities together, such as working together on a project, exchange of stimulating ideas, and outdoor activities.
Enlargement	The subscale of ADS-R that assesses an amputee's disability to acknowledge the other values in life that are in direct conflict with the disability by enlarging their scope of values.
Non-Amputated Limb Pain	Pain in the non-amputated limb, usually opposite to the affected limb.
Pain Intensity	The quality of pain, described as mild, moderate or severe.
Pain-related Interference	A disruption caused by pain in mood, sleep, general activity, enjoyment of life and relationship with other people.
Residual Limb Pain (RLP)	Pain in remaining part of the amputated limb.
Perceived Social Stigma	Self-stigmatization in relation to negative social stereotype attitudes as a result of a visible disability.

Phantom Limb	Pain in the missing part of the limb.
Pain (PLP)	
Post-Amputation	The amputation-associated pains such as PLP, RLP, pain
Pain	in non-amputated limb, back, neck, shoulder and hip pain.
Subordination	The subscale of ADS-R that assesses an amputee's ability to realize that there are other important aspects of life than disability such as family, friends and work.
Transformation	The subscale of ADS-R that assess amputees' ability of not comparing self to individuals without disability and appreciating their unique assets.

Epigraph

The more we discover, the more we know, the more we penetrate just below the surface of our normal lives – the more our imagination staggers... What we feel, even as we learn, is an ever-renewed sense of wonder, indeed, a powerful sense of awe – and of Divine inspiration (Prince Karim Aga Khan IV, 2008).

Chapter One: Background and Overview

1.1 Introduction

Aristotle said “man is by nature a social animal; an individual who is unsocial naturally and not accidentally...is either a beast or a God” (Politics, 328 B.C. as cited in Dautenhahn, 1995). Humans have a general desire to belong and to love which is usually satisfied within an intimate relationship (Perlman, 2007). Partners in a dyadic relationship satisfy each other’s relational needs, making dyadic relationships an important consideration in health and healing experiences of either partner.

The term *dyad* in this study is used to denote two heterosexual individuals linked in an intimate relationship. The term dyadic adjustment is used interchangeably with marital adjustment in the literature (Locke, 1951; Fitzpatrick & Best, 2009; Spanier, 1979). In this study, *dyadic adjustment* refers to the way a heterosexual couple adjust to each other’s values and needs on a continuum of well-adjusted to maladjusted. In relational family health practice, the term family incorporates the immediate environment of an individual in which family relationships, such as the spousal relationship, have significant effects on health and healing behaviours (Anderson, 2000; Anderson, & Tomlinson 1992; Smith & Friedemann, 1999).

There is an abundance of research related to heterosexual dyadic (in this study married or partnered couples) relationship adjustment, quality, satisfaction and stability; effects of satisfied and dissatisfied dyadic relationships on health; and the effects of demographic variables such as age, sex, occupation, and education on dyadic relationships (Hatch & Bulcroft, 2004; Henry, Berg, Smith, & Florsheim, 2007; Luong,

Charles, & Fingerman, 2010; Levenson, Carstensen, & Gottman, 1993; Heiman et al., 2011; Rook, Mavandadi, Sorkin, & Zettel, 2007; Smith et al., 2009; Umberson & Montez, 2010). While interpretations of the significance of these factors to the dyadic relationship vary, there is a common consensus that a healthy, satisfied and well-adjusted dyadic relationship has positive effects on both partners. In the context of a marital dyad, a well-adjusted relationship acts as a buffer in stressful situations and supports spouses from the negative effects of stress (Gardner & Oswald, 2004; Gove, 1973; House, Robbins, & Metzner, 1982; Murray, 2000; Story & Bradbury, 2004). The above findings are particularly important as chronic conditions present numerous physical, emotional, and psychosocial stressors that may affect dyadic relationships. In this study the relationship between amputation as a chronic condition and dyadic adjustment of heterosexual couples was explored.

1.2 Conceptual and Operational Definitions of Stressors and Dyadic Adjustment

1.2.1 Stressors

According to Bodenmann (2005), stress is a threatening situation and stressors are the demands placed by a stressful situation that affects physical and psychological well-being of an individual. In this study, amputation is considered a major chronic stress that brings additional stressors such as anxiety, depression, perceived social stigma, post-amputation pain, body image concerns and disability to the dyadic relationship.

1.2.2 Dyadic Adjustment

The literature search revealed a lack of clarity and specificity in the conceptualization and definition of dyadic adjustment. Social scientists researching

dyadic relationships have used the term dyadic adjustment interchangeably with marital adjustment, quality, satisfaction, happiness, and integration to describe a well-functioning dyadic relationship. Dyadic adjustment is considered the most important factor in determining dyadic relationship quality, stability and longevity. Well-adjusted dyadic relationships are thought to be associated with high relationship quality and stability (Locke, 1951; Fitzpatrick & Best, 2009; Spanier, 1979). Commonly used definitions in the literature for dyadic adjustment or marital adjustment are given by Lock (1951) and Spanier (1976). Locke (1951) defined marital adjustment as “the process of adaptation of the husband and the wife in such a way as to avoid or resolve conflicts sufficiently so that the mates feel satisfied with the marriage and each other, develop common interests and activities, and feel that the marriage is fulfilling their expectations” (p. 45). According to Spanier (1976), dyadic adjustment is “a process, the outcome of which is determined by the degree of: 1) troublesome dyadic differences; 2) interpersonal tensions and personal anxiety; 3) dyadic satisfaction; 4) dyadic cohesion; and 5) consensus on matters of importance to dyadic functioning” (p. 17).

In this study dyadic adjustment refers to the way a couple adjusts to each other’s interests, values and differences such that it minimizes conflicts, fulfils their expectations and allows them to stay satisfied in a relationship. It is an ever-changing process of adaptation that can be studied at any point in time on a continuum of a well-adjusted to maladjusted. The construct of dyadic adjustment can be assessed by evaluating its three components which include: 1) dyadic consensus; 2) dyadic satisfaction; and 3) dyadic cohesion (see table 1).

Table 1. *Definition of Components of Dyadic Adjustment*

Components	Definition
Dyadic Consensus	The extent of a couple's agreement on important matters such as career decisions, religion, conventionality and how frequently a couple demonstrates affection to each other.
Dyadic Satisfaction	The degree to which the dyad is satisfied within the relationship and is committed to continue. Dyadic satisfaction can be measured through low frequency and intensity of negative interactions, quarrels, and discussions of separation.
Dyadic Cohesion	The frequency of couple's engagement in positive interactions and compassionate activities together such as working together on a project, exchange of stimulating ideas, and outdoor activities.

Note. Adapted from Fitzpatrick, M. A., & Best, P. (1979). Dyadic adjustment in relational types: Consensus, cohesion, affectional expression, and satisfaction in enduring relationships. *Communication Monographs*, 46(3), 167-178. doi: 10.1080/03637757909376004

1.3 Significance of the Study

Amputation is a life changing event for a couple. It introduces several stressors including pain, disability, actual or perceived social stigma, body image disturbance, anxiety and depression into the relationship. Researchers have explored these stressors in order to understand factors affecting adjustment to amputation (Atherton & Robertson,

2006; Behel, Rybarczyk, Elliott, Nicholas, & Nyenhuis, 2002; Cohen, Gambel, Raja, & Galvagno, 2011; Horgan & MacLachlan, 2004). For example, a few researchers have specifically explored the impact of amputation on sexual satisfaction (Bodenheimer, Kerrigan, Garber, & Monga, 2000; Ide, Watanabe, & Toyonage, 2002; Walters & Williamson, 1998). In a systematic review of 11 studies conducted between the years 1945–2006, Geertzen, Van Es, and Dijkstra (2009) concluded that most male amputees were not satisfied with their sexual lives. Male amputees faced more sexual problems than females, likely due to traditional position of the man during sex (i. e. on top). However, in most studies, including all 11 cited by Geertzen et al. (2009), researchers examined the effects of amputation on sexual satisfaction from the perspective of amputees only; none involved spousal opinions. Sexual satisfaction is an important factor in assessing a couple's adjustment; however it is only one determinant of dyadic adjustment to amputation and there is an obvious gap in the literature regarding dyadic adjustment to amputation that involves the perception of *both* spouses.

Spouses play an integral role in the health and healing experience of individuals suffering with chronic conditions, such as amputation. Researchers have involved spouses in their studies almost exclusively in relation to how they impact an amputee's adjustment to amputation-related phantom limb pain, a distinct phenomenon unique to patients with amputation (Flor, Kerns, & Turk, 1987; Furst & Humphrey, 1983; Geertzen et al., 2009; Lerner et al., 1993). For example, Flor et al. (1987), using a survey method, examined 32 chronic pain patients (including phantom limb pain) and their spouses from the Veterans Administration Medical Center, West Haven, Connecticut, U.S. They

focused on the effect of spousal responses to amputation on amputee's adjustment to phantom limb pain. They found solicitous spousal responses were associated with higher phantom pain intensity and higher phantom pain-related interference, whereas spousal punishing and ignoring responses were correlated with lower pain intensity and higher functioning levels in amputees with phantom pain. Flor and his colleagues explained these findings using an operant conditioning model of reward and punishment, in which pain behaviour can be positively and negatively influenced by significant others' responses. They suggested that rewarding or punishing attitudes of the spouse can yield a significant impact on amputee's pain-related interference with activities. They further explained spouses' solicitous responses may have reinforced amputees' pain behaviours resulting in higher pain intensity and pain-related interference. Jensen et al. (2002) reported similar findings in their study of 61 lower limb amputees with phantom limb pain, using a survey method; spousal solicitous responses were positively correlated with depression and higher pain-related interference of activities in amputees.

In short, researchers have primarily focused on the amputee's adjustment to amputation-associated stressors without involving spouses' opinions. Spouses were only assessed in terms of how they influenced amputee's adjustment to amputation-related stressors. To the best of the student investigator knowledge, no studies have been conducted that have studied the relationship between dyadic adjustment and amputation-associated stressors involving both spouses. Therefore the intent of this research was to add to the body of knowledge of dyadic adjustment and amputation-related stressors.

1.4 Purpose of the Study and Research Questions

The purpose of this study was to examine dyadic adjustment within married or partnered couples in which one spouse had at least one amputation. The relationship of other demographic variables such as age, sex and length of the relationship to dyadic adjustment were also considered.

The primary research question was: is there a relationship between dyadic adjustment and amputation-related stressors including anxiety, depression, low adaptation to disability, perceived social stigma, altered body image, and post-amputation pain?

A secondary research question was: is there a relationship between dyadic adjustment and age, sex of the amputee and spouse, and length of relationship?

1.5 Summary

In this chapter the significance of the study, its purpose and research questions were discussed. In chapter two, three, four and five, the literature review, research methods, instruments, ethical considerations, results and future implications of the study will be discussed.

Chapter Two: Literature Review

2.1 Introduction

In this chapter an overview of the literature on amputation, stressors associated with amputation, theoretical perspectives underpinning the research and dyadic adjustment will be presented.

2.2 Amputation and Associated Stressors

2.2.1 Amputation

The word amputation is derived from the Latin word *amputatio* which means ‘to cut around’ (Ham & Cotton, 1991). Amputation is one of the oldest known surgical procedures; amputation was performed in ancient times to remove gangrene, to remove damaged limbs, and to save lives. Amputation was also used for ritual sacrifice and punishment purposes (Kostuik, 1981).

2.2.2 Epidemiology of Amputation

In the U.S., of the 120,000 amputations performed annually, 40–70% are done on people with diabetes (Lavery et al., 2010). This costs the U.S. health care system approximately three billion dollars per year (\$38,077 per amputation procedure) (Shearer, Scuffham, Gordoio, & Oglesby, 2003). In Canada, there is a paucity of published data on the epidemiology of amputation or cost to the health-care system. However, based on data that are available it appears that lower limb amputations are more common than upper limb amputations; most upper limb amputations are a result of trauma and congenital or early childhood amputations (Brent et al., 2011; McDonnell, Eng, & McKay, 1988; O’Brien, Patrick, & Caro, 2003). The major cause of lower limb amputations is

Diabetes Mellitus (DM), a chronic condition whose prevalence is increasing in Canada and worldwide. In Alberta in 1995, the total number of lower limb amputations was 484, of which DM accounted for 51 % (n = 246). Forty-nine percent (n = 238) of amputations resulted from other causes such as trauma, cancer, congenital and bone/joint diseases. In 2009, the total number of lower limb amputations in Alberta increased to 571 with the rate of DM-related amputations increasing to 67% (n = 381) (Brent et al., 2011).

This increase in amputation rate is likely due in part to the increase in Alberta's population over the past decade and to changes in life style such as lack of exercise, sedentary life style, and diet, all of which may lead to increased risk for cardiovascular disease and diabetes. According to Johnson and Balko (2011), in the US, the age-adjusted prevalence of known diabetes increased from 2.8% in 1980 to 5.3% in 2005. In Alberta, the North, Edmonton and South health zones have the highest age-adjusted prevalence of diabetes, while Calgary and the Central Zones are below the provincial rate. As well, Calgary and the Central zones have a lower age-adjusted incidence of diabetes compared to the rest of the province (Johnson & Balko, 2011). According to the Canadian Diabetes Association (CDA; 2009), the number of DM-related amputations in Canada is expected to increase from 210,000 in the year 2000 to 630,000 by 2020. Most of the data sources cited do not differentiate between levels of amputations such as digits, foot and knee amputations, therefore statistics should be interpreted cautiously.

2.2.3 Reasons of Amputation

2.2.3.1 Chronic Disease-Related Amputations

Amputation is often a result of chronic diseases such as DM, PAD; foot ulcers, or bone and joint diseases (Mirolla, 2004; Ziegler-Graham, MacKenzie, Ephraim, Trivison, & Brookmeyer, 2008). Seven of 10 non-traumatic limb amputations are now considered the result of DM or related complications (CDA, 2011). The Canadian Association of Wound Care (2011) revealed in 2006, more than 4,000 Canadians had a limb amputation due to DM. In 2008, 621,000 Canadians suffered from nerve damage related to DM leading to foot ulcers, and a non-healing foot ulcer was the leading cause of lower limb amputations.

2.2.3.2 Trauma

Traumatic amputations occur as a result of direct or indirect injury to the limb or part of the limb. Common causes for injuries are motor vehicle collisions and work-related injuries. According to Occupational Health and Safety Canada, the majority of traumatic lower limb amputations occur in the young (20-54 years of age), predominantly male, working population. Labourers (processing, manufacturing and utilities), chefs, truck drivers, carpenters and construction workers were the leading occupation categories for traumatic amputations (Birch, 2009). According to National Trauma Registry (NTR) Canada, traumatic amputations accounted for 28.3% of total injuries in 2004-2005 (NTR, 2006) and the rates declined to 12.5% in 2008-2009 (NTR, 2011). The possible reasons for this decline could be attributed to increased safety awareness of organizations and

workers, and initiatives taken by occupational health and safety organizations to improve safety.

2.2.3.3 Congenital or Early Childhood Acquired Amputation

Congenital or early childhood acquired amputations relate to children born without limb(s) or those children who had a congenital limb deformity that led to acquired amputation. McDonnell et al. (1988) estimated that the incidence of congenital or acquired childhood amputation ranged from 1:15,000 to 1:7,500.

2.2.4 Economic Burden of Amputation in Canada

In Canada, the estimated cost of an amputation related to DM is between \$35,000 and \$50,000 (Shannon, 2007). These costs include but are not limited to: acute care admissions, readmissions for debridement and major stump revisions, rehabilitation, use of prosthetic devices and medical equipment, refitting of prosthesis, and long-term facility residential care.

The economic burden of amputation is not limited to the health care system. Amputation causes disability, loss of productivity; loss of employment and delayed return to work that further contributes to financial strain on the economy. Hebert and Ashworth (2006) established older age, higher amputation levels, and subsequent surgical procedures as predictors of delayed return to work. According to the Alberta Workers' Compensation Board, total days of disability related to amputation ranged from 0 to 1664, with a mean of 366 days, and 23% of amputees did not return to work at all (Hebert & Ashworth, 2006). This has significant implications for dyadic adjustment, in that established roles and responsibilities within the dyadic structure need to be realigned.

2.2.5 Effects of Amputation on Individuals and Dyads

In this study, amputation is considered a chronic condition that causes stress and can affect dyadic adjustment. The term *chronic condition*, often used interchangeably with chronic disease, refers to a medical state that is expected to last longer than three months, does not resolve spontaneously and is rarely cured completely (Patra et al., 2007). Chronic conditions often result in the inability to perform some or all of the tasks of life, and may result in ongoing care needs that affect quality of life in individuals and families (O'Halloran, Miller, & Britt, 2004; Stewart et al., 1989).

2.2.6 Stressors Associated with Amputation for Amputees

Amputation is a life changing event that brings challenges to an amputee's life such as anxiety, body image concerns and disability. A review of the literature revealed factors affecting adjustment to amputation include age, sex, level of education, cause, site and level of amputation and co-morbidities. Long treatment periods due to infections, non-healing stumps, hospitalization related to revisions and debridement, frequent clinic visits, refitting of prosthesis, and pain are several challenges that an amputee faces on a regular basis. These challenges could potentially make amputees prone to psychological and emotional problems. Body image concerns and actual or perceived feelings of societal attitudes towards disability may further increase the stress level (Atherton & Robertson, 2006; Dunn, 1996; Hanley et al., 2004; Wald & Alvaro, 2004).

In this study six major amputation-associated stressors commonly documented in the literature were examined. These included anxiety, depression, perceived social stigma, altered body image, post-amputation pain and low adaptation to disability

(Atherton & Robertson, 2006; Fisher & Hanspal, 1998; Gallagher, Franchignoni, Giordano, & MacLachlan, 2007; Horgan & MacLachlan, 2004; Rybarczyk, Nyenhuis, Nicholas, Cash, & Kaiser, 1995; Wetterhahn, Hanson, & Levy, 2002). The literature review of the studies related to amputation-associated stressors is summarized in table 2. These stressors are conceptually defined below.

2.2.6.1 Anxiety

Anxiety refers to “relatively temporary states of unpleasant feelings of tension and apprehension accompanied by arousal of the autonomic nervous system” (Vingerhoets, 1998, p. 32). Anxiety is prevalent among amputees of all ages and backgrounds (Coffey, Gallagher, Horgan, Desmond, & MacLachlan, 2009; Dunn, 1996) with reported anxiety symptom rates of 24% to 37% especially during the first two years post-amputation (Hawamdeh, Othman, & Ibrahim, 2008; Horgan & MacLachlan, 2004; Singh, Hunter, & Philip, 2007).

2.2.6.2 Depression

Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) defines depression as five or more symptoms that persists every day for two weeks and negatively affects the previous level of functioning such as activities of daily living, social interactions and work. These symptoms include depressed mood, loss of interest, insomnia or hypersomnia, fatigue, significant weight changes, psychomotor agitation or retardation, suicidal ideation, diminished concentration, and feeling of worthlessness (Gruenberg, Goldstein, & Pincus, 2005). According to the World Health Organization (2011), depression is the second leading contributor to the overall global disease burden,

affecting approximately 121 million people worldwide. It can negatively affect health outcomes such as acceptance and adjustment to loss or rehabilitation results.

Post-amputation depression has been reported to occur in 20 to 30% of amputees several years after amputation, with common risk factors being young, low education level, female, negative body image, phantom limb pain, maladjustment or dissatisfaction with prosthesis, and lack of social support (including unstable marriages or dyadic relationships) (Atherton & Robertson, 2006; Dunn, 1996; Hanley et al., 2004; Wald & Alvaro, 2004). Other researchers indicated that on average in the general population, single (never-married, separated, divorced or widowed) individuals reported higher levels of depression than people in stable partnered relationships (Frech & Williams, 2007; Karney & Bradbury, 1995; Karney & Crown, 2007). Chronic conditions appear to increase depressive symptoms approximately twice as much in non-partnered individuals than persons with non-distressed dyadic relationships (Chisholm et al., 2003; Tellez-Zenteno, & Cardiel, 2002). In a cross-sectional telephone survey of 914 amputees, Darnall et al. (2005) found a significant positive correlation between depression and being divorced or separated ($p < 0.004$), which may indicate the importance of non-distressed dyadic relationships in adjusting to amputation-related depression.

2.2.6.3 Perceived Social Stigma

Perceived social stigma refers to individuals' view of their disability in relation to negative social stereotype attitudes (Rybarczyk et al., 1995). The feeling of self-consciousness and perceived stigmatization due to the visibility of a physical difference to others poses a serious challenge to the amputee's adjustment. To the amputee, the

amputated limb may impart a distorted sense of self that overrides other personality characteristics, leading to social discomfort and social isolation (Schaffalitzky et al., 2010). Rybarczyk et al. (1995) conducted a survey in 112 lower limb amputees from a group of five affiliated prosthetic clinics in the Chicago metropolitan area. These researchers found even 17 years post-amputation, perceived social stigma was an independent predictor of depression after controlling for the effects of age at the time of amputation, time since amputation, site of the amputation, self-rated health, and perceived social support. Thus the amputees' perceptions of social stigma may impact their spouses' ability to respond to the needs of the amputee, leading to social isolation and altered dyadic adjustment.

2.2.6.4 Altered Body Image

Altered body image associated with amputation is another significant concern amongst amputees. The concept of body image is defined as a mental image of one's self (Breakey, 1997b). Rybarczyk and Behel (2008) indicated body image is a part of one's self-concept. It is an evolving concept that includes the attitudes, experiences and perceptions related to one's body, its capabilities and endurance. Breakey (1997a) studied the perception of body image in 90 traumatic lower limb amputees using a correlational study design. In his study he proposed that an amputee experiences three distinct body images over time: a pre-amputation intact body, a body with a lost limb, and a body with an artificial limb. The incongruity between current altered body image and former body image resulted in emotional stress. If this discrepancy continued it

caused chronic anxiety and depression, therefore an amputee had to come to terms with his body image in order to achieve psychological wellbeing (Breakey, 1997b).

Breakey (1997a) also found perception of negative body image was positively correlated with lower self-esteem, anxiety and depression in traumatic lower limb amputees. DM-related amputation is usually a planned procedure and occurs in stages. Therefore, it is often assumed that these amputees have more time to adjust and come to terms with the loss and altered body image. However, similar results were found by Coffey et al. (2009) in which DM-related lower limb amputees' perception of altered body image was significantly related to anxiety and depression.

An individual's negative perception of altered body image interferes with the body movement required for carrying out daily activities (Deusen, 1996). Wetterhahn et al. (2002) conducted a survey of 56 lower limb amputees from North America using convenience and snowball sampling. They studied the relationship between regular participation in physical activity and body image among lower limb amputees. These researchers reported that people who found it hard to accept their body image distortion were more likely to reject their prosthesis, thus reducing their chances of living life to its fullest potential. Conversely, amputees with a positive self-image tend to find positive meaning in their amputation which increases their sense of control over amputation-associated stressors (Horgan & MacLachlan, 2004). Using data from a mail-in survey, Dunn (1996) also found a significant negative correlation between depression and optimism ($p < 0.05$), and perceived control over disability ($p < 0.05$) in 138 upper and lower

limb amputees of all causes. These amputees were all golfers and members of the Eastern Amputee Golf Association (EAGA).

Positive self-image also enhances adjustment to new body image and decreases social discomfort (Dunn, 1996; Horgan & MacLachlan, 2004). Using survey methodology, Murray, Holmes, and Griffin (1996) studied 167 healthy married and dating couples from the Ontario Science Centre and University of Waterloo. They suggested a partner's positive perception affects the dyadic relationship positively despite the individual's self-doubts and negative self-image. Sacco and Phares (2001), found in a sample of 99 couples drawn from community and mental health facilities in Florida, USA, that regardless of an individual's level of self-esteem or depression, couples were mutually satisfied when their partners view them positively. These findings may signify the importance of a stable dyadic relationship in adjusting to an altered self-image.

2.2.6.5 Post-Amputation Pain (PAP)

Pain following limb amputation is common, with 50% to 90% of amputees experiencing some kind of amputation-related pain, and 76% of amputees suffering more than one type of pain (Cohen et al., 2011; Hanley et al., 2009). For example, Hanley et al. (2009) indicated that in a sample of 104 upper limb amputees, 79% experienced Phantom Limb Pain (PLP), 71% had Residual Limb Pain (RLP), 52% suffered back pain, 43% complained of neck pain and 33% reported pain in the non-amputated limb. PLP refers to intense sensation or pain in any part of the amputated limb whereas RLP is pain in the remaining part of the amputated limb (Richardson, 2010). PLP is more prevalent and chronic in nature than RLP, with 80% to 90% of amputees experiencing some degree

of PLP (Chahine & Kanazi, 2007; Giummarra, Gibson, Georgiou-Karistianisa, & Bradshaw, 2007). While several central, spinal and peripheral nervous systems theories have been proposed to explain PAP, the exact cause has yet to be fully explained (Weeks, Anderson-Barnes, & Tsao, 2010). Chronicity of PAP and lack of promising treatments may pose an additional challenge to the quality of the dyadic relationship, thus affecting dyadic adjustment.

2.2.6.6 Adaptation to Disability

Disability refers to the physical or mental impairment that restricts one's capacity to perform usual activities (House et al., 2009; WHO, 2011). In this study, the term *disability* refers to physical disability caused by amputation. *Adaptation to disability* is conceptualized as a dynamic process that describes amputees' experiences of coming to terms with and exhibiting a positive attitude towards self and others in relation to their disability. Adaptation to disability is interchangeably used with acceptance of disability in this thesis.

Responses and adaptation to amputation-related physical disability are affected by factors such as age at the time of disability, extent of disability, difficulties related to prosthesis fitting, actual or perceived social stigma, and physical appearance (Almagor, Jaffe, & Lomranz, 1978; Breakey, 1997a; Moore 1998; Schaffalitzky, Gallagher, Desmond, & MacLachlan, 2010). Researchers have also placed emphasis on an individual's perceptions of disability rather than disability itself (Dembo, Leviton, & Wright, 1956; Dunn 1996; Oaksford, Frude, & Cuddihy, 2005). Dembo et al. (1956) explained that adaptation includes a process of value change related to feelings of loss

associated with the onset of disability. By assessing the process of value change the researcher measures individuals' ability to adapt to disability so that it does not interfere with the major domains of life. The process of value change includes: *Enlargement of scope of values*, whereby a person is able to recognize values other than those that are in conflict with having a disability; *Subordination of physique*, whereby a person is able to ignore his/her physical disability and appearance; *Containment of disability effects*, whereby a person does not see the disability beyond the actual physical impairment; and *Transformation from comparative values to asset values*, whereby a person does not compare self to others and is able to recognize personal strengths and abilities.

Similar to any chronic condition that results in physical disability, an amputee with a lower acceptance of disability may experience strong negative feelings, usually manifested as anger, denial, or depression. An amputee with a higher level of adaption realizes that the disability is only one characteristic in context with many other abilities and strengths. These individuals are typically able to exhibit pride, contentment, or happiness (Oaksford et al., 2005; Saradjian, Thompson, & Dipak 2008; Sporer et al., 2009). Adjusting to a new functional level/limitations and learning to live with an artificial limb may well affect the overall psychological wellbeing of an amputee (Atherton & Robertson, 2006; Dembo et al., 1956; Wright, 1983).

Table 2. *Summary of Studies Examining Amputation-related Stressors*

Authors/ Year	Title	Research Method/ Sample	Variables Studied	Relevant Findings
Almagor et al. (1978)	The relation between limb dominance, acceptance of disability, and the phantom limb phenomenon.	Survey and interviews of 18 double amputees who lost their limb in military service	Adaptation to disability	No statistically significant correlation between phantom limb phenomenon (including PLP) and acceptance of disability.
Atherton & Robertson (2006)	Psychological adjustment to lower limb amputation amongst prosthesis users.	Cross-sectional survey of 67 adult lower limb prosthesis users	Anxiety Depression Body image	Prevalence of Anxiety 29.9 % and depression 13.4%. Significant positive association between body image disturbance and anxiety ($p<0.003$) and depression ($p<0.0005$).
Breakey(a) (1997)	Body image: The lower limb amputee.	Correlational survey of 90 unilateral traumatic amputees	Anxiety Depression Body image	Significant positive correlation between anxiety ($p<0.0001$), depression ($p<0.0001$) and altered body image. No statistical significant association between body image and age, and time since amputation.
Coffey et al. (2009)	Psychosocial adjustment to diabetes-related lower limb amputation.	Cross-sectional survey of 38 DM-related lower limb amputees, recruited from two limb-fitting centres	Anxiety Depression Body image	Prevalence of anxiety 18 % and depression 18%. Significant positive correlation between altered body image and anxiety ($p<0.01$), and depression ($p<0.01$).

Authors/ Year	Title	Research Method/ Sample	Variables Studied	Relevant Findings
Darnall et al. (2005)	Depressive symptoms and mental health service utilization among persons with limb loss: Results of a national survey.	A Cross-sectional survey of 914 amputees who were members of Amputee Coalition of America	Depression PAP-PLP and RLP	Prevalence of depression 28.7%. Significant positive correlation between depression and being divorced or separated ($p<0.004$), being comorbid for 1 condition ($p<0.007$), being comorbid for 2 or more conditions ($p<0.001$), PLP ($p<0.001$) and RLP ($p<0.001$).
Desmond & MacLachlan (2010)	Prevalence and characteristics of phantom limb pain and residual limb pain in the long term after upper limb amputation.	Descriptive study of 141 upper limb amputees who were members of the British Limbless Ex-Service Men's Association	PAP-PLP and RLP	Prevalence of PLP 42.6% and RLP 43.3%. Significant positive association between lifestyle interference and PLP ($p<0.001$) and RLP ($p<0.001$).
Deusen (1996)	Body image of non-clinical and clinical populations of men: A literature review.	Literature review from 1959 to 1993 on body image and occupational therapy for men	Body image	PLP is negatively associated with body image and body movements.
Dunn (1996)	Well-being following amputation: Salutary effects of positive meaning, optimism, and control	A mail-in survey of 138 amputees who were members of the Eastern Amputee Golf Association	Depression Perceived control over disability	Significant negative correlation between depression and optimism ($p<0.05$), perceived control over disability ($p<0.05$) and being young ($p<0.05$).

Authors/ Year	Title	Research Method/ Sample	Variables Studied	Relevant Findings
Fisher & Hanspal (1998)	Phantom pain, anxiety, depression, and their relation in consecutive patients with amputated limbs: Case report.	A survey of 93 amputees (29 with PLP were compared to 64 with no PLP) from Prosthetic rehabilitation clinic	PAP-PLP Anxiety Depression	No statistically significant relationship between the 2 groups. Overall anxiety was more prevalent (mean 3.9) than depression (mean 2.9).
Hanley et al. (2009)	Chronic pain associated with upper-limb loss.	Cross-sectional survey of 104 upper limb amputees, 6 months post-amputation	PAP	<p>90% of amputees reported PAP, with 76% reporting more than one type of pain. Prevalence of PLP, 79%; RLP, 71%; back pain, 52%; neck pain, 43%; and non-amputated-limb pain 33%.</p> <p>Significant positive association ($p<0.05$) between PLP and prosthesis use.</p> <p>Non-amputated-limb pain caused the highest levels of pain-related interference (mean 4.2) and disability days (mean 18.4).</p> <p>No statistically significant association between PAP and age, time since amputation, and cause of amputation.</p>

Authors/ Year	Title	Research Method/ Sample	Variables Studied	Relevant Findings
Hawamdeh et al. (2008)	Assessment of anxiety and depression after lower limb amputation in Jordanian patients.	A survey of 56 unilateral lower limb amputees from Jordan	Anxiety Depression	<p>Prevalence of anxiety 37% and depression 20%. Significant positive association between anxiety and lack of social support ($p<0.004$), traumatic amputation ($p<0.006$), and below knee amputation ($p<0.01$).</p> <p>Significant positive association between depression and lack of social support ($p<0.01$), and traumatic amputation ($p<0.002$). No statistically significant association between depression and below knee amputation.</p> <p>No statistically significant association between anxiety and depression and sex, employment, and marital status.</p> <p>No statistically significant correlation between anxiety and depression, and PAP and prosthesis use</p>

Authors/ Year	Title	Research Method/ Sample	Variables Studied	Relevant Findings
Horgan & MacLachlan (2004)	Psychosocial adjustment to lower limb amputation: A review.	Literature review from 1965-2004 on psychological adjustment to amputation	Anxiety Depression Body image PAP	Depression and anxiety were high during the first 2 years post-amputation and then started to decline. Altered body-image associated with increased activity restriction, depression, and anxiety. Factors associated with positive adjustment to amputation include greater time since amputation, more social support, greater satisfaction with the prosthesis, active coping attempts, optimism, lower level of amputation and lower levels of PLP and RLP.
Marshall et al. (2002)	Pain site and impairment in individuals with amputation pain.	Community-based survey of 478 lower limb amputees	PAP	Significant positive correlation between pain-related interference and PLP ($p<0.001$), RLP ($p<0.001$) and back pain ($p<0.05$).
Moore (1998)	Acceptance of disability and its correlates.	A mail-in survey of 1,266 adults with disabilities who were actively involved in vocational rehabilitation services from 3 states of USA	PSSS Adaptation to disability	Significant positive correlation between adaptation to disability and PSSS ($p<0.001$), chronic pain ($p<0.001$), being young ($p<0.001$), married ($p<0.01$) and congenitally disabled ($p<0.001$). No statistically significant association between acceptance of disability and sex.

Authors/ Year	Title	Research Method/ Sample	Variables Studied	Relevant Findings
Rybarczyk et al. (1995)	Body image, perceived social stigma and the prediction of psychosocial adjustment to leg amputation.	A survey of 112 lower limb amputees from five prosthetic clinics in USA	Body image PSSS Depression	Significant positive correlation between depression and altered body image ($p<0.001$), and PSSS ($p<0.001$).
Singh et al. (2007)	The rapid resolution of depression and anxiety symptoms after lower limb amputation.	Cohort study of 105 lower limb amputees from rehabilitation ward	Anxiety Depression	<p>Anxiety and depression resolved significantly from the time of admission, 26.7% and 24.8% respectively, to 3.8% and 4.8% respectively at the time of discharge.</p> <p>Significant positive correlation ($p<0.01$) between depression and presence of other medical conditions.</p> <p>Significant positive correlation ($p<0.05$) between anxiety and living in isolation.</p> <p>No statistically significant association between anxiety, and depression and level of amputation, age, and sex.</p>

Authors/ Year	Title	Research Method/ Sample	Variables Studied	Relevant Findings
Singh et al. (2009)	Depression and anxiety symptoms after lower limb amputation: The rise and fall.	Prospective study of 68 lower limb amputees admitted to a rehabilitation ward.	Anxiety Depression	<p>Prevalence of depression 17.6% and anxiety 19.1% but resolved during inpatient rehabilitation. The incidences then rose again significantly ($p<0.001$) for both anxiety and depression after discharge.</p> <p>Significant positive correlation ($p<0.002$) between depression and having comorbidities.</p> <p>Significant negative correlation ($p<0.003$) between anxiety and being young.</p> <p>No statistically significant association between anxiety, and depression and age, sex, living in isolation and prosthesis use.</p>
Sporner et al. (2009)	Psychosocial impact of participation in the National Veterans Wheelchair Games and Winter Sports Clinic.	Cross-sectional study of 132 participants from National Veterans Wheelchair Games and Winter Sports Clinic, USA. 43% participants were amputees.	Adaptation to disability	84% of the respondents who reported taking part in sports had a high acceptance of disability and increased mobility.

Authors/ Year	Title	Research Method/ Sample	Variables Studied	Relevant Findings
Wald & Alvaro (2004)	Psychological factors in work-related amputation: Considerations for rehabilitation counselors.	Literature review from 1975 to 2003 on the psychological factors associated with the adjustment and outcome of work-related amputation.	Anxiety Depression Body image PAP	Work-related injury increases the risk of anxiety, depression, body image disturbances, and chronic pain.
Wetterhahn et al. (2002)	Effect of participation in physical activity on body image of amputees.	A survey of 56 lower limb amputees from five facilities from Canada and 5 states of U.S. using convenience and snowball sampling.	Body image	Significant positive correlation ($p < 0.05$) between regular participation in physical activity and body image.

Note. PSSS = Perceived Social Stigma; PAP = Post-Amputation Pain; PLP = Phantom Limb Pain; RLP = Residual Limb Pain. Only research articles pertaining to amputation-associated stressors are included in this table. Results included are only for those stressors that are studied in this study.

2.2.7 Stressors Associated with Amputation for Spouses

As with other chronic illnesses, amputation brings stressors such as disability, uncertainty, depression, financial concerns, and family role changes that can affect dyadic relationships and alter adjustment. Researchers have found that a chronic condition affecting one spouse can have negative effects on the other spouse, as well as disrupting dyadic relationship quality over a five-year period (Strawbridge, Wallhagen, & Shema, 2007; Wallhagen, Strawbridge, Shema, & Kaplan, 2004). Rowat and Knafl (1985) studied stressors affecting 40 spouses of chronic pain patients using an exploratory descriptive design. They found spouses of chronic pain patients experienced physical, psychological and emotional distresses, including sleep disturbance, headaches, poor appetite, fear, irritability and sadness as a result of their partner's chronic pain. Blyth, Cumming, Brnabic, and Cousins (2008) examined 500 community dwelling 65 and older adults and found caregiver role strain as a predictor of dyadic satisfaction. They suggested with time caregiver role strain causes ill health effects and psychological distress in spouses of chronic pain patients.

Several theories and processes are discussed in the literature to explain the dyadic nature of chronic conditions and the effect of one partner's stress on another. *Spillover effect* is one of the ways to explain this cause and effect (Brock & Lawrence, 2008). Spillover effect occurs when stress in one area of life affects another area of life for the same individual. Spillover effect arises within one's self, and affects an individual's major domains of life, including spousal relationships. Positive spillover occurs when an amputee accepts amputation-associated changes positively. This positivity translates into contentment with other roles at home or with one's spouse. Negative spillover occurs

when an amputee reacts negatively to amputation-associated stressors. These reactions exhaust and preoccupy the amputee's mind thus negatively impacting behavior and experiences with their spouse. Negative spillover effects tend to focus on emotional reactions of the sufferer and make the caregiving role of the spouse more challenging. Negative spillover effects can also lead to emotional distress in spouses and can affect their mental health (Brock, & Lawrence, 2008; Holmes, & Deb, 2003).

Another phenomenon is *stress crossover*, which supports the transfer of stress from one spouse to another. Stress crossover refers to a process by which stress experienced by one spouse affects the level of stress of another spouse. Crossover is “inter-individual transmission of stress” (Westman, 2011, p. 177). Possible explanations for this phenomenon could be that feelings of stress and reactions to stress can be transmitted to others; stress experienced by one spouse may also increase demands for support from the other spouse, thus resulting in role strain. Additionally, if spouses fail to fulfil these demands they feel guilty and anxious which further affects their mood and satisfaction in a relationship. This creates a cycle of negative crossover of stress, role strain, and mood in both spouses that exhausts coping resources within the dyadic relationship and results in maladjustment (Westman, & Etzion, 1995).

Researchers have established the crossover effect of anxiety and depression from one partner to the other in relation to health problems, work-family conflict and financial problems (Bakker, Westman, & van Emmerik, 2009; Gorgievski-Duijvesteijn, Giessen, & Bakker, 2000; Howe, Levy, & Caplan, 2004). Thus, the phenomenon of living with stressors associated with a chronic condition such as amputation may create a web of negative consequences for both partners that can strain and negatively affect dyadic

adjustment (Anderson & Valentine, 1998; Karney & Crown, 2007; Karney, Story, & Bradbury, 2005; Story & Bradbury, 2004).

2.2.8 Factors Affecting Dyadic Adjustment

There are several factors that can affect dyadic adjustment including age, sex, length of relationship, and health status. In a cross-sectional study, Hatch and Bulcroft (2004), and Smith et al. (2009) studied young, middle and old age couples. They found that younger couples tend to disagree more than older couples as older couples have fewer issues to quarrel about (e.g. child rearing and career decisions). However, issues related to retirement, finances, relocation and deteriorating health could pose new challenges for older couples. Older couples (age sixty-five years and above) may be more likely to demonstrate more affection and spend more time together due to retirement and fewer family responsibilities such as child rearing and paid jobs.

Dyadic disagreements and conflicts decrease with increasing length of marriage. Johnson, White, Edwards, & Booth (1986) found dyadic disagreements were lower in couples who were married for more than 15 years. One possible explanation could be that partners develop tolerance for each other with time and learn to share common interests. Hatch and Bulcroft (2004) revealed the frequency of disagreements in couples married for more than 30 years were less compared to couples married for less than 5 years. In an observational study, Levenson et al. (1993) studied 151 middle aged and older couples. They found that regardless of length of marriage older couples tend to conflict less as they use more passive coping and deal with conflict less negatively than younger people.

It has been reported that men tend to benefit more psychologically from marriage than women (Fowers, 1991; Heiman et al., 2011; Kiecolt-Glaser & Newton, 2001). Married men tend to report greater satisfaction with life than single men whereas women report higher satisfaction levels when single than married. At all ages husbands reported a higher level of satisfaction than do wives (Kiecolt-Glaser & Newton, 2001; Fowers 1991; Umberson & Montez, 2010). Women are less likely to share their disease burden with their spouses than men. Women also tend to be more sensitive towards their chronically ill spouse's care needs due to their caregiver role, than do men. Comparatively, women suffer more physically, socially, emotionally and psychologically by their spouse's illness than do men (Berg & Upchurch, 2007; Kaufman & Taniguchi, 2006). Several researchers maintained wives caring for a chronically ill spouse experienced lower levels of dyadic satisfaction than husbands providing care to a chronically ill spouse (Berg & Upchurch, 2007; Flor et al., 1989; Hafstrom & Schram, 1984; Kaufman & Taniguchi, 2006).

While the literature on chronic conditions and dyadic relationships suggests that chronic condition related stressors affect dyadic relationship quality (Anderson & Valentine, 1998; Karney & Crown, 2007; Karney et al., 2005; Story & Bradbury, 2004; Strawbridge et al., 2007; Wallhagen et al., 2004), little is known about amputation and its effects on dyadic adjustment. This study will provide baseline data for further research to develop couple centered interventions and support them in living with an amputation.

2.3 Theoretical Framework

2.3.1 Dyadic Adjustment in the Context of Chronic Stress

Spouses face stresses resulting from actual or potential situations. These situations can initiate numerous major, minor, acute and chronic stressors that can affect dimensions of a relationship, including dyadic satisfaction, dyadic consensus, dyadic pattern of affection, dyadic cohesion and dyadic problem solving abilities; together these constitute dyadic adjustment. Adjustment is a dynamic process which comprises either accommodating one's self to the situation or changing the situation to accommodate one's need (Lazarus, 1976). Stress is a situation that can take a toll on a person's adaptive resources (Lazarus, 1976), thus taxing a dyadic relationship. Stressful situations can create an adjustive crisis resulting in several physical, psychological and emotional disturbances. Researchers investigating marriage and stress have affirmed that major and chronic stressors affect the dyadic relationship more negatively than minor and temporary stressors (Berg, & Upchurch, 2007; Bodenmann, 2005; Karney & Bradbury, 1995; McCain, & Smith, 1994; Story & Bradbury, 2005). Stress is a complex phenomenon that can affect an individual and a dyadic relationship in many ways. Several theories and models have been proposed to explain physiological and psychological reactions that accompany stress and further deplete adjustive resources. In this study, two renowned theories, General Adaptation Syndrome and Transactional Model of Stress, were used to understand and explain stress reactions affecting the dyadic relationship.

2.3.2 General Adaptation Syndrome

Hans Selye, an endocrinologist and the pioneer of stress research, proposed a biological model of stress focused on the intensity of stressful situations and

neuroendocrine effects on the body. He presented his seminal model of stress, *General Adaptation Syndrome*, in 1956. Selye described stress as a body's defense mechanism designed to protect the body from environmental stressors. According to Selye (1956), there is a uniform physiological reaction that follows the sequence of alarming reaction, recovery or resistance, and exhaustion. The body reacts to stress by initiating the fight and flight mechanism which he named *alarm reaction*. This is followed by a *recovery or resistance stage* during which the body restores its energy. If the stress persists *exhaustion* occurs.

Selye's purely physiological explanation and lack of cognitive appraisal of stress has brought this theory into question (Hobfoll 1989; McCain & Smith, 1994).

Researchers examining psychosocial responses to stress allege that stress reactions vary amongst individuals due to their unique backgrounds, experiences, and personalities.

Every individual's response is unique based on their perception of stress (Karney et al., 2005; Lazarus & Folkman 1984; Randall, & Bodenmann, 2009). Despite receiving criticism, Selye's theory still provides a relevant explanation of physiological reactions of the body to stress.

2.3.3 Transactional Model of Stress

In the early 1960s, the psychologist Richard Lazarus offered psychological and psychosocial influences on appraisal of stress. He argued the intensity of stress depends on cognitive appraisal of the situation by an individual. In 1984, Lazarus presented a transactional model of stress with his colleague Susan Folkman, in which stress is seen as the result of imbalances between demands exerted by stressors and available coping resources (Bodenmann, 2005; Hobfoll, 1989). The transactional model is based on the

assumption that stress entails a reciprocal relationship between environment and person and depends on the individual's subjective evaluation of the situation. In the transactional model, when individuals encounter a threatening situation they enter into the first stage known as primary appraisal. *Primary appraisal* refers to the perception of stress by an individual. If an individual perceives no threat then there is no stress. However, if individuals perceive the situation as harmful or challenging, they enter the second stage known as secondary appraisal. *Secondary appraisal* refers to the evaluation of available coping resources such as physical capabilities, spouse, family, friends, self-esteem and self-efficacy. If individuals feel they have enough resources to cope with the situation it turns into positive stress. The perception of positive stress leads to well adaptive coping strategies and the person starts to find positive meaning. On the other hand, if during secondary appraisal individuals feel they do not have enough resources, the stress turns into negative stress and leads to maladaptive coping behaviours (Laubmeier, Zakowski, & Bair, 2004; Lazarus & Folkman 1984; Zakowski, Hall, Klein, & Baum, 2001).

In this study amputation is considered a dyadic stress, defined as a stress that concerns both spouses, but the appraisal of stress may be different (Bodenmann, 2005). An amputee may experience amputation-related pain and altered body image anxiety whereas a spouse may find caregiver role and changes in other spousal responsibilities stressful. Partners can affect each other's appraisal of stress through mutual influence, spillover and crossover effects. Partners influence each other's behavior, referred to as mutual influence (Bodenmann, 2005; Madhyastha, Hamaker, & Gottman, 2011). For instance a spouse of an amputee may exhibit a negative affect (emotion or mood) or

behavior in response to an amputee's negativity related to amputation-associated pain. Johansen and Cano (2007) studied 79 couples with chronic musculoskeletal pain using self-report surveys. They found one spouse's mood and sadness was related to the other spouse's mood and affect as evident by the presence of greater depressive symptoms in spouses. Similarly partners may share or deplete adjustive resources through these processes of mutual influence, spillover and crossover (Brock & Lawrence, 2008; Westman & Etzion, 1995). In short in a dyadic relationship, stress and adjustive resources are reciprocal in nature and their positive or negative effects can affect the dyadic adjustment to amputation.

2.4 Summary

In chapter two a review of the literature pertaining to amputation and dyadic adjustment was presented. Stressors associated with amputation for dyads and possible mechanism's such as spillover, crossover and mutual influence were also discussed to explain the reciprocity of stress from one spouse to another. Selye's *General Adaptation Syndrome* and Lazarus and Folkman's *Transactional Model of Stress* were presented as theories to assist in understanding the physiological and psychosocial effects of amputation-associated dyadic stress on dyadic adjustment. Dyadic adjustment was discussed in relation to the potential negative effects of amputation-related stressors on the dyadic relationship. In the following chapter a detailed description of the study design used to examine the relationship between amputation-associated stressors and dyadic relationships will be provided.

Chapter Three: Research Methods

3.1 Introduction

The purpose of this chapter is to describe the purpose of the study, research design, data collection procedures, instruments in details.

3.2 Purpose of the Study

Amputation is a life changing event that brings multiple stressors to an amputee's life. These stressors not only affect the individual but may also alter the spousal stress level and affect the overall dyadic relationship. Previously, research has been done to understand the dyadic relationship in the context of chronic conditions such as cancer, diabetes, hypertension, and congestive heart failure (Rowat & Knafl, 1985; Stewart et al., 1989; Strawbridge et al., 2007; O'Halloran et al., 2004; Wallhagen et al., 2004).

However, none of the studies conducted within the Canadian context involving both spouses actually address amputation-associated stressors and their relationship to overall dyadic adjustment. Therefore the primary aim of this study was to explore the relationship between amputation-related stressors and dyadic adjustment.

3.3 Research Questions

Amputation is a dyadic stress and stressors associated with amputation can negatively affect dyadic relationships. The primary research question was: is there a relationship between dyadic adjustment in couples in which one spouse had at least one amputation and amputation-associated stressors including anxiety, depression, perceived social stigma, altered body image, post-amputation pain and low adaptation to disability? The secondary research question was: are there relationships between dyadic adjustment and age, sex of the amputee and spouse, and length of relationship?

3.4 Study Design

3.4.1 Research Method

A survey method with a descriptive correlational study design was used to answer the research questions. According to Polit and Beck (2006) this design is useful when a researcher is interested in describing the relationship among variables without seeking to establish a cause and effect relationship. Descriptive designs provide detailed information about the study variables while correlation designs identify the possibility, strength and direction of relationships among variables without predicting the causation connection (Wood & Ross-Keer, 2006). When a phenomenon of interest is beyond the researcher's ability to control, manipulate and randomize, correlation design is considered a useful method for clinical research (Lobiondo-Wood & Haber, 2009). This study met the purpose of descriptive correlational design as its primary goal was to describe the dyadic adjustment between couples in which one spouse had at least one amputation and to explore if there was any relationship between dyadic adjustment and amputation-associated stressors.

3.4.2 Study Sample.

The ideal would have been to use a probability sampling technique and power calculation as this would allow the student investigator to make statistical inferences (i.e. generalizations) from the sample of dyads with amputation to all dyads with amputation. Probability sampling would provide greater external validity for the findings. However, due to the limited availability of dyads with amputation that could be recruited in a timely manner for this thesis research, a non-probability convenience sample was used.

Over a period of four months (February 2012 to June 2012), a convenience sample of 26 married or cohabitating heterosexual couples in which one spouse had experienced at least one amputation were recruited. Couples represented different cities in Alberta and were recruited from three sites. Although convenience sampling is the weakest type of sampling in quantitative research, it is the most common due to accessibility of participants and cost effectiveness (Loiselle, & Profetto-McGrath, 2011; Polit & Beck, 2006). However, caution is warranted in interpreting and generalizing findings due to the risk of bias. Potential biases are discussed in chapter five under limitation of the study.

3.4.3 Recruitment

The participants were recruited from three sites: 1) the Alberta Amputee Sports & Recreation Association (AASRA); 2) a privately owned prosthetic clinic; and 3) the amputee clinic at Foothills Medical Centre (FMC). Site access approval was obtained from authorized personnel prior to Conjoint Health Ethics Review Board (CHREB) submission.

3.4.4 Site Descriptions

A brief description of the sites is as follows:

- AASRA was founded in 1977, with the purpose of bringing amputees together in the community to help each other. The organization promotes and encourages outdoor sports amongst Alberta amputees to maintain and enhance their wellbeing. It also supports amputees in their initial post-amputation phase in the hospital and post-discharge through one-to-one and support group meetings.

- *The privately owned prosthetic clinic* is located in Calgary, Alberta, and is run by a certified prosthetist. The purpose of this clinic is to provide professional prosthetic care to amputees (while hospitalized and post-discharge). The prosthetist works directly with physiatrists, therapists and other health care professionals to provide quality care to amputees.
- *The amputee clinic*, located at FMC, Calgary, Alberta is an outpatient referral service of the Division of Physical Medicine and Rehabilitation for amputees.

Overall twelve (46%) participants were recruited from AASRA, twelve (46%) were enrolled from the amputee clinic and two (8%) were recruited from the prosthetic clinic. There was an 8% ($n = 2$) participant overlap between sites, with data for these two participants collected only once.

3.4.5 Procedure

After ethics approval was obtained from the Conjoint Health Ethics Review Board (CHREB) the student researcher contacted the AASRA President and Director of the prosthetic clinic to initiate contact with clinic participant members and to provide a brief study summary and the researchers' contact information. Willing participants contacted the student researcher directly by phone or by email. Two separate packages (one for the amputee and one for the spouse) containing the appropriate demographic form, instruments, and informed consent form were then mailed to both partners, with a self-addressed return envelope enclosed. The student researcher also gave out packages directly to participants at AASRA's monthly and annual meetings.

The student researcher attended the amputee clinic held every Friday from 9:00 am to 3:30 pm. Study posters were placed in the clinic to encourage participation. The

student researcher sought eligible participants through discussion with the clinician and potential participants were subsequently approached to explain the purpose of the study and obtain consent. Spouses were included in this process, if present at the clinic. A research assistant was trained to assist in data collection (i.e. explanation of the study purpose, inclusion/exclusion criteria and ethical considerations; and direct observation of the recruitment process). All participants were informed that completing the instruments could be tiring as it would take approximately 35 to 45 minutes for an amputee, and 3 to 5 minutes for the spouse to complete. After indicating willingness to participate, consent forms were signed by participants. When spouses were not present at the clinic visit their packages, including consent forms, were given to the amputees along with instructions for completion. Reminder emails and phone calls were made if packages were not received within three weeks of distribution to improve the response rate.

3.4.6 Inclusion/Exclusion Criteria

Initially couples were recruited based on the following inclusion criteria: a) heterosexual to maintain homogeneity of the sample; b) married or cohabitating couples with one partner having one or more DM-related lower limb amputation; c) time since first amputation more than three months to assess the effects of chronicity of the amputation on dyadic adjustment; and d) age 18 years of age or older (as most diabetic partnered or married lower limb amputees are adults, DM-related amputations occur later in life, and are legally able to consent to participate). Exclusion criteria included: a) non-English speaking couples; b) patients having terminal pain or cancer pain, due to the risk of mixed analysis with bereavement and loss of spouse; and c) toe amputation as it does not have the same debilitating effects as other types of limb amputations.

During the initial three weeks of data collection the student researcher was only able to recruit two couples based on the above mentioned selection criteria. Therefore, after discussion with the student's supervisory committee, amendments were submitted to the Conjoint Health Ethics Review Board (CHREB) to expand the selection criteria in order to enable timely completion of the study. Revised inclusion criteria related to item *b) married or cohabitating couples with one partner having one or more DM-related lower limb amputation*, which was expanded to *married or cohabitating couples with one partner having one or more amputation*. Exclusion criteria *c) toe amputation* was also modified to *toe and digits amputation*. Remaining selection criteria stayed the same.

3.5 Data Collection

In this study, the intent was to collect data regarding amputation-associated stressors and dyadic adjustment in couples where one spouse had experienced at least one amputation. Likert scale and dichotomous (yes/no) response-based instruments were used to assess amputation-associated stressor variables in amputees and components of dyadic adjustment in amputees and their spouses.

Demographic data of amputees and spouses were collected to obtain basic information related to amputation and relationship (see Appendix A for amputee demographic form and Appendix B for spousal demographic form). Six psychometric self-administered instruments were used to assess stressors associated with dyadic adjustment and relationship quality following amputation. For the amputees, these included: The Hospital Anxiety and Depression Scale (HADS; Appendix C), Perceived Social Stigma Scale (PSSS; Appendix D), Amputee Body Image Scale (ABIS; Appendix E), Brief Pain Inventory (BPI; Appendix F), and Adaptation to Disability Scale-Revised (ADS-R;

Appendix G). The Revised Dyadic Adjustment Scale (RDAS; Appendix H) was administered to both amputees and spouses to assess the overall dyadic adjustment to amputation. Formal permission was sought and obtained from the developer(s) for use of each of the scales presented below.

3.6 Stressors-Related Measurement Scales

3.6.1 The Hospital Anxiety and Depression Scales (HADS)

The HADS was used in this study to assess anxiety and depression in amputees. The HADS was developed by Zigmond and Snaith in 1983 for use in a study examining medical outpatient clinic patients (between the ages of 16 and 65), who suffered from a wide variety of illnesses. HADS was purchased for use in this study from GL Assessment Education Group through their official website (www.gl-assessment.co.uk). HADS is a 14-item instrument that has been used previously in studies related to amputation (Coffey et al., 2009; Fisher & Hanspal, 1998). Although the word ‘hospital’ in the title suggests that it is only valid in a hospital setting, the HADS has been validated for use in community, primary care, and general population settings (Bjellanda, Dahl, Haug, & Neckelmann, 2002; Snaith, 2003).

HADS is divided into an anxiety subscale (HADS-A) and a depression subscale (HADS-D), both containing seven items rated on a 0–3 Likert scale (where 0 = Not at all and 3 = Most of the time). Bjellanda et al. (2002) conducted a review of 747 studies in which the HADS was used. Researchers revealed Cronbach’s alpha for subscales HADS-A varied from 0.68 to 0.93 (mean 0.83) and for subscale HADS-D from 0.67 to 0.90 (mean 0.82). They further noted that correlations between HADS and other commonly used instruments, including the General Health Questionnaire (GHQ-28), the

Clinical Anxiety Scale, the Spielberger's State-Trait Anxiety Inventory (STAI), the Montgomery Asberg Depression Rating Scale and the Beck's Depression Inventory (BDI), were in the Cronbach alpha range of 0.49 to 0.83, indicating good convergent validity. The HADS takes 2-5 minutes to complete. Scores range from 0 to 21 for each subscale, with a score of 0 to 7 on either subscale considered normal. A score of 8 to 10 is suggestive of the presence of the respective anxiety or depressive state, and a score of 11 or higher indicates the possibility of mood disorder (Zigmond & Snaith, 1983; Snaith, 2003).

3.6.2 The Perceived Social Stigma Scale (PSSS)

The PSSS is a 22-item amputee scale developed by Bruce Rybarczyk and colleagues for use in a study examining lower limb amputees in 1995. This scale has previously been used with amputees to assess perceived social stigma (Gallagher & MacLachlan, 2000) and was used in this study for this purpose.

The PSSS includes fourteen negative attributes and eight antonyms of negative attributes. Participants were instructed to insert each attribute in the statement "As a person with an amputation, others see me as...", and rate the statement on a four point Likert scale ranging from 1 (not at all true) to 4 (very much true). A total score is obtained by reversing the scores on the antonyms and then summing all 22 scores. Scores range from 0 to 88, with a score of 1 to 44 reflecting presence of no to mild perceived social stigma. A score of 45 to 88 indicates the presence of moderate to severe perceived social stigma. Rybarczyk et al. (1995) found PSSS Cronbach's alpha was 0.91 when tested on 112 amputees at five different prosthetic centres, indicating internal consistency of items on the instrument.

3.6.3 The Amputee Body Image Scale (ABIS)

The ABIS was developed and used in a study examining lower limb amputees by James Breakey in 1997 when he was a lecturer in the Division of Physical Medicine and Rehabilitation at Stanford University, California, USA. The ABIS is a 20-item instrument specifically designed to measure amputation-related body image disturbance in lower limb amputees and was used in this study to measure amputee's perceptions of body image. Item number 2, *I avoid wearing shorts in public because my prosthesis would be seen*, was modified to, *I avoid wearing shorts or a short sleeve shirt in public because my prosthesis would be seen* to make it applicable to upper limb amputees. The instrument assesses amputees' perceptions and feelings about their body image on a 5 point Likert scale, ranging from 0 (none of the time) to 5 (all of the time). Total scores range from 0 to 100, with a higher score indicating more serious body image concerns. Three items in this scale are reversed scored (Breakey, 1997a) to reduce response bias of the participants. ABIS has been translated into other languages (Safaz, Yilmaz, Goktepe, & Yazicioglu, 2010) and is significantly correlated ($p < 0.05$) with the Multidimensional Body Self Relations Questionnaire (MBSRQ) (Wetterhahn et al., 2002). Breakey (1997a) reported the Cronbach coefficient alpha was 0.88 and internal consistency was 0.70 in a sample of 90 lower limb amputees.

3.6.4 The Brief Pain Inventory (BPI)

The BPI is a 23 item, self-administered tool that was used to assess the patient's pain intensity and pain-related interference on a scale of 0 to 10. Higher scores indicate higher pain intensity and higher pain-related interference. It takes about 15 minutes to complete (Beth, McMillan, & Hagan 2003; Cleeland & Ryan, 1994). The BPI is a

widely used pain assessment tool across cultures and languages, for clinical pain assessment and research purposes. It was originally developed to assess cancer patients' pain (Ger, Ho, Sun, Wang, & Cleeland, 1999; Serlin, Mendoza, Nakamura, Edwards, & Cleeland, 1995; Uki, Mendoza, Cleeland, Nakamura, & Takeda, 1998).

Test-retest reliability of the BPI was assessed in a sample of 109 outpatient pain clinic patients, and scores were 0.98 for pain severity and 0.97 for pain interference (Radbruch et al., 1999). Alpha coefficients ranged from 0.81 to 0.91 for the Pain Interference Subscale and 0.81 to 0.89 for the Pain Severity Subscale of the BPI (Ger et al., 1999; Tan, Jensen, Thornby, & Shanti, 2004). BPI has also been used in studies conducted on post-amputation pain (Marshall, Jensen, Ehde, & Campbell, 2002; Robinson et al., 2004). Marshall et al. (2002) used the BPI in lower limb amputees and found a significant positive correlation between post-amputation pain and pain-related interference with activities of daily living (ADL; as post-amputation pain increased, pain-related interferences with ADL also increased).

3.6.5 The Adaptation to Disability Scale-Revised (ADS-R)

ADS-R is a self-administered 32-item instrument that assesses the level of adjustment to disability among individuals with disabilities. It was used in this study to measure the level of adjustment to the amputation-related disability. The original scale was developed in 1971 by Linkowski for use with patients with disabilities and was revised by Groomes and Linkowski in 2007.

The ADS-R is a four point Likert scale where 1 = strongly disagree and 4 = strongly agree. This scale is based on four subscales derived from Dembo et al. (1956) value change process that identifies four major shifts in an individual's value system,

influencing adaptation to disability. These include: (a) enlargement of the scope of values, (b) subordination of physique, (c) containment of disability effects, and (d) transformation from comparative to asset values. The ADS-R scale measured respondents' adjustment to disability, resulting in a single summative score of low adaptation to disability (scores of 28 to 60), medium adaptation to disability (scores of 61 to 93), and high adaptation to disability (scores of 94 to 124). The four subscales: enlargement, subordination, containment, and transformation are summed individually, and subsequently a single ADS-R score is calculated. Overall, Linkowski (1971) and Groomes and Linkowski (2007) studied 356 individuals with various disabilities, including amputation and diabetes, and found the ADS-R scale maintains high to moderate internal consistency among all four subscales. The alpha coefficients were: enlargement 0.82, subordination 0.71, containment 0.88 and transformation 0.88. In addition, overall reliability for the revised ADS-R was Cronbach's $\alpha = 0.93$. This instrument takes 6 to 7 minutes to complete.

3.7 The Dyadic Adjustment Measurement Scale: Revised Dyadic Adjustment Scale (RDAS).

The RDAS (Busby, Crane, Larson, & Christensen, 1995) is the revised version of Dyadic adjustment Scale originally developed by Graham Spanier (1976) to use with married or cohabiting couples. The RDAS is a shorter version of the DAS with acceptable levels of construct validity and adequate internal consistency. Additionally, it maintains the strength of the original scale to distinguish between distressed and non-distressed couples (Crane, Middleton, & Bean, 2000; Busby et al., 1995). The RDAS is a 14 item scale (divided into 3 subscales) that measures dyadic satisfaction, dyadic

cohesion, and dyadic consensus to assess dyadic adjustment of married or cohabitating couples. In this study it was used to measure elements of dyadic adjustment related to amputation. The RDAS is a self-administered instrument that takes 3 to 5 minutes to complete with scores ranging from 0 to 69. The cut point for distinguishing between distressed and non-distressed couples is 48 (Crane et al., 2000). A score between 0-48 indicates a distressed relationship and a score in the 49-69 range indicates a non-distressed relationship. Busby et al. (1995) studied 242 couples of which 98 were receiving marital therapy from a clinical program at two different centres. They reported the items on the RDAS were internally consistent at both centres. The alpha coefficient for dyadic satisfaction was 0.85, for dyadic cohesion was 0.80, and for dyadic consensus was 0.81. The overall reliability of the RDAS has been demonstrated with a coefficient alpha of 0.90. The correlation between the RDAS and Kansas Marital Satisfaction Scale (KMSS) is 0.78 (Crane et al., 2000); the correlation between the RDAS and DAS is 0.97, and the RDAS and Marital Adjustment Test is 0.68 (Busby et al., 1995), thus demonstrating convergent validity between instruments.

3.8 Ethical Considerations

Ethics approval was obtained from the University of Calgary Conjoint Health Research Ethics Board (CHREB). Participants were informed of the purpose of the study, that participation was voluntary, and that they could decline to answer any question and were free to withdraw from the study at any time. Participants signed the appropriate patient or spousal consent form (see Appendix I for patient consent form and Appendix J for spousal consent form). A copy of the consent form was given to participants for their records. Participants were made aware there was no financial

benefit involved in this research. Participants were also informed that the instruments might invoke some discomfort or feelings of sadness and they could discuss these with the researcher at any time; they could also be referred to resource personnel to assist them with these feelings. None of the participants reported any unpleasant feelings.

Maintaining confidentiality is another essential principle of research ethics. Maintaining confidentiality refers to the assurance from the research team that the participant's identifiable information will be kept secure and will not be disclosed to any other parties not involved in research (Wood & Ross-Kerr, 2006). In this study confidentiality of participant's data was maintained at all times. Data were organized by subject codes, and hard copy personal information (e.g. telephone numbers, demographic data, instruments responses) were kept in a secure, locked cabinet in the principle investigator's locked research office at the University of Calgary. Demographic and survey data were entered into a secure password-protected University of Calgary computer database and only accessible to the researchers and the CHREB. Hard copy data will be shredded and electronic copies data will be erased after 12 years (as per CHREB policy; non-RCT data must be kept for 12 years).

3.9 Data Analysis

All data were coded and entered in IBM SPSS Statistics Standard Edition 2010 (<http://www-01.ibm.com/software/analytics/spss/products/statistics/stats-standard/>). Following data entry, the data set was screened for errors in data entry accuracy, outliers and missing values. To maintain data entry accuracy and check for outliers in the entered data, the student researcher assessed the data against the data sheets and variable ranges. The data were then corrected for any discrepancies. Missing data are a common problem

in research especially using the survey method as often respondents miss or do not respond to one or two items (Downey & King, 1998; Finch, 2010; Raaijmakers, 1999). For missing values in instruments, both the Expectation Maximization (EM) technique and item mean substitution were used.

The EM technique to replace missing values was introduced by Little and Rubin in 1987. The EM process consists of 2 steps. The first step E, expects the likelihood of the missing value using the current estimate for the parameter. The second step M, computes the missing value by maximizing the expected likelihood found in the step E (Allison, 2001; Little & Rubin, 2002). EM is an effective technique often used to handle missing data. It overcomes some of the limitations of other techniques, such as mean substitution or regression substitution that underestimates the standard errors (Schafer, 1997; Schafer & Olsen, 1998). One assumption of EM is that data are missing completely at random. Before replacing missing values via EM, Little's MCAR (Missing Completely At Random) test was undertaken. A non-statistical significant finding is consistent with the assumption that data are completely missing at random and EM can be used to replace missing values. In this study, two of the instruments had no missing values (BPI and ABIS) thus the MCAR was run for the remaining four instruments. The results were not statistically significant for three instruments (HADS: $p = 0.683$; ADS-R: $p = 1.000$; RDAS: $p = 0.476$) indicating values were missing completely at random (no identifiable pattern in the missing data). After establishing that the data were missing completely at random, using the SPSS program 19.0 - Missing Value Analysis, the EM technique was used to replace the missing values. The PSSS did not satisfy the EM assumption of MCAR. Item number 16 '*attractive*' was shown to be not missing

completely at random therefore the item mean substitution technique was used to replace missing values for PSSS.

Data analysis was divided into three phases:

- 1) Characteristics of study participants obtained from demographic forms, including age, sex, education, employment status, income, marital status, length of relationship, and number of children were described using means, standard deviations, frequencies and percentages as appropriate.
- 2) Spearman's rank order correlation coefficient was used to describe the strength and direction of the relationship between stressor variables and dyadic adjustment to answer the primary research question: is there a relationship between amputation-associated stressors including anxiety, depression, low adaptation to disability, perceived social stigma, altered body image and post-amputation pain, and dyadic adjustment in couples in which one spouse had at least one amputation?

Spearman's rank order correlation is one of the most common non-parametric statistical methods used in nursing research for correlational analysis. Non-parametric tests are used with: a) small sample sizes (e.g. $n < 30$), b) when the level of measurement of the dependent variable is not interval or ratio level (in this study data were categorical or ordinal), c) when random sampling is not used (convenience sample in this study), d) when observations are not independent of one another (in this case, participants at each recruitment site were involved in some form of interaction with one another), e) when variability of scores for participants from each recruitment site are not similar (homogeneity of variance), and f) when an assumption of normality (scores on the dependent variable are normally distributed) of the data cannot be made about the

population from which the sample was drawn. Spearman's rank order correlation is a rank order, ordinal scale correlation which is less sensitive to linearity and outliers in data as compared to Pearson r , the parametric correlation coefficient designed for interval level data (Sprinthall, 2007; Williamson, 1981). This is because, when using Spearman's ρ , the raw score data are transformed into numbers that represent their position in an ordered list; for example the raw scores are ordered from lowest to highest and the lowest score is assigned a rank of 1, the next highest is assigned a rank of 2 and so on; thus the ranks are compared vs. the actual scores.

The correlation analysis ranges from -1 to +1 with +1 indicating a perfect (positive) correlation between two variables: as X increases Y increases, whereas -1 describes an inversely proportional correlation between two variables: as X increases Y decreases; 0 denotes no correlation between variables (Lobiondo-Wood & Haber, 2009; Ross-Kerr, & Wood, 2006). The effect size or strength of the association between variables is reflected in the ' r ' value in the correlations. Cohen (1998) suggested $r=.10$ to $.29$ or $r=-.10$ $-.29$ was a small correlation; $r=.30$ -.49 or $r=-.30$ -.49 was a medium correlation; and $r=.50$ -1.0 or $r=-.50$ —1.0 should be interpreted as a large correlation.

3) A correlation analysis between demographic data and dyadic adjustment variables was conducted using Spearman's rank order correlation coefficients (ρ) to explore the secondary research question: is there a relationship between dyadic adjustment and, age, sex of amputee and spouse, and length of relationship? The Mann Whitney U test is a non-parametric test used to compare two independent groups. Assumptions of the Mann Whitney U test are that the sample does not need to be normally distributed and it can be

used for small sample size (≥ 5). In this study it was used to compare the difference between sex and RDAS overall and subscales scores (Nacher, 2008).

3.10 Summary

In this chapter details of the research method used in the study were discussed. The results will be presented in Chapter 4.

Chapter Four: Research Results

4.1 Introduction

The intent of this chapter is to present the findings and analysis. This chapter is divided into three sections:

- 1) Descriptive statistics explaining sample characteristics pertaining to this study
- 2) Correlations between dyadic adjustment and amputation-associated stressors.
- 3) Correlations between dyadic adjustment and demographic variables (age and sex of amputee and spouse, and length of relationship).

Spearman rank order correlation was computed to obtain correlations between all measures and their subscales scores. The data for all the instruments were nominal or ordinal. Spearman rank order correlations were also conducted between amputees' and spousal age, and length of relationship and RDAS overall adjustment scores, and subscale scores. The Mann Whitney U test was used to explore the difference between sex and RDAS overall adjustment scores and subscales scores. Results are presented in tables and charts as appropriate.

4.2 Response Rate

Thirty three packages containing the assessment instruments were distributed and 26 were returned completed, resulting in a 79% response rate. Four respondents missed completing one instrument from the package; they were contacted by their preferred method of contact (e.g. phone, email or in person) to complete the instrument. Out of the 33, two respondents returned blank packages. Another participant sent an apology as his marital status had changed since receiving the packages. The remaining four did not return the packages.

4.3 Section One: Descriptive Statistics

4.3.1 Demographic Variables

The majority of the amputees were male ($n = 18$, 69.2%) and Caucasian ($n = 25$, 96.2%), prosthesis users, with nearly half of the overall sample ($n = 12$, 46%) involved in some kind of sports-related activities. Ten (38.5%) amputees had some college level education and nine (34.6%) were working full time. The majority of the spouses were female ($n = 18$, 69.2%) and also Caucasian ($n = 23$, 88.5%). Ten (38.5%) spouses had some college level education while twelve (46.2%) spouse were working full-time. The demographic variables of amputees and spouses are outlined in Table 3.

All the couples were married except one. Amputees' average age was 56 years (SD 13.63) ranging from 22 years to 73 years. Spouses' average age was 56 years (SD 14.04) ranging from 26 years to 79 years. Figure 1 indicates the age distribution of amputees and spouses.

Table 3. *Demographic Variables of Amputees and Spouses (n = 26 dyads)*

Variables	Amputee		Spouse	
	n	%	n	%
Sex				
Male	8	69.2	18	30.8
Female	18	30.8	8	69.2
Ethnicity				
Caucasian	25	96.2	23	88.5
Asian	1	3.8	3	11.5
^a Level of education				
High school or less	5	19.2	7	26.9
College	10	38.5	10	38.5
University	6	23.1	5	19.2
Professional degree	5	19.2	3	11.5
Employment/finances				
Working full time	9	34.6	12	46.2
Working part time	3	11.5	6	23.1
Unemployed	4	15.4	0	0
Retired	8	30.8	7	26.9
Homemakers	1	3.8	1	3.8
Studying	1	3.8	0	0

Note. ^aone missing value in spouses' level of education.

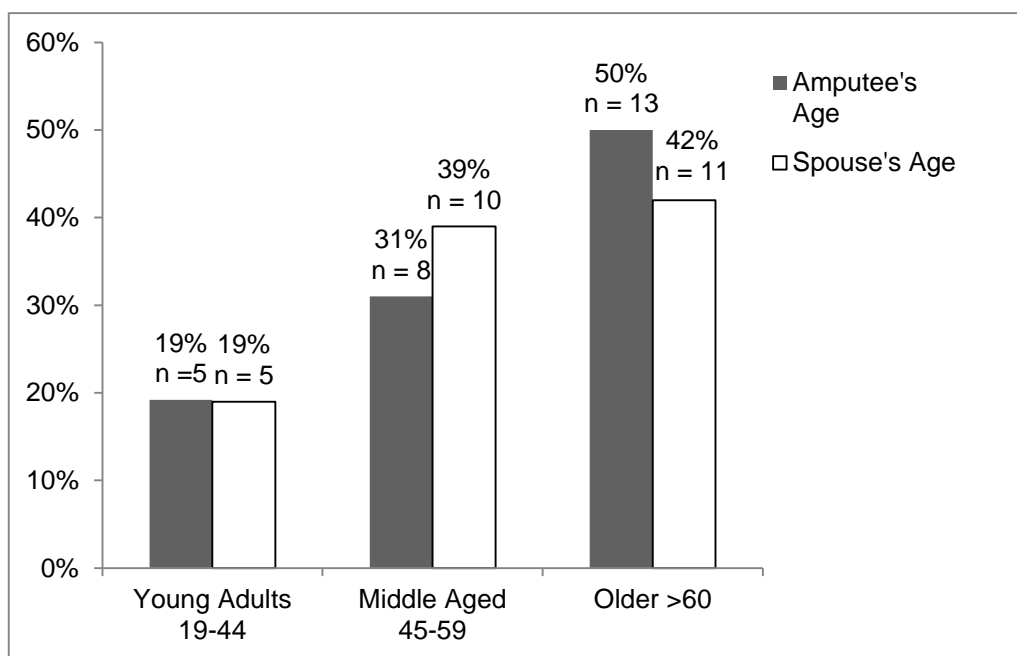


Figure 1. Age Distribution of Amputees and their Spouses (n = 26 dyads)

4.3.2 Relationship Variables

The 26 couples who participated in this study had been together for an average of 30.4 years (SD 15.52), ranging from 3 to 56 years. More than half of the couples (n = 14, 53.8%) had maintained their dyadic relationship over 30 years. Figure 2 depicts the length of relationship of the couples.

Seventeen (65.4%) amputees started the relationship before amputation and nine (34.6%) started their relationship after amputation. Six (23.1%) amputees had a previous marriage/relationship of whom two (7.7 %) started and ended their relationship before amputation and two (7.7 %) started and ended their relationship after amputation. Two (7.7 %) amputees started their relationship before amputation and ended after amputation. The average number of children for the amputee was 2.19 (SD 1.29) and for the spouse

was 2.04 (SD 1.39) ranging from zero to five children. The difference in the number of children between amputees and spouses was likely due to step children in blended families. As expected there was a significant positive correlation found between amputee's age and spouse's age ($r = .945$, $p < 0.01$) and length of relationship ($r = .912$, $p < 0.01$).

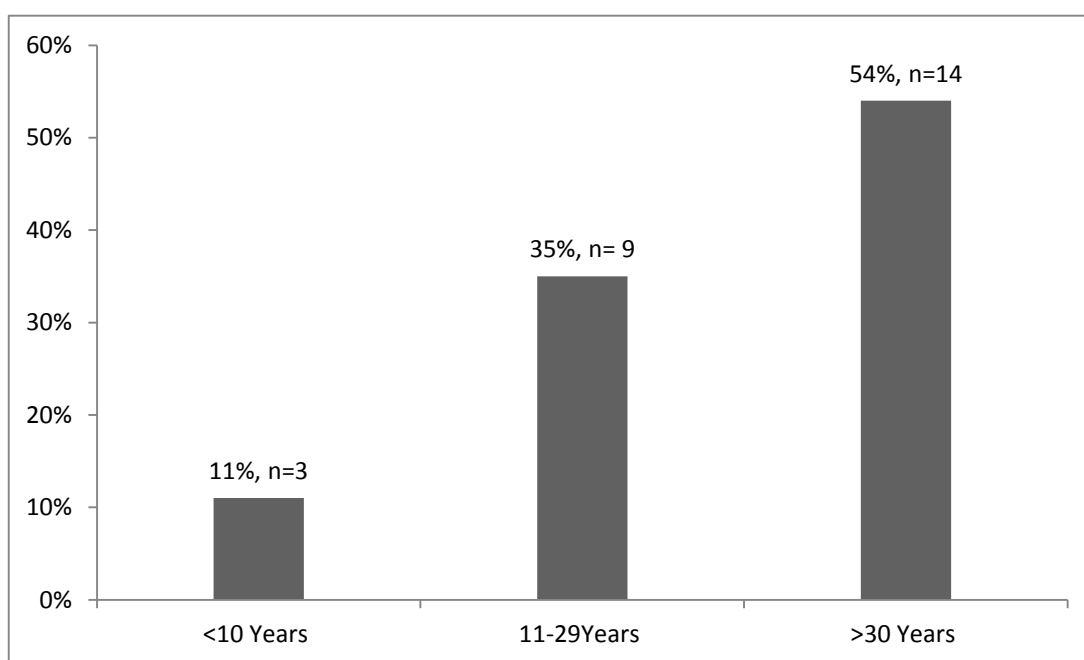


Figure 2. Length of Relationship of Couples (n = 26 dyads)

4.3.3 Amputation Variables

The major cause of amputation (n = 8, 30.8%) was trauma. More than half of the amputees (n = 23, 88.4%) had suffered lower limb amputations and 10 (38.5%) amputees had subsequent amputations ranging from 1 to 10 per amputee. The average age at the time of first amputation was 38.58 years (SD 21.52), ranging from 3 months to 72 years.

Less than half of the amputees ($n = 11$, 42.3%) had their first amputation during young adulthood (ages 19-44 years). Average time elapsed after first amputation was 17.65 years (SD 18.42), ranging from 0 to 67 years. Figure 3 indicates the age distribution of amputees at the time of first amputation.

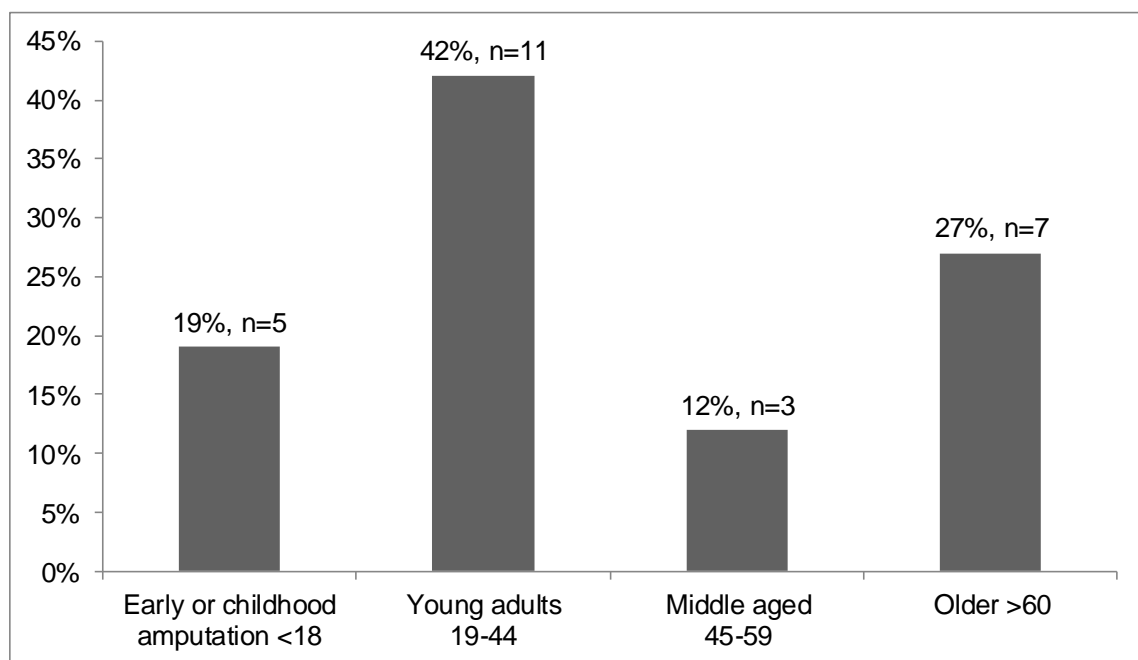


Figure 3. Age Distribution of Amputees at the Time of their First Amputation ($n = 26$)

Twenty-two amputees (84.6%) were using a prosthesis. Fourteen (53.84%) amputees had other health conditions such as hypertension, high cholesterol, cardiac disease, lung disease, rheumatoid arthritis, osteoarthritis, and hypothyroidism. Amputation-related characteristics of amputees are summarized in Table 4.

Table 4. *Amputation Variables of Amputees (n =26)*

Variable	n	%
Reason for amputation		
Trauma	8	30.8
Diabetes Mellitus	7	26.9
Congenital	3	11.5
Osteomyelitis	3	11.5
Cancer	2	7.7
Necrotizing fasciitis	2	7.7
Toxic shock syndrome	1	3.8
Site of amputation		
Upper	3	11.5
Lower	22	84.6
Both	1	3.8
Level of amputation		
Shoulder	1	3.8
Lower arm	2	7.7
Above knee	6	23.1
Below knee	16	61.5
Below knee and upper arm	1	3.8
Any subsequent amputation	10	38.5
Prosthesis	22	84.6

4.4 Section Two: Correlations between Dyadic Adjustment and Amputation-Associated Stressors

The primary research question was: is there a relationship between dyadic adjustment and amputation-related stressors including anxiety, depression, perceived social stigma, altered body image, post-amputation pain low adaptation to disability? Data describing each instrument are presented first, followed by correlational analyses of dyadic adjustment and stressor variables.

Means, standard deviations, and ranges of each scale and their subscales are presented first and are summarized in Table 5.

Table 5. *Mean and Frequencies of Measurement Scales and their Subscales (n = 26)*

Measurement Scales	Subscales	Mean	SD	Min-Max
ABIS	No subscale	45.96	17.27	22-88
PSSS	No subscale	38.31	9.96	24-68
HADS	Anxiety	6.65	4.19	0-14
	Depression	4.88	4.68	0-16
BPI	Pain Intensity	3.40	2.59	0-10
	Pain interference	3.54	3.18	0-9
ADS-R-TS	Overall	103.81	19.9	43-124
	Enlargement	29.77	6.35	11-36
	Subordination	16.0	3.13	9-20
	Containment	27.81	6.54	12-36
	Transformation	30.23	5.61	11-36
RDAS-A-TS	Overall	51.46	8.31	28-66
	Consensus	23.85	3.67	9-20
	Satisfaction	15.58	2.21	10-19
	Cohesion	12.04	3.38	5-19
RDAS-S-TS	Overall	50.46	9.68	28-64
	Consensus	23.54	4.44	10-20
	Satisfaction	15.53	2.89	10-19
	Cohesion	11.58	3.25	5-18

Note: ABIS = Amputee Body Image Scale; PSSS = Perceived Social Stigma; HADS = Hospital Anxiety and Depression Scale. BPI = Brief pain Inventory; ADS-R = Adaptation to Disability Scale-Revised-Total score; RDAS-A-TS = Revised Dyadic adjustment Scale-Amputee-Total Score; RDAS-S-TS = Revised Dyadic adjustment Scale-Spouse-Total Score.

Table 6. *Spearman's Rank Order Correlations among All Measurement Scales (n = 26)*

	1	2	3a	3b	4a	4b	5	6	7
1. ABIS	—								
2. PSSS	.567**								
3a. HADS-A	.574**	.332							
3b. HADS-D	.490*	.315	.608**						
4a. BPI-I	.325	.190	.156	.362					
4b. BPI-PRI	.55**	.199	.494*	.745**	.640**				
5. ADS-R	.626**	.551**	.431*	.522**	.589**	.635**			
6. RDAS-A-TS	.180	.041	.504**	.284	.045	.203	.063		
7. RDAS-S-TS	.279	.225	.274	.376	.263	.504**	.387	.617**	—

Note. ABIS = Amputee Body Image Scale; PSSS = Perceived Social Stigma; HADS-A = Hospital Anxiety and Depression Scale-Anxiety; HADS-D = Hospital Anxiety and Depression Scale- Depression; BPI-I= Brief Pain Inventory-Intensity; BPI-PRI= Brief pain Inventory- Pain-Related Interference; ADS-R = Adaptation to Disability Scale-Revised; RDAS-A-TS = Revised Dyadic adjustment Scale-Amputee-Total Score; RDAS-S-TS = Revised Dyadic adjustment Scale-Spouse-Total Score.

* $p < .05$. ** $p < .01$.

4.4.1 The Hospital Anxiety and Depression Scale (HADS) Scores of Amputees

The HADS was used in this study to assess anxiety and depression in the amputees. Ten (38.4%) participants obtained anxiety (HADS-A) scores above the normal range (i.e. > 8); half of these participants (n = 5, 19.2%) scored borderline abnormal (8-10) and half (n = 5, 19.2%) scored abnormal (11-21). Scores for the depression scale (HADS-D) tended to be lower; only six (23.1%) participants obtained scores above the normal range (i.e. > 8) of which two (7.7%) participants scored borderline abnormal (8-10) and four (15.4%) participants scored abnormal (11-21).

Figure 4 shows frequencies and comparisons of HADS-A and HADS-D.

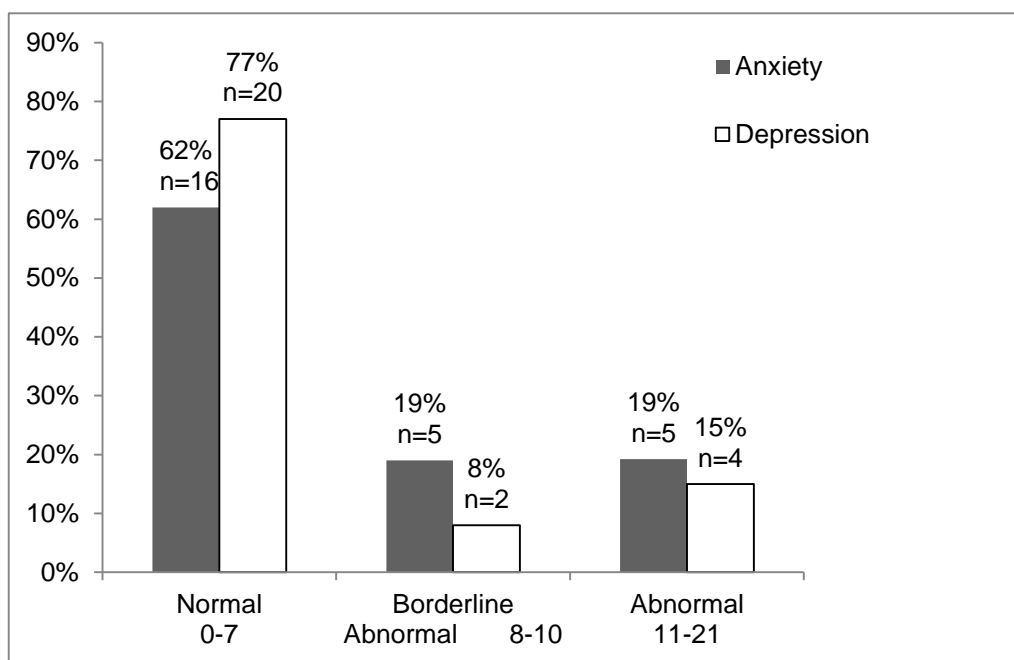


Figure 4. Frequencies and Comparison of the Hospital Anxiety and Depression Scale (HADS) subscales: Anxiety (HADS-A) and Depression (HADS-D) (n = 26)

Anxiety (HADS-A) was significantly positively correlated with depression (HADS-D) ($r = .608$, $p < 0.01$), body image disturbance (ABIS) ($r = .574$, $p < 0.01$), and pain-related interference (BPI subscale) ($r = .494$, $p < 0.05$), as well as negatively correlated with adaptation to disability (ADS-R) ($r = .431$, $p < 0.05$). Depression also had a significantly positive relationship with body image disturbance (ABIS) ($r = .490$, $p < 0.05$), and pain-related interference (BPI subscale) ($r = .745$, $p < 0.01$). Depression was negatively correlated with adaptation to disability (ADS-R) ($r = .522$, $p < 0.01$).

4.4.2 The Perceived Social Stigma Scale (PSSS) Scores of Amputees

The PSSS was used in this study to measure amputees' perceived social stigma. Only six (23.1%) amputees reported problems with perceived social stigma. PSSS was only strongly positively correlated with body image concerns (ABIS) ($r = .567$, $p < 0.01$) and negatively linked with adaptation to disability (ADS-R) ($r = .551$, $p < 0.01$).

4.4.3 The Amputee Body Image Scale (ABIS) Scores of Amputees

The ABIS was used in this study to assess an amputee's perceptions of body image. Six (23.1%) amputees scored above the normal range (i.e. > 50) indicating moderate to severe body image concerns. Some of the amputees answered not applicable to a few items as they were not using prosthesis or rarely using prosthesis. The scores were significantly positively related to perceived social stigma (PSSS) ($r = .567$, $p < 0.01$), anxiety (HADS-A) ($r = .574$, $p < 0.01$), depression (HADS-D) ($r = .490$, $p < 0.05$), and pain-related interference (BPI subscale) ($r = .511$, $p < 0.01$). In addition, body image disturbance (ABIS) was also negatively associated with adaptation to disability (ADS-R) ($r = .626$, $p < 0.01$).

4.4.4 The Brief Pain Inventory (BPI) Scores of Amputees

The BPI scale was used to describe pain and pain-related interference in amputees. Pain intensity subscale scores, as measured using the Brief Pain Inventory (BPI), ranged from 0 (no pain) to 10 (as bad as you can imagine) with an overall pain intensity of 4.01 (SD 2.32). Four of 26 amputees (15.4%) indicated they were experiencing no pain related to amputation. Twenty-two (84.6%) reported experiencing some kind of amputation-related pain and half of these participants reported having more than one type of pain. Of those experiencing some kind of pain, phantom limb pain was the most prevalent amongst the majority of amputees ($n = 15$, 68.2%); 8 (36.5%) amputees experienced low back pain and 6 (31.8%) participants suffered non-amputated limb pain. Thirteen (59%) of all 22 amputees in the study experienced other kinds of pain, including shoulder, neck, arm, hand, wrist, residual limb pain, and prosthesis-induced pain. Of the 22 amputees with pain, 9 (41%) did not take anything to relieve pain and the remaining 13 (59%) used medications, physiotherapy, acupuncture, chiropractor or IntraMuscular Stimulation (IMS) to relieve pain. The average pain-related interference was 4.18 (SD 3.04) with scores ranging from 0-9, with 0 being no interference and 10 being complete interference. Figure 5 illustrates frequencies and comparisons of BPI subscales.

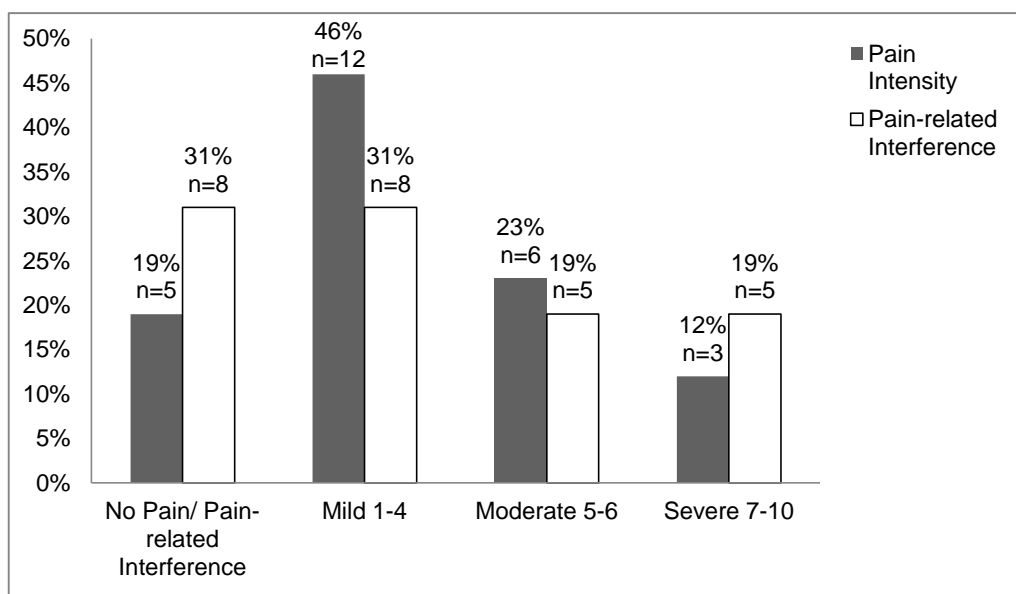


Figure 5. Frequencies and Comparisons of the Brief Pain Inventory (BPI) Subscales: Pain Intensity and Pain-related Interference (n = 26)

Eight of 26 amputees (30.8%) indicated they were not experiencing any pain-related interference. The remaining 18 amputees reported the most commonly affected areas of life were their normal work (n = 10, 55.5%) walking ability (n = 10, 55.5%), mood (n = 9, 50%) and enjoyment with life (n = 9, 50%). Figure 6 outlines areas affected moderately to severely by pain-related interference.

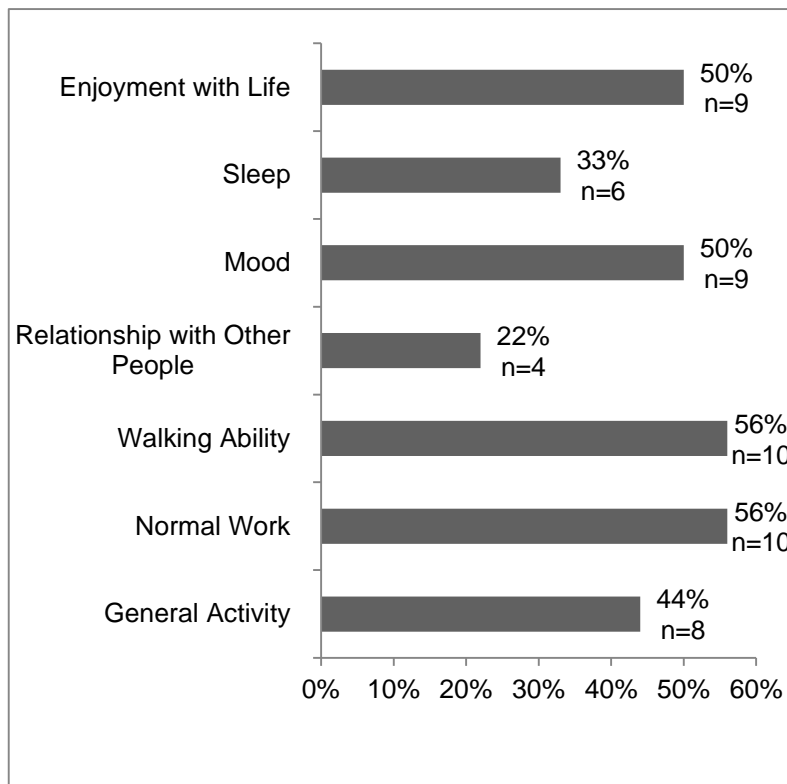


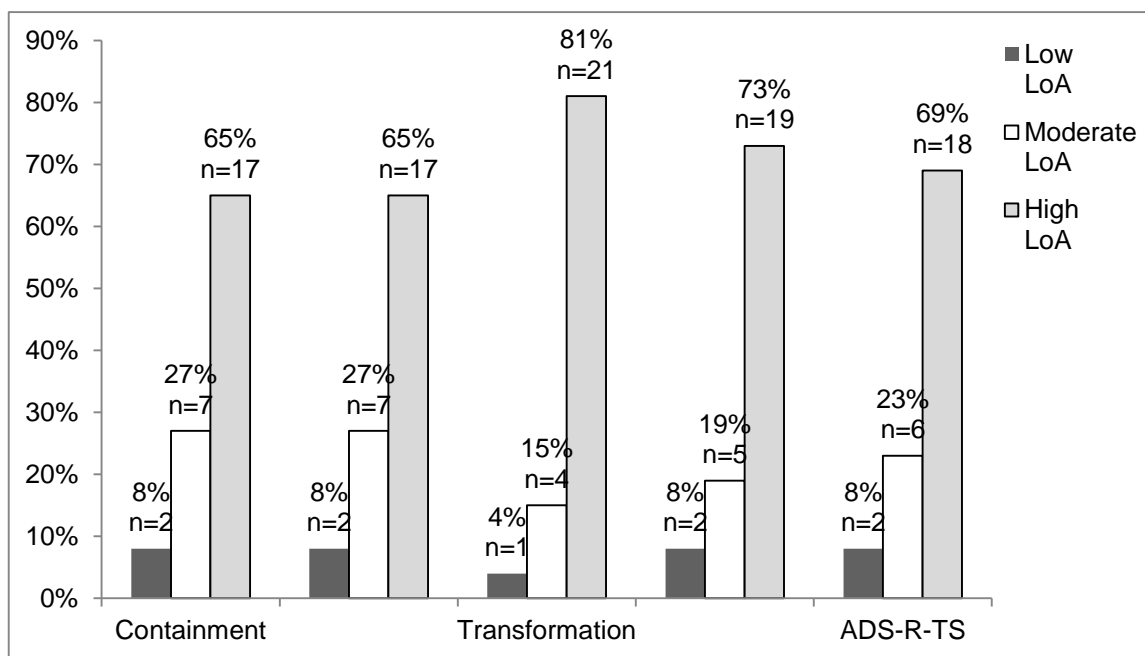
Figure 6. Frequencies of Areas Affected Moderately to Severely by Pain-related Interference (n = 18)

Pain intensity was only significantly positively correlated with pain-related interference ($r = .640$, $p < 0.01$). Pain-related interference was positively correlated with anxiety (HADS-A) ($r = .494$, $p < 0.05$), depression (HADS-D) ($r = .745$, $p < 0.01$), and body image disturbance (ABIS) ($r = .511$, $p < 0.01$). Adaptation to disability was

negatively correlated with both BPI subscales: pain intensity ($r = .589$, $p < 0.01$) and pain-related interference ($r = .635$, $p < 0.01$).

4.4.5 The Adaptation to Disability Scale-Revised (ADS-R) Scores of Amputees

The ADS-R was used in this study to assess the level of adjustment to the amputation-related disability. Only 2 (7.7%) amputees indicated a low level of adaptation to disability. Figure 7 describes frequencies and comparisons of results of ADS-R subscales and total score.



Note. LoA = Level of Adaptation; ADS-R-TS = Adaptation to Disability Scale-Revised-Total-Score

Figure 7. Frequencies and Comparisons of the Adaptation to Disability Scales-Revised (ADS-R) Subscales and Total Score (n = 26)

ADS-R was significantly negatively correlated with perceived social stigma (PSSS) ($r = .551$, $p < 0.01$), anxiety (HADS-A) ($r = .431$, $p < 0.05$), depression (HADS-D)

($r = .522$, $p < 0.01$) and BPI subscales: pain intensity ($r = .589$, $p < 0.01$) as well as pain-related interference ($r = .635$, $p < 0.01$). All ADS-R subscales were positively correlated. Table 7 presents the Spearman's rank order correlations among the ADS-R subscales and total score.

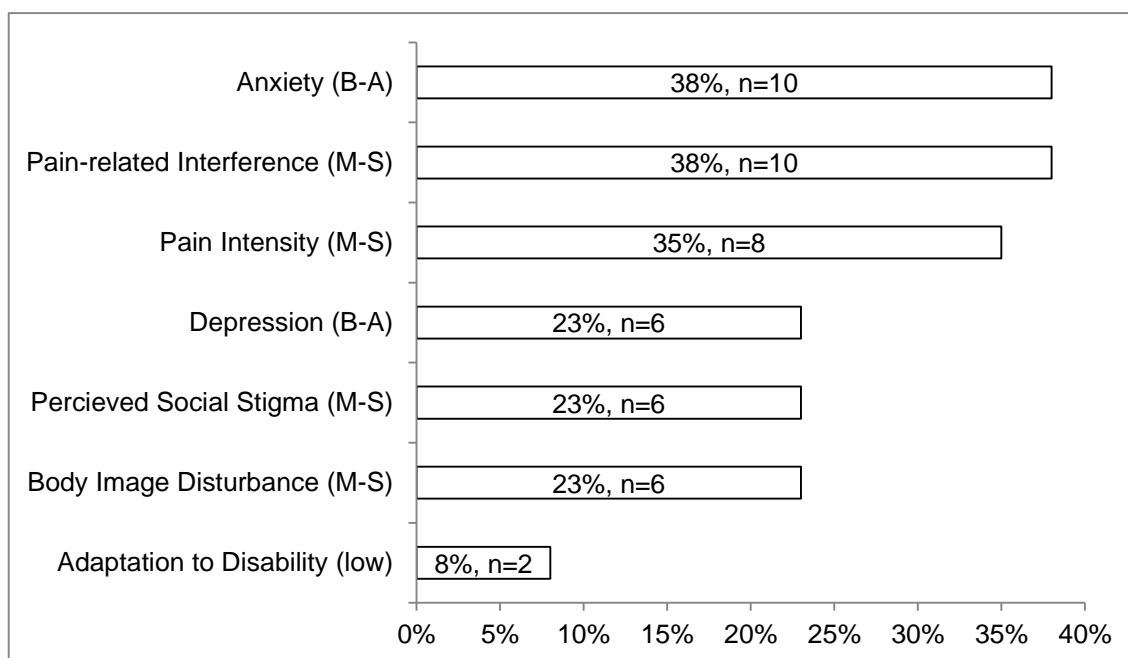
Table 7. *Spearman's Rank Order Correlations among the ADS-R Subscales and Total Score ($n = 26$)*

	1	2	3	4	5
1. Enlargement	—				
2. Subordination	.479*				
3. Containment	.804**	.364			
4. Transformation	.852**	.601**	.869**		
5. ADS-R Total Score	.893**	.643**	.898**	.963**	—

Note. ADS-R = Adaptation to Disability Scale-Revised.

* $p < .05$. ** $p < .01$.

Overall 2 (8%) of the amputees indicated low levels of adaptation to disability; 6 (23%) reported body image concerns, perceived social stigma and depression. Moderate to severe pain intensity was prevalent amongst nine (35%) amputees. Ten (38 %) amputees depicted pain-related interference and anxiety as a major source of stress related to amputation. Figure 8 describes extent of amputation-associated stressors on amputees.



Note. M-S = Moderate to Severe; B-A = Borderline abnormal to Abnormal.

Figure 8. Frequencies and Comparisons of Amputation-Associated Stressors (n =26)

4.4.6 The Revised Dyadic Adjustment Scale (RDAS) Scores of Amputees and their Spouses

The RDAS was used to measure components of dyadic adjustment in the amputees and their spouses and to explore if there was a relationship between amputation-associated stressors and dyadic adjustment. RDAS was administered to both amputees and their spouses. Scores on each subscale were summed and total RDAS scores were obtained separately for amputees and spouses.

Amputee and spouse's overall dyadic adjustment scores were significantly positively correlated ($r = .617, p < 0.01$). Significant positive correlations were also found between RDAS subscales. Amputee's consensus subscale was significantly positively correlated with spouse's satisfaction ($r = .405, p < 0.05$) and cohesion ($r = .394, p < 0.05$)

subscales. However, there tended to be a lower association ($r = .382$, $p = 0.054$) between amputee's consensus subscale and spouse's consensus subscale. The amputee's satisfaction subscale was significantly positively correlated with all of the spouse's subscales: consensus ($r = .550$, $p < 0.01$), satisfaction ($r = .622$, $p < 0.01$) and cohesion ($r = .581$, $p < 0.01$). The amputee's cohesion subscale was significantly positively correlated with the spouse's consensus ($r = .542$, $p < 0.01$) and cohesion ($r = .473$, $p < 0.05$) subscales. However, there was a lower association ($r = .383$, $p = 0.058$) between the amputee's cohesion subscale and the spouse's satisfaction subscale. Table 8 presents Spearman's rank order correlations among the RDAS subscales and total scores for amputees and spouses of the RDAS subscales between amputees and spouses.

Overall, 8 (30.8%) amputees were distressed in their dyadic relationship and 9 (34.6 %) spouses reported significant levels of distress within their relationship. On the RDAS subscale consensus, 9 (34.6%) amputees indicated distress and ten (38.5%) spouses showed distress. Six (23.1%) amputees and 7 (26.9%) spouses reported dissatisfaction in their relationship on the RDAS subscale satisfaction. Distressed dyadic cohesion was also stated by 10 (38.5%) amputees and 11 (42.3%) spouses. Figure 9 displays comparison of amputees and spouses' perception of distressed relationship as reported on the RDAS subscales and overall adjustment scores.

Table 8. *Spearman's Rank Order Correlations among the RDAS Subscales and Total Scores for Amputees and Spouses*

	1	1a	1b	1c	2	2a	2b	2c
1. RDAS-A-TS	—							
1a. Consensus	.886**							
1b. Satisfaction	.843**	.694**						
1c. Cohesion	.886**	.635**	.636**					
2. RDAS-S-TS	.617**	.414*	.636**	.578**				
2a. Consensus	.566**	.382	.550**	.542**	.932**			
3b .Satisfaction	.517**	.405*	.622**	.383	.795**	.689**		
4c. Cohesion	.542**	.394	.581**	.473*	.884**	.730**	.609**	—

Note. ; RDAS-A-TS = Revised Dyadic adjustment Scale-Amputee-Total Score; RDAS-S-TS = Revised Dyadic adjustment Scale-Spouse-Total Score.

* $p < .05$. ** $p < .01$.

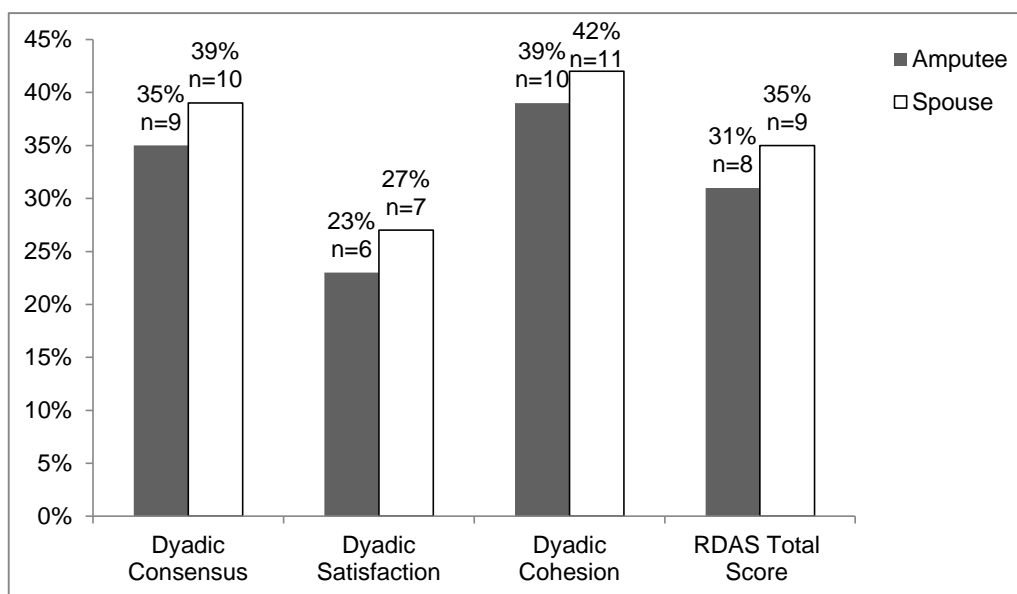


Figure 9. Frequencies and Comparisons of Couple's Perceptions of Relationships on the RDAS and its Subscales (n =26 dyads)

In terms of dyadic adjustment, anxiety was statistically significantly negatively correlated with the amputees' RDAS subscales consensus ($r = .492, p < 0.05$) and cohesion ($r = .458, p < 0.05$), which indicated anxiety increased as consensus and cohesion decreased. The spouses' RDAS subscale cohesion was negatively correlated with amputee's pain-related interference (BPI subscale) ($r = .447, p < 0.05$). The spouses' RDAS subscale satisfaction was negatively correlated with amputee's HADS-D ($r = .404, p < 0.05$) and pain-related interference (BPI subscale) ($r = .627, p < 0.01$) indicating spouses' satisfaction, frequency and intensity of conflicts, and desire to stay together decreased as the amputees' depression and pain-related interference scores increased.

The spouses' RDAS subscale cohesion was positively correlated with the ADS-R overall scores ($r = .410, p < 0.05$) and subscale containment ($r = .516, p < 0.01$). The RDAS subscale satisfaction was positively correlated with the ADS-R subscale containment ($r = .460, p < 0.05$), and the RDAS subscale consensus was positively correlated with the ADS-R subscale containment ($r = .421, p < 0.05$) and enlargement ($r = .396, p < 0.05$). Spearman's rank order correlations among all the measurement scales are shown in Table 6.

4.5 Section Three: Association between RDAS and Demographic Variables

To answer the secondary research question, is there a relationship between dyadic adjustment, age and sex of amputees and spouses, and length of relationship, the Spearman's rank order correlation analysis was used to assess the relationships between variables. The Mann Whitney U test was used to explore differences between sex and dyadic adjustment. The results of the Spearman's rank order correlations analysis revealed there was no statistically significant correlation between amputee's and spouse's age, length of relationship and the RDAS overall adjustment scores. There were also no statistically significant correlations between RDAS subscales for amputees and spouses except in the amputee cohesion subscale. Here, a significant positive correlation between the amputee's RDAS cohesion subscale with the spouse's age ($r = .407, p < 0.05$) and length of relationship ($r = .400, p < 0.05$) was revealed. These results indicated that an amputee's ability to engage in positive interactions increased as the length of dyadic relationship and the age of the spouse increased.

To determine if males and females differed in their assessment of dyadic adjustment, a Mann Whitney U test was done. Results revealed there were no statically

significant differences between males and females in RDAS subscale scores; consensus ($p = 0.659$), satisfaction ($p = 0.888$), and cohesion ($p = 0.632$) and total score ($p = 0.667$) for amputees and spouses. These results are shown in Table 9.

Table 9. *The Mann Whitney U Test Results for Sex and Dyadic Adjustment (n = 52)*

	Sex	n	Mean Rank	Sum of Ranks	Mann Whitney U Test	Asymp. Sig. (2-tailed)
Consensus	Male	26	27.42	713.00	314.000	-.441
	Female	26	25.58	665.00		.659
	Total	52				
Satisfaction	Male	26	26.21	681.50	330.500	-.141
	Female	26	26.79	696.50		.888
	Total	52				
Cohesion	Male	26	27.50	715.00	312.000	-.479
	Female	26	25.50	663.00		.632
	Total	52				
RDAS-TS	Male	26	27.40	712.50	314.500	-.431
	Female	26	25.60	665.50		.667
	Total	52				

Note: RDAS-TS = Revised Dyadic adjustment Scale-Total Score

4.6 Summary

In relation to the primary research question regarding relationships between amputation-related stressors and dyadic adjustment, the most common amputation-associated stressors reported by the amputees were pain-related interference and anxiety. The majority of couples appeared to be well-adjusted overall, with non-distressed relationships. Anxiety did however negatively affect dyadic adjustment in the amputees, especially altering the amputee's consensual activities and positive interactions with their

spouses. Spouses' perceptions of satisfaction within the dyadic relationship and cohesion and consensual abilities were also decreased by the amputee's increased perception of pain-related interference, anxiety and depression.

The secondary research question was regarding the relationships between dyadic adjustment and demographic variables. There was a significant positive relationship between the dyadic adjustment of amputees, especially in the cohesion subscale, and spouses' age and length of relationship. There was no statistical significance found between any of the demographic variables and dyadic adjustment of spouses.

The dyadic relationship in amputees appeared to be negatively correlated with their anxiety, whereas spouses' dyadic adjustment decreased with higher scores of amputee's pain-related interference and depression. Age and length of relationship positively correlates with dyadic adjustment in amputees. In contrast, there was no relationship found between spousal dyadic adjustment and demographic variables.

Chapter Five: Discussion and Conclusion

5.1 Introduction

In chapter five the study findings will be summarized, conclusions that can be drawn from the results presented, and limitations and implications for practice discussed.

The results of the study supported amputation as a dyadic stress and amputation-associated stressors as negatively affecting dyadic relationships. Stressors that cause distress in the relationship for one spouse can also have a negative effect on the other spouse. The stressors causing distress in a relationship differed for amputees and spouses, the amputation-associated stressors decreased their consensuses, satisfaction and cohesion within the relationship. Anxiety was found to be the most significant stressor that decreased an amputee's ability to agree with their spouse on major decisions such as career and religion. It also reduced the degree to which amputees shared common interests and compassionate activities with their spouses.

Spousal perception of dyadic adjustment was decreased by the amputee's perception of pain-related interference and depression; this mainly reduced spousal ability to participate in mutual dyadic activities and their desire to stay within the relationship. However, an amputee's high acceptance of disability was also shown to have positive effects on spousal dyadic adjustment.

Dyadic adjustment is a complex phenomenon and there are many other factors that can positively and negatively affect the relationship. For example, based on the study results, as the age and length of relationship increased, dyadic adjustment increased. However, there was no statistically significant difference between sex and dyadic adjustment found, possibly due to small sample size.

5.2 Amputation-Associated Stressors

Separate amputation-associated stressors that were studied in this research are discussed in detail below for amputees and spouses in relation to the findings and the literature.

5.2.1 Anxiety and Depression

Anxiety and depression in amputees was evaluated using HADS subscales: HADS-A (anxiety) and HADS-D (depression). Anxiety (38%) was one of the most prevalent amputation-associated stressors found in amputees who participated in this study, while depression was prevalent in 23% of amputees. These results were comparatively higher than the normative values for anxiety (12.6%) and depression rates (3.6%) found in the general adult population, as provided by Crawford, Henry and Taylor (2001). Anxiety in this study was also slightly higher than the reported anxiety levels in other amputation-related studies. For example Hawamdeh et al. (2008) reported anxiety rates of 24% in a study examining 56 unilateral lower limb amputees from Jordan. Singh et al. reported anxiety rates of up to 37% in a study in which anxiety was measured in a sample of 105 lower limb amputees from rehabilitation ward. In relation to depression, the findings were similar to other studies (Atherton & Robertson, 2006; Darnall et al., 2005; Dunn, 1996; Hanley et al., 2004; Wald & Alvaro, 2004). For example Darnall et al., (2005) reported a 28.7% rate of depression post-amputation, similar to the x% found in this study.

Crawford et al. (2001) cautioned that anxiety and depression results can be positively skewed in the presence of other health conditions. In this study, more than half the amputees had other medical conditions such as cardiac, lung and bone diseases. The

amputation and presence of other chronic conditions can help explain anxiety and depression levels in present study. Singh et al. (2009) described a significant positive relationship ($p < 0.002$) between depression and having comorbidities. Darnall et al. (2005) further revealed that having one condition significantly ($p < 0.007$) increased the risk of depressive symptoms in amputees and having two or more conditions posed an even greater risk ($p < 0.001$).

Numerous factors, including age, sex, level of education, type of work and financial status can contribute to anxiety and depressive symptoms in the general population (Christensen et al., 1999; McLean & Anderson, 2009; Mirowsky & Ross, 1992). In amputees, anxiety and depression can be aggravated by repeated hospitalizations for stump revisions, rehabilitation, amputation-related pain, body image concerns, perceived social stigma, and prosthesis fitting, refitting and follow-ups (Coffey et al., 2009; Dunn, 1996; Hawamdeh et al., 2008; Horgan & MacLachlan, 2004; Singh et al., 2007).

Body image disturbance was significantly linked with anxiety ($r = .574$, $p < 0.01$), and depression ($r = .490$, $p < 0.05$). These findings support the results of Horgan and MacLachlan's (2004) literature review of studies from 1945-2004 on psychological adjustment to amputation, and Coffey et al. (2009) who studied diabetes-related lower limb amputees. These researchers also revealed body image disturbance was significantly negatively related to activity restriction, anxiety and depression in amputees.

A positive relationship between pain-related interference and anxiety ($r = .494$, $p < 0.05$), and depression ($r = .745$, $p < 0.05$) was also found. This finding supports the work of Arola, Nicholls, Mallen, and Thomas (2010), who studied community-dwelling

adults (age >50 years) for 3 years. These researchers found pain-related interference over time was a risk factor for developing anxiety and depression at three year follow-up.

These findings suggest that body image disturbance and pain-induced interference may be risk factors for psychological distress (anxiety and depression) in amputees.

5.2.2 Perceived Social Stigma and Altered Body Image

Perceived social stigma and altered body image in amputees was evaluated using PSSS and ABIS scales respectively. Twenty-three percent of amputees reported perceived social stigma and 23% also indicated body image concerns. Perceived social stigma is intertwined with body image as both are based on perception of others and could also be related to altered body image (Rybarczyk & Bhel, 2008; Varni & Setoguchi, 1996).

Perceived social stigma and altered body image can be affected by demographic and amputation variables such as age, sex, type and level of amputation (Williamson, 1995). However, in this study, the analysis was only conducted between perceived social stigma, body image disturbance, and other identified amputation-associated stressors. Perceived social stigma and altered body image was significantly positively correlated ($r = .567, p < 0.01$).

Rybarczyk et al. (1995) revealed perceived social stigma and altered body image as independent predictors of depression in amputees. Similarly, altered body image was not only related to depression ($r = .490, p < 0.05$) but also to anxiety ($r = .574, p < 0.01$) and pain-related interference ($r = .511, p < 0.01$) in this study. However, there was no statistically significant relationship ($r = .315, p = 0.117$) found between perceived social stigma and depression or any other identified amputation-associated stressors.

The non-statistically significant results of perceived social stigma could potentially be explained in three ways. First, it may be the sample size was not large enough to yield any statistically significant results for perceived social stigma. Second, 46 % of the sample was from AASRA, an organization that promotes sports in amputees, and the lack of perceived social stigma may reflect a biased sample selection. Most AASRA member amputees participate in some kind of sports and receive encouragement through prizes and medals. Positive sport experiences aid in reducing perceived social stigma by enhancing self-concept and self-esteem (Shephard, 1991; Sporer et al., 2009; Vanderstraeten & Oomen, 2010). Perceived social stigma is related to societal attitudes towards disability and participation in sports supports adaptation to disability. Third, use of prosthesis helps in reducing disability-related restrictions and supports the maximum level of functioning possible; in this study 84.6% of amputees were using prosthesis.

Body image disturbance in the present study was significantly positively associated with anxiety ($r = .574$, $p < 0.01$), and depression ($r = .490$, $p < 0.05$). These findings are supported by Breakey (1997a) and Coffey et al. (2009) who studied traumatic lower limb amputees and diabetes-related amputees respectively. They explained if amputees found it difficult to accept their new body image, they could end up suffering from chronic anxiety and depression.

Altered body image was also significantly positively related to pain-induced interference ($r = .511$, $p < 0.01$). These findings support the research conducted by Deusen, (1996), Pucher, Kicking, and Frischenschlager (1999) and Wetterhahn et al. (2002). They explained a distorted self-image interferes with the movements necessary to perform activities, as motor activity is affected by somatosensory processing of the

brain. It is also related to increased frequency of phantom limb pain, less functional abilities and poor rehabilitation outcomes.

Pain intensity and related interference in amputees was evaluated by using the BPI subscales: pain intensity and pain interference. Pain intensity (35%) was the second most common stressor identified by the amputees, with the majority of amputees experiencing one or more type of pain; PLP being the most common type of pain reported. These findings are similar to those of other researchers studying amputation-related pain (Chahine & Kanazi, 2007; Cohen et al., 2011; Desmond & MacLachlan, 2010; Giummarra et al., 2007; Hanley et al., 2009). Researchers also reported significant positive correlations between amputation-related pain, anxiety and depression (Fisher & Hanspal, 1998; Henly et al., 2004; Marshall et al., 2002). However, the pain intensity subscale in this study did not yield statistical significant relationships with any other identified amputation-related stressors. One notable finding of the BPI subscales was that while 85% (n = 22) of amputees experienced mild to severe pain intensity, pain-related interference was reported by only 69% (n = 18), and only 50% (n = 13) took measures to relieve pain. This may mean that pain for amputees is not always interfering and with time some amputees may learn to live with it.

Pain-related interference (38%) was one of the most common stressors reported by amputees, and the most commonly affected areas were their normal work and walking abilities as reported by 56% of the participants. The majority of participants were lower limb amputees and amputation-related pain may have been seen to be interfering with their walking abilities and performance of their daily work routine. Desmond and MacLachlan (2010) also found significant positive association between lifestyle

interference and PLP ($p < 0.001$) whereas Hanley et al. (2009) suggested that pain in the non-amputated-limb caused the highest levels of pain-related interference (mean 4.2) and disability days (mean 18.4). In the study sample PLP (68.2%) was more prevalent than non-amputated limb pain (31.8%). However, due to the small sample size and nature of correlational study design it is difficult to conclude which pain caused more interference. Correlational studies do not infer a cause and effect relationship, simply that there is a relationship.

5.2.3 Adaptation to Disability

Adaptation to amputation-related disability was evaluated by ADS-R overall and subscales scores. Adaptation to disability can be affected by several factors such as age, sex, age at the time of amputation, site and level of amputation, extent of disability, use of prosthesis and prosthesis-related issues such as fitting, refitting, and prosthesis induced-pain (Breakey, 1997a; Schaffalitzky et al., 2010; Wright, 1983).

The majority of amputees in this sample appeared to be well adjusted with respect to their disability. The amputees were primarily male prosthesis users. Being male and satisfactorily using prosthesis has been shown to be associated with better adaptation to disability as shown by other researchers (Murray 2008; Murray & Fox, 2002; Nicholas et al., 1993). While satisfaction with prosthesis was not assessed in this study, use of prosthesis does allow greater control over a disability and improves overall functioning such as activities of daily living, normal work, and leisure activities.

Adaptation to disability was however, negatively associated with other identified stressors such as perceived social stigma ($r = .551$, $p < 0.01$), anxiety ($r = .431$, $p < 0.05$), depression ($r = .522$, $p < 0.01$), pain intensity ($r = .589$, $p < 0.01$) and pain-related

interference ($r = .635$, $p < 0.01$). These study findings also support those reported by Dunn (1996) and Moore (1998). Dunn (1996) examined 138 amputees and found negative associations between perceived control over disability and depression. Moore (1998), in a study of 1,266 adults with disabilities also found a negative relationship between adaptation to disability and perceived social stigma. However, Almagor et al. (1978) did not find any statistically significant correlation between phantom limb phenomenon (including PLP) and acceptance of disability. Based on this study results, the importance of adaptation to disability may have a buffering effect against other amputation-associated stressors such as perceived social stigma, anxiety, depression, pain intensity and pain-related interference.

As mentioned earlier, 46% of the sample was drawn from AASRA, an organization that promotes sports in amputees. Dunn (1996) studied members of the Eastern Amputee Golf Association (EAGA), an amputee association that promotes golf in amputees and encourages their participation through prizes, awards and medals (<http://www.eaga.org>). Dunn (1996) found the majority of participants were able to find positive meaning in their lives, had low depression rates, high self-esteem and greater control over their disability. Spörner et al. (2009) also found participation in sports was related to a higher acceptance of disability and increased mobility. They studied 132 physically disabled participants from the National Veterans Wheelchair Games and the Winter Sports Clinic in USA. Shephard (1991), and Vanderstraeten and Oomen (2010) mentioned two types of benefits, psychological and sociological, of sports for physically disabled people. Psychological advantages include reduced anxiety and depression, improved mood, increased self-esteem and self-efficacy. Sociological gains include

reduced perceived social stigma, improved socialization and increased productivity.

Thus, a possible explanation of these positively skewed results in this study could be that the majority of the amputees were male, prosthesis users, with nearly half of the overall sample involved in some kind of sports-related activities.

5.3 Amputation-Associated Stressors and Dyadic Adjustment of Amputees

5.3.1 Anxiety

Overall the most common amputation-associated stressors for amputees were anxiety, pain intensity and related interference. However, in relation to dyadic adjustment, amputee anxiety was found to be the most influencing factor in this study. Anxiety was shown to affect overall dyadic adjustment ($r = .504, p < 0.01$) especially consensus ($r = .492, p < 0.05$) and cohesion ($r = .458, p < 0.05$) abilities of amputees within the relationship.

Consensus in dyadic adjustment refers to agreement on decision making, religious values, conventionality, affectional expression, and sex relations. Dyadic cohesion entails spending time and enjoying activities together such as working together on a project, exchange of stimulating ideas, and outdoor activities. Tavallai et al. (2009) studied dyadic adjustment in healthy controls and patients with long term hemodialysis using HADS and RDAS. They found that compared to healthy participants, patient's anxiety affected their overall dyadic adjustment and especially affected their satisfaction in their relationship. Baucom and Epstein (1990) asserted anxiety has a bidirectional relationship to dyadic functioning. Anxiety can distress a dyadic relationship and a distressed dyadic relationship can elicit anxiety symptoms. Dehle and Weiss (2002) stated anxiety creates a feeling of apprehension, nervousness, fluctuating mood, and

inability to relax that can affect day to day dyadic interactions and affectional expression in a dyadic relationship. Although inferences cannot be made based on this study, preliminary findings suggest that anxiety can affect dyadic relationships and warrants further study.

5.4 Amputation-Associated Stressors and Dyadic Adjustment of Spouses

5.4.1 Pain-Related Interference

Pain-related interference in amputees was found to be the most dominant amputation-associated stressor negatively altering spouses' dyadic adjustment. Study results revealed overall dyadic adjustment ($r = .504, p < 0.01$) and especially spousal satisfaction within the relationship ($r = .627, p < 0.01$) and cohesion ($r = .447, p < 0.05$) were the most affected domains. One notable finding in this study that differs from other studies was that although amputee's pain-related interference was reducing dyadic adjustment in spouses, amputees' pain intensity had no statistically significant correlations with any of the subscales and total score of spouses' dyadic adjustment.

There is an abundance of research examining chronic pain variables and their effect on dyadic relationship variables such as adjustment, quality, and satisfaction. The most commonly assessed pain variables have been pain intensity, spousal responses towards pain behaviours, pain-related interference/pain-associated disability/pain-related activity limitations, and actual pain-related interference in chronic pain sufferers and spousal perceived (underestimated or overestimated) pain-related interference (Cano et al., 2004; Gauthier, Thibault, & Sullivan, 2008; Holtzman & DeLongis 2007; Newton-John & Williams 2006; Riemsma, Taal, & Rasker, 2000). Most researchers affirmed that chronic pain and related disability decreases dyadic satisfaction and adjustment due to

disturbed mood, feeling of helplessness, and depression in spouses (Holtzman & DeLongis, 2007; Pence et al., 2006; Stampfer et al., 1997; Reese, Somers, Keefe, Mosley-Williams & Lumley, 2010).

5.4.2 Depression

Depression in amputees was found to be significantly associated with diminished spouses' satisfaction within the relationship ($r = .404$, $p < 0.05$). This may indicate symptoms associated with depression, such as low mood, lack of energy/desire to participate in activities, apathy, and feelings of hopelessness/worthlessness in amputees can lead to depressive symptoms, poor mood, and lack of desire to stay together in spouses. It also affects spousal satisfaction through poor quality dyadic interactions, and increased frequency of dyadic discord. Researchers have found negative associations between depression and dyadic relationship variables, especially dyadic satisfaction (Bakker et al., 2009; Flor, Turk, & Scholz, 1987; Gorgievski-Duijvesteijn et al., 2000; Howe et al., 2004; Rowat & Knafl, 1985) and this is consistent with this study.

5.4.3 Adaptation to Disability

An amputee's high adaptation to disability was associated with better dyadic adjustment in spouses. There was a strong significant positive association found between high adaptation to disability in amputees, especially during containment phase, and spouses' consensus ($r = .421$, $p < 0.05$), satisfaction ($r = .460$, $p < 0.05$) and cohesion ($r = .516$, $p < 0.01$) domain of dyadic adjustment. These results suggest a spouse's ability to participate in positive interactions and activities with an amputee, and the perception of satisfaction in a dyadic relationship is enhanced when an amputee starts to see disability as it is and does not allow this to interfere with other aspects of life.

There may be a bidirectional relationship between adaptation to disability and marriage. Moore (1998) studied 1266 adults with physical disabilities and found being married was associated with high adaptation to disability. Mancini and Bonanno (2006) indicated well-adjusted dyadic relationships led to high adaptation to disability when they studied 1,532 older married couples using a modified version of dyadic adjustment scale. In the study sample, the majority of couples were well-adjusted within their relationship. This may have supported the amputees in achieving high adaptation to disability.

In short, amputees' perception of dyadic adjustment was negatively affected by amputees' anxiety, whereas spouses' dyadic adjustment, especially satisfaction, within the relationship was decreased by two amputation-associated stressors: amputee's pain-related interference and depression. High adaptation to disability in the amputees was related to enhanced dyadic adjustment in the spouses.

These findings can be explained by transactional model of stress Lazarus and Folkman 1984. If either partner perceives amputation as a threatening or challenging situation they enter into secondary appraisal, which is the evaluation of available resources such as physical capabilities, spouse, family, friends, self-esteem and self-efficacy. If partners feel that resources are not enough to adjust to the situation, the situation turns into negative stress, whereas if the partners feel resources are enough, the situation turns into positive stress. Amputation-associated stressors such as anxiety, depression and pain-related interference may lead to decreased physical capabilities and low self-esteem in amputees, thus affecting the perception of dyadic relationship in a negative way for both partners. On the other hand, high adaptation to disability is related to limiting the effect of disability as it is and finding positive meaning in life. This

affects both partners in a positive way and supports the perception of a well-adjusted dyadic relationship. It was evident that an amputee's adaptation to disability appeared to support the spouse's desire to stay within the relationship and was associated with fewer conflicts. There is also a possibility that the dyadic relationships in this study were distressed before amputation and amputation-associated depression and pain-related interference aggravated spousal responses negatively.

5.5 Dyadic Adjustment and Demographic Variables

The secondary research question, in which the relationship between demographic variables and dyadic adjustment was examined, yielded few statistically significant associations. The significant positive relationships found were between amputee's cohesion, spouse's age ($r = .407, p < 0.05$) and length of relationship ($r = .400, p < 0.05$). This is consistent with other studies (Hatch & Bulcroft, 2004; Henry et al., 2007; Johnson et al., 1986; Levenson et al., 1993; Rook et al., 2007) demonstrating that as age and length of relationship increases, most couples develop similar interests, mutual friends and social activities that enhance cohesion between spouses. Moreover, as age and length of relationship increase, children, family and work responsibilities decrease and couples find more time to spend with each other.

One notable finding in this study was that increased spouses' age and length of relationship appeared to enhance amputees' perceptions of cohesion but not spouses' perceptions. Possibly, due to pain or amputation-related disability, amputees had more time to spend at home or found more time to engage in activities together. Spouses, due to caregiver role strain and possibly financial constraints, could not find a similar amount of time and energy to participate in activities together. As evident from the demographic

data nearly half of the amputees were retired, unemployed or studying, whereas none of the spouses were retired, unemployed or studying and comparatively more spouses were working full time than amputees.

5.6 Limitations of the Study

The present study has certain limitations that need to be taken into account when considering the results and contributions of the study to amputation and dyadic adjustment.

Due to time constraints, the study was conducted using a small convenience sample; conducting the study over a longer period of time would have allowed recruitment of a larger sample more representative of the overall amputee population, As having a partner was the critical inclusion criterion, being a single, divorced, or widowed amputee further decreased the recruitment rates. Recruiting couples for a study is far more challenging than recruiting individuals, often related to the availability and willingness of both the partners to participate. Researchers have shared these concerns and have suggested recruitment strategies such as limiting exclusion criteria, incentives to participate, and decreasing research burden might increase recruitment rates (Hill, Rubin, Peplau, & Willard 1979; Karney et al., 1995; Voils et al., 2011; Wampler 1982).

Convenience sampling can also bring some biases to the study that may account for limitations. These include:

- a) Selection or sampling bias: the most common issue in convenience sampling is that the selection of the sample is not random but is based on the researcher's judgment and feasibility of recruiting participants. Therefore, in this study the convenience sample may not have been representative of the entire population

and led to under-representation or over-representation (AASRA participants) of particular groups within the sample. Selection or sampling bias can be a result of other biases such as omission bias and inclusion bias.

- b) Omission bias occurs when a researcher omits a group from the sample. In this study, there was no omission bias as researchers did not exclude any group.
- c) Inclusion bias occurs when a researcher deliberately includes a group in the sample. This is common in convenience sampling as those groups that are more willing to participate are included in the study. This may skew the results as the sample group may have a narrow demographic range or distinct characteristics and may not be representative of the population.

The survey method itself contains certain inherent limitations including response set biases, incorrect answers and lack of verification of answers. Response set biases include: a) social desirability set bias: a respondent tendency to answer in a socially desirable manner; b) extreme response set bias: a respondent tendency to express feeling/attitudes in extreme responses such strongly agree or strongly disagree; c) acquiescence response set bias: a respondent tendency to agree (yea-sayers) or disagree (nay-sayers) regardless of content. Instruments with negative and positive answers can aid in reducing these biases (Lobiondo-Wood & Haber, 2009; Polit & Beck, 2006) and the instruments used for this study did have positive and negative responses build into the items.

The student researcher knew some of the participants on a personal and professional level thus increasing the probability that some respondents might have answered on the basis of social desirability, and some might have answered incorrectly to

hide their identity. To minimize this, confidentiality and privacy was reinforced in every step of research as suggested by Polit and Beck (2006). Moreover, this study sample is based in only one province of Canada which can affect its generalizability. In addition, most study participants were Caucasian and thus not a true reflection of Canadian multicultural society. Therefore, research studies with a much larger national, multiethnic sample would be required to ensure generalization of the findings.

Another limitation could be related to the 7 potential couples that either did not complete or return the instruments. This indicates there may be a difference between the couples who returned the completed packages and those couples who did not. This might have implications to amputation-associated stressors and dyadic adjustment as data obtained from these potential participants may have impacted the study results. Possible explanations for not returning the completed instruments may have included:

- a) Answering the questions in instruments may have provoked or acknowledged certain feelings that the person might not be willing to or be able to accept at that point in time.
- b) Their dyadic relationship status might have changed since receiving the packages as indicated by one of the potential participants.
- c) Potential participants may not have found the study important or were too busy to find time to complete the instruments.

5.7 Implications for Practice

Based on the results of this research, having a chronic condition appears to negatively affect the dyadic relationship, a belief substantiated by research results reported in the literature on other chronic conditions and dyadic relationship variables

(Anderson & Valentine, 1998; Karney & Crown, 2007; Karney et al., 2005; Story & Bradbury, 2004; Strawbridge et al., 2007; Wallhagen et al., 2004). For example, Tavallaii et al. (2009) compared dyadic adjustment between healthy participants and patients on long term hemodialysis. They found the RDAS total score ($p < 0.001$) and its subscales ($p < 0.05$) indicated significant distress in the individuals with the chronic condition than in healthy participants. This study also indicated that more than one fourth of the participants were distressed within their relationships, thus may benefit from professional support in order to attain dyadic adjustment within their relationship. These study findings have important implications to health care professionals in terms of moving to relational family health practices, available educational support in inpatient and outpatient facilities, and research initiatives involving both the spouses.

Health care practitioners as a part of a helping profession possess the power to make a profound difference in an individual and couple's health and healing experiences. However, they sometimes fail to recognize this opportunity by focusing solely on patient's adjustment to disease while leaving their partners, who share their disease burden and can be a great support in adjusting to the disease, behind (Ekberg, Griffith, & Foxall, 1986; Savundranayagam & Orange, 2011; Ward-Griffin & McKeever, 2000). This study endorses student investigator's belief that amputation is a dyadic event that leads to dyadic stress. Sources of stress can differ in amputees and spouses, but they both experience amputation-associated stressors of some kind.

This study supports the need for health care practitioners, including nurses, to work within relational family health practice framework. In this context, human experiences are dynamically connected to their relations and family relationships have

significant effects on health and healing experiences of an individual (Anderson, 2000; Anderson & Tomlinson 1992; Smith & Friedemann, 1999). Relational family health practices guide health care practitioners in supporting family relationships, such as the spousal relationship, through caring conversations and providing knowledge around what to expect and how to deal with it. This support will enable families, especially spouses, to be a continuous at-home support for amputees, thereby enhancing an amputee's ability to adjust to amputation-associated stressors.

Support from spouses have been shown to contribute in improving the medical outcomes in high-risk populations, and reducing the rate of adverse stress responses, premature death, depression, mental illness, and chronic disability (Gardner & Oswald, 2004; Kiecolt-Glaser & Newton, 2001; Mirolla, 2004). Supporting distressed relationships during difficult times of their lives may ultimately result in decreased readmissions and prevent depletion of resources at the system level. This support from health care practitioners may enhance a couple's ability to buffer each other against negative outcomes of a chronic condition (Gardner & Oswald, 2004; Gove, 1973; House et al., 1982; Murray, 2000; Story & Bradbury, 2004). Health care practitioners working within this framework can better support non-distressed couples in maintaining, and distressed couples in achieving their relationship adjustment by constantly assessing, not only amputees but also their spouses, for any sign of distress.

Sometimes spouses feel ashamed or embarrassed to share their feelings with health team members (Ekberg, Griffith, & Foxall, 1986; Savundranayagam & Orange, 2011; Ward-Griffin & McKeever, 2000). Health care professionals can take the initiative in asking relationship questions and in building therapeutic relationships with patients

and their spouses during inpatient and outpatient follow-up visits. Several communication strategies, such as openness, active listening, paraphrasing, caring conversations, and questioning, are mentioned in the literature as being helpful in allowing nurses to explore a couple's relationship (Doane & Varcoe, 2005; Hartrick, 1997; Jonsdottir, Litchfield, & Pharris, 2004; Schneider & Fake 2010). Through these strategies health care practitioners enter into a relationship in a meaningful way, critically analyze family priorities and incorporate their knowledge and expertise to develop a mutual plan of care (Doane & Varcoe 2007).

Identifying amputation-associated stressors for both amputees and their spouses is an initial step in planning supportive interventions for these couples. These may include arranging workshops around common amputation-associated stressors, the trajectory of amputation, and stress management. Providing available information to new amputees on support groups, recreational activities for the disabled, disability benefits, provincial and national programs that can support these couples financially, and couple's counselling can positively support these couples in their struggle of attaining dyadic adjustment.

The investigators provide a beginning framework for other researchers interested in supporting couples dealing with a partner's chronic condition. Researching an amputee's adjustment is not enough; involving spouses in research is also an important consideration in attaining an overall picture of dyadic relationship. It is suggested that future studies should involve spouses in research initiatives involving patients with chronic conditions.

5.8 Recommendations for Future Research

The methodologies used in this study may not accurately reflect the true picture of dyadic adjustment due to the small, primarily Caucasian male convenience sample. Replication of this study, using quota sampling to enable a larger multiethnic and more balanced sex-based sample may depict a more complete picture of dyadic adjustment. Comparison of amputee couples with healthy controls may also support the notion of identifying stressors unique to amputation. Research designed to evaluate couple-based interventions for distressed couples can add valuable information to evidence based practice.

In future, a mixed method study of dyadic adjustment post-amputation could be designed to enhance and broaden the understanding of the phenomenon using both quantitative and qualitative methods. Quantitative studies focus on discrete aspects of experience; adding a qualitative component would bring an emphasis to the wholeness of experience thus providing deeper insight into this complex and multifaceted human experience (Polkinghorne, 2005).

5.9 Summary

In this chapter the results of the study findings for amputees and their spouses, study limitations and recommendations for future research initiatives were discussed.

Dyadic adjustment in relation to amputation-associated stressors and demographic variables of amputees and spouses using a correlational survey method were explored. Results indicated the most common amputation-associated stressors for amputees were anxiety, pain intensity and related interference. However, anxiety was the only stressor identified as negatively affecting an amputee's dyadic adjustment within the relationship.

The amputee's depression and pain-related interference were the most challenging stressors for spouses in order to maintain or attain dyadic adjustment while high adaptation to disability in amputees was positively associated with spouses' dyadic adjustment. The spouse's age and length of relationship was positively associated with amputee's dyadic adjustment whereas there was no statistically significant difference found between sex and dyadic adjustment.

Amputation affects both spouses and their adjustment within the relationship. The extent and sources of stress may differ between spouses but they both experience some type of amputation-associated stressors. Any assessment, intervention or research initiative of an individual living with a chronic condition is incomplete without also assessing spousal involvement in the adjustment process, when appropriate.

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APPENDIX A: AMPUTEE DEMOGRAPHIC FORM

Demographic Form (Amputee)

Please circle the appropriate answers

First name _____ **Last name** _____ **Study ID:** _____

Gender: 1) Male 2) Female **Preferred contact:** 1) Phone 2) Email 3) Mail

Phone #: _____ **Email:** _____

Address (if preferred contact is mailing) _____

_____ **City** _____ **Province** _____ **Postal code** _____

DOB: yyyy/mo/d **Current age:** _____ **Age at the time of first amputation:** _____

Level of education:

- | | |
|------------------------|------------------------|
| 1) High school or less | 2) College |
| 3) University | 4) Professional degree |

Ethnicity:

- | | |
|---------------------|---------------------------|
| 1) African American | 2) Caucasian |
| 3) Hispanic | 4) Native American |
| 5) Asian | 6) Other (Please specify) |

Employment/Finances:

- | | |
|--|----------------------|
| 1) Working full time | 2) Working part-time |
| 3) Unemployed due to amputation/caregiver role | 4) Homemakers |
| 5) Retired | 6) Studying |
| 7) Disabled benefits / old-age pension | |

Before amputation who was contributing more financially: 1) Amputee 2) Spouse

Are you 1) Married 2) Partnered

Length of relationship: _____ **Number of children:** _____

Relationship started: 1) Before amputation 2) After amputation

Previous marriages/common in law relationships: 1) Yes 2) No

If yes please answer the following:

Length of relationship: _____

Relationship started: 1) Before amputation 2) After amputation

Relationship ended: 1) Before amputation 2) After amputation

Date/year of first amputation: yyyy/mo/d **Any subsequent amputations:** 1) Yes 2) No

If yes please answer the following:

Number of amputations: _____ **Date/year of most recent amputation:** yyyy/mo/d

(only applicable to amputees who had more than one amputation)

Site of amputation:

1) Upper 2) Lower 3) Both

Level of amputation:

1) Shoulder 2) Upper arm 3) Elbow 4) Lower arm 5)

Wrist

6) Other (please specify)

7) Pelvis 8) Hip 9) Above the knee 10) Below or through the knee

11) Ankle 12) Other (please specify)

Before amputation you were: (only applicable to upper limb amputees)

1) Right handed 2) Left handed

Reason for amputation:

1) Vascular disease 2) Diabetes

3) Cancer 4) Congenital

5) Trauma 6) Other (please specify)

Prosthesis:

1) Yes

2) No

Other health conditions:

1) High cholesterol

2) High blood pressure

3) Other (please specify)

APPENDIX B: SPOUSAL DEMOGRAPHIC FORM

Demographic Form (Spouse)

Please circle the appropriate answers

First name_____ **Last name**_____ **Study ID:**

Gender: 1) Male 2) Female **Preferred contact:** 1) Phone 2) Email 3) Mail

Phone #:_____ **Email: -**

Address (if preferred contact is mailing)

_____ **City**_____ **Province**_____ **Postal**

code_____

DOB: yyyy/mo/d **Age:** _____

Level of education:

1) High school or less

2) College

3) University

4) Professional degree

Ethnicity:

1) African American

2) Caucasian

3) Hispanic

4) Native American

5) Asian

6) Other (Please specify)

Employment/Finances:

1) Working full time

2) Working part-time

- 3) Unemployed due to amputation/caregiver role 4) Homemakers
5) Retired 6) Studying
7) Disabled benefits / old-age pension

Before amputation who was contributing more financially:

- 1) Amputee 2) Spouse

Are you: 1) Married 2) Partnered

Length of relationship: _____ **Number of children:** _____

Relationship started: 1) Before amputation 2) After amputation

APPENDIX C: THE HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS)

Hospital Anxiety and Depression Scale (HADS)

The questionnaire is design to help your clinician to know how you feel. Read each item below and underline the reply which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire. Do not take too long over your replies. Your immediate reaction to each item will probably be more accurate than a long thought-out response.

I feel tense or 'wound up:		I feel as if I am slowed down:	
3	Most of the time	Nearly all the time	3
2	A lot of the time	Very often	2
1	From time to time, occasionally	Sometimes	1
0	Not at all	Not at all	0
I still enjoy the things I used to enjoy:		I get a sort of frightened feeling like 'butterflies' in the stomach:	
0	Definitely as much	Not at all	0
1	Not quite so much	Occasionally	1
2	Only a little	Quite Often	2
3	Hardly at all	Very Often	3
I get a sort of frightened feeling as if something awful is about to happen:		I have lost interest in my appearance:	
3	Very definitely and quite badly	Definitely	3
2	Yes, but not too badly	I don't take as much care as I should	2
1	A little, but it doesn't worry me	I may not take quite as much care	1
0	Not at all	I take just as much care as ever	0
I can laugh and see the funny side of things:		I feel restless as I have to be on the move:	
0	As much as I always could	Very much indeed	3
1	Not quite so much now	Quite a lot	2
2	Definitely not so much now	Not very much	1
3	Not at all	Not at all	0
Worrying thoughts go through my mind:		I look forward with enjoyment to things:	
3	A great deal of the time	As much as I ever did	0
2	A lot of the time	Rather less than I used to	1
1	From time to time, but not too often	Definitely less than I used to	2
0	Only occasionally	Hardly at all	3

I feel cheerful:

- 3 Not at all
- 2 Not often
- 1 Sometimes
- 0 Most of the time

I can sit at ease and feel relaxed:

- 0 Definitely
- 1 Usually
- 2 Not Often
- 3 Not at all

I get sudden feelings of panic:

- 3 Very often indeed
- 2 Quite often
- 1 Not very often
- 0 Not at all

I can enjoy a good book or radio or TV program:

- 0 Often
- 1 Sometimes
- 2 Not often
- 3 Very seldom

APPENDIX D: THE PERCEIVED SOCIAL STIGMA SCALE (PSSS)

Perceived Social Stigma Scale

Please insert each attribute in the statement "*As a person with an amputation, others see me as...*", and rate the statement as either "not at all true" (1), "somewhat true" (2), "mostly true" (3), or "very much true" (4).

	Not At All	Somewhat	Mostly	Very Much
	True	True	True	True
1. Burden				
2. Different	1	2	3	4
3. Unhappy	1	2	3	4
4. Clumsy	1	2	3	4
5. Slow	1	2	3	4
6. Pitiful	1	2	3	4
7. Noticeable	1	2	3	4
8. Weird	1	2	3	4
9. Strange	1	2	3	4
10. Worthless	1	2	3	4
11. Dependent	1	2	3	4
12. Handicapped	1	2	3	4
13. Shameful	1	2	3	4
14. Defenseless	1	2	3	4
15. Intelligent	1	2	3	4
16. Attractive	1	2	3	4
17. Friendly	1	2	3	4
18. Worth Knowing	1	2	3	4
19. Confident	1	2	3	4
20. Normal	1	2	3	4
21. Healthy	1	2	3	4
22. Able-Bodied	1	2	3	4

Permission granted by Bruce Rybarczyk on September 5th, 2011 via email for the study "Stressors-Associated with Dyadic Relationship Stability Following Amputation.

Rybarczyk, B. D., Nyenhuis, D. L., Nicholas, J. J., Cash, S. M., & Kaiser, J. (1995). Body image, perceived social stigma, and the prediction of psychosocial adjustment to leg amputation. *Rehabilitation Psychology*, 40, 95-110.

APPENDIX E: THE AMPUTEE BODY IMAGE SCALE (ABIS)

Amputee Body Image Scale

This questionnaire is designed to measure how you see and feel about your body image. It is not a test so there are no right or wrong answers. Please answer each item as carefully and as accurately as you can by placing the appropriate number beside each question as follows:

1 = None of the time
2 = Rarely
3 = Some of the time

4 = Most of the time
5 = All of the time

1. _____ Because I am an amputee, I feel more anxious about my physical appearance in social situations than when I am alone.
2. _____ I avoid wearing shorts or short sleeves shirt in public because my prosthesis would be seen.
3. _____ I like my overall physical appearance when wearing my prosthesis.
4. _____ It concerns me that the loss of my limb impairs my body's functional capabilities in various activities of daily living.
5. _____ I avoid looking into a full-length mirror in order *not* to see my prosthesis.
6. _____ Because I am an amputee, I feel anxious about my physical appearance on a daily basis.
7. _____ I experience a phantom limb.
8. _____ Since losing my limb, it bothers me that I no longer conform to society's ideal of normal appearance.
9. _____ It concerns me that the loss of my limb impairs my ability to protect myself from harm.
10. _____ When I am *not* wearing my prosthesis, I avoid situations where my physical appearance can be evaluated by others (e.g., avoid social situations, swimming pool or beach activities, physical intimacy).
11. _____ The loss of my limb makes me think of myself as *disabled*.
12. _____ I like my physical appearance when *not* wearing my prosthesis.
13. _____ When I am walking, people notice my limp or stump.
14. _____ When I am wearing my prosthesis, I avoid situations where my physical appearance can be evaluated by others (e.g. avoid any social situations, swimming pool or beach activities, physical intimacy).
15. _____ People treat me as disabled.
16. _____ I like the appearance of my stump anatomy.
17. _____ I wear baggy clothing in an attempt to hide my prosthesis.
18. _____ I feel I must have four normal limbs to be physically attractive.
19. _____ It is important the size of my prosthesis and remaining anatomy of the affected limb are the same size as the other limb.

- 20._____ I avoid looking into a full-length mirror in order *not* to see my stump anatomy.

Permission granted by James Breakey on September 5th, 2011 via email for the study “Stressors-Associated with Dyadic Relationship Stability Following Amputation”.

Breakey, J. W. (1997). Body image: The lower-limb amputee. *Journal of Prosthetics & Orthotics*, 9(2), 58-66.

APPENDIX F: THE BRIEF PAIN INVENTORY (BPI)

STUDY ID #

HOSPITAL #

Brief Pain Inventory (Short Form)

Date.....

Time.....

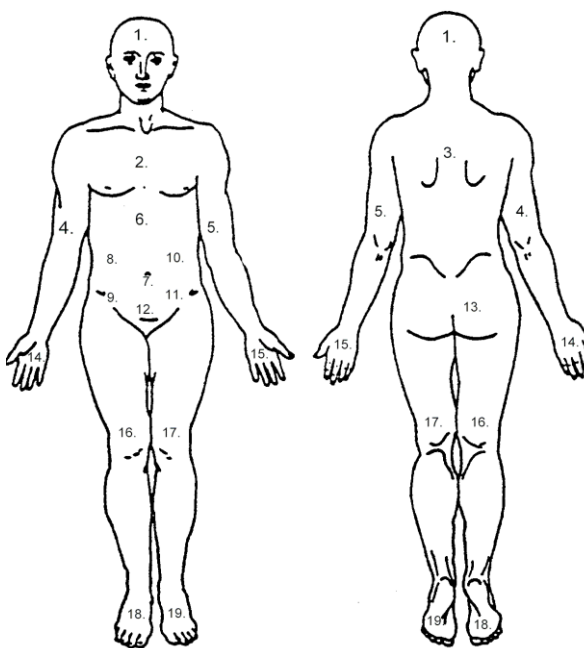
Name

1. Throughout our lives, most of us have had minor aches and pains from time to time. Have you had pain, other than these everyday kinds of pain, today?

Yes

No

2. On the diagram, shade the area where you feel pain. Put an X on the area that hurts the most.



2. Please rate your pain by circling the one number that best describes your pain **at its worst** in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10

No
pain

pain as bad
as you can imagine

3. Please rate your pain by circling the word that best describes your pain **at its least** in the last 24 hours.

0	1	2	3	4	5	6	7	8	9	10
No pain										pain as bad as you can imagine

4. Please rate your pain by circling the word that best describes your pain **on average**.

0	1	2	3	4	5	6	7	8	9	10
No pain										pain as bad as you can imagine

5. Please rate your pain by circling the word that best describes your pain **right now**.

0	1	2	3	4	5	6	7	8	9	10
No pain										pain as bad as you can imagine

6. What treatments or medications are you receiving for your pain?

7. In the past 24 hours, how much relief have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you received.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
No Relief										Complete Relief

9. Circle the one number that describes how, during the past 24 hours, pain has interfered with your:

A. General activity

0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes

B. Mood

0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes

C. Walking ability

0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes

D. Normal work (includes both work outside the home and house work)

0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes

E. Relations with other people

0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes

F. Sleep

0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes

G. Enjoyment of life

0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes

**APPENDIX G: THE ADAPTATION TO DISABILITY SCALE-REVISED (ADS-
R)**

Read each statement below and circle the number that indicates to what extent you agree or disagree with the statement.				
	Strongly Disagree	Disagree	Agree	Strongly Agree
1. With my disability, all areas of my life are affected in some major way. C	1	2	3	4
2. Having my disability, I am unable to do things like people without disabilities do. T	1	2	3	4
3. Disability or not, I am going to make good in life. E	1	2	3	4
4. Because of my disability, I have little to offer other people. T	1	2	3	4
5. Good physical appearance and physical ability are the most important things in life. S	1	2	3	4
6. A person with a disability is restricted in certain ways, but there is still much s/he is able to do. E	1	2	3	4
7. No matter how hard I try or what I accomplish, I could never be as good as the person who does not have my disability. T	1	2	3	4
8. It makes me feel very bad to see all the things that people without disabilities can do that I cannot	1	2	3	4

C				
S	9. The most important thing in this world is to be physically capable.	1	2	3 4
T	10. Because of my disability, other people's lives have more meaning than my own.	1	2	3 4
C	11. Because of my disability, I feel miserable much of the time.	1	2	3 4
E	12. Though I have a disability, my life is full.	1	2	3 4
T	13. The kind of person I am and my accomplishments in life are less important than those of persons without disabilities.	1	2	3 4
S	14. A physical disability affects a person's mental ability.	1	2	3 4
C	15. Since my disability interferes with just about everything I try to do, it is foremost in my mind practically all of the time.	1	2	3 4
E	16. There are many things a person with my disability is able to do.	1	2	3 4
C	17. My disability in itself affects me more than any other characteristic about me.	1	2	3 4
E	18. There are many more important things in life than physical ability and appearance.	1	2	3 4
	19. Almost every area of life is closed to me.	1	2	3 4

T					
C	20. My disability prevents me from doing just about everything I really want to do and from becoming the kind of person I want to be.	1	2	3	4
E	21. I feel like an adequate person regardless of the limitation of my disability.	1	2	3	4
C	22. My disability affects those aspects of life that I care most about.	1	2	3	4
T	23. A disability such as mine is the worst possible thing that can happen to a person.	1	2	3	4
S	24. You need a good and whole body to have a good mind.	1	2	3	4
E	25. There are times that I completely forget that I have a disability.	1	2	3	4
T	26. If I didn't have my disability, I think I would be a much better person.	1	2	3	4
C	27. When I think of my disability, it makes me so sad and upset that I am unable to do anything else.	1	2	3	4
T	28. People with disabilities are able to do well in many ways.	1	2	3	4
E	29. I feel satisfied with my abilities and my disability does not bother me too much.	1	2	3	4
	30. In just about everything, my disability is annoying to me so that I can't enjoy anything.	1	2	3	4

C					
S	31. Physical wholeness and appearance make a person who s/he is.	1	2	3	4
E	32. I know what I can't do because of my disability, and I feel that I can live a full life.	1	2	3	4

APPENDIX H: THE REVISED DYADIC ADJUSTMENT SCALE (RDAS)

RDAS-Revised Dyadic Adjustment Scale

Name _____

Date _____

Most people have disagreements in their relationships. Please indicate below the extent of agreement or disagreement between you and your partner for each item.

	Always Agree	Almost Always Agree	Occasionally Agree	Frequently Disagree	Almost Always Disagree	Always Disagree
1. Religious matters						
2. Demonstrations of affection						
3. Making major decisions						
4. Sex relations						
5. Conventionality (correct or proper behavior)						
6. Career decisions						

	All the Time	Most of the time	More often than not	Occasionally	Rarely	Never
7. How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
8. How often do you and your partner quarrel?						
9. Do you ever regret that you married (or lived together)?						
10. How often do you and your mate "get on each other's nerves"?						

	Every Day	Almost Every Day	Occasionally	Rarely	Never
11. Do you and your mate engage in outside interests together?					

How often would you say the following events occur between you and your mate?

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
12. Have a stimulating exchange of ideas						
13. Work together on a project						
14. Calmly discuss something						

Busby, D. M., Crane, D. R., Larson, J. H., & Christensen, C. (1995). A revision of the Dyadic Adjustment Scale for use with distressed and non-distressed couples: Construction hierarchy and multidimensional scales. *Journal of Marital and Family Therapy*, 21(3), 289-308.

APPENDIX I: PATIENT CONSENT FORM**PATIENT CONSENT FORM**

TITLE: Stressors-Associated with Dyadic Relationship Stability Following Amputation

SPONSOR: University Faculty of Nursing Research Grant

INVESTIGATORS:

PI: Dr. Theresa Lynn Green

Co-investigator: Anila Virani, BScN, MN Student

Co-investigator: Dr. James Alexander Rankin

Co-investigator: Dr. Sean Peter Dukelow

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

Amputation can have debilitating effects on individuals and families. Uncertainty, fear, depression, financial concerns, occupational and family role changes, body image anxiety, changed sense of self and identity, social discomfort, adjustment to prosthesis, perceived social stigma, post-amputation pain, and disability are a few sources of stress experienced by amputees. These stressors may also affect their partner and ultimately the dyadic relationship and researchers have reported that a chronic condition of one spouse had negative effects on the well spouse's well-being and marital quality over a five-year

period. The phenomenon of amputation creates a web of negative consequences for both partners that can strain the marital relationship and potentially alter dyadic relationship quality and stability.

This study is designed to examine the relationship between stressors associated with amputation and dyadic relationship quality and stability in couples in which one spouse has at least one amputation. There will be a total of 10-15 couples recruited to participate in this study. Participants will be recruited from the Alberta Amputee Sports and Recreation Association (AASRA), an amputee support group; the amputee clinic in the Physiatry department at Foothills Medical Centre and Prosthetic Concepts, a privately owned prosthetic clinic in Calgary. Participants are encouraged to refer other participants through their own personal contacts.

WHAT IS THE PURPOSE OF THE STUDY?

The aim of this study is to examine the stressors associated with amputation that may affect the dyadic relationship quality and stability in couples where one spouse has at least one amputation.

WHAT WOULD I HAVE TO DO?

You will be asked to participate in filling out questionnaires one time only, after your clinic visit. This will only require 35-45 minutes of your time. If you prefer, you can complete the questionnaires on the phone at your convenience or take a self-addressed return envelope home. Your participation is voluntary. You do not have to answer any questions you do not wish to answer, and you may withdraw from the study anytime.

WHAT ARE THE RISKS?

There are no foreseeable risks to you as a result of your participation in this research.

Participation in this study will have no impact on any health services that you are receiving or could receive. The disadvantages with your participation are minimal.

Sometimes, mentioning issues like amputation and marital adjustment can leave you feeling unsettled. For most people this is a transient feeling. If you need to discuss your feelings with someone, the researchers can put you in touch with services that may be able to help. Some of these services are free.

WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study there may or may not be a direct benefit to you. If you are in the study because you have been identified as having had an amputation your condition may be improved during the study but there is no guarantee that this research will help you. The information we get from this study may help us to provide better treatments in the future for patients with amputations.

There are no direct benefits to participating in the study. The information we get from this study may help us to assist couples in the future in which one spouse has experienced at least one amputation.

DO I HAVE TO PARTICIPATE?

Your participation is voluntary and you may withdraw from the study anytime without jeopardizing your health care. You do not have to answer any questions you do not wish to answer. Please call one of the researcher numbers mentioned below if you would like to withdraw.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

There are no costs involved.

WILL MY RECORDS BE KEPT PRIVATE?

Only the student researcher, the supervisory team (mentioned above) and the University of Calgary Conjoint Health Research Ethics Board will have access to the records. All personal information that could be used to identify you, such as your name or initials, date of birth, gender, ethnic origin and medical and health-related information will be kept strictly confidential in a secure, locked filing cabinet in a secure, locked research office. Your information will be analyzed using only the ID number mentioned on the questionnaire.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Theresa Green (403) 220-2464

or

Anila Virani (403) 400- 4460

If you have any questions concerning your rights as a possible participant in this research, please contact The Director, Office of Medical Bioethics, University of Calgary, at 403-220-7990.

Participant's Name

Signature and Date

Investigator/Delegate's Name

Signature and Date

Witness' Name

Signature and Date

This study has been approved by the Conjoint Health Research Ethics Board.

A signed copy of this consent form has been given to you to keep for your records and reference.

APPENDIX J: SPOUSAL CONSENT FORM

SPOUSAL CONSENT FORM

TITLE: Stressors Associated with Dyadic Relationship Stability Following Amputation

SPONSOR: University Faculty of Nursing Research Grant

INVESTIGATORS:

PI: Dr. Theresa Lynn Green

Co-investigator: Anila Virani, BScN, MN Student

Co-investigator: Dr. James Alexander Rankin

Co-investigator: Dr. Sean Peter Dukelow

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

Amputation can have debilitating effects on individuals and families. Uncertainty, fear, depression, financial concerns, occupational and family role changes, body image anxiety, changed sense of self and identity, social discomfort, adjustment to prosthesis, perceived social stigma, post-amputation pain, and disability are a few sources of stress experienced by amputees. These stressors may also affect their partner and ultimately the dyadic relationship and researchers have reported that a chronic condition of one spouse

had negative effects on the well spouse's well-being and marital quality over a five-year period. The phenomenon of amputation creates a web of negative consequences for both partners that can strain the marital relationship and potentially alter dyadic relationship quality and stability.

This study is designed to examine the relationship between amputation and dyadic relationship quality and stability in couples in which one spouse has at least one amputation. There will be a total of 10-15 couples recruited to participate in this study. Participants will be recruited from the Alberta Amputee Sports and Recreation Association (AASRA), an amputee support group; the amputee clinic in the Physiatry department at Foothills Medical Centre and Prosthetic Concepts, a privately owned prosthetic clinic in Calgary. Participants are encouraged to refer other participants through their own personal contacts.

WHAT IS THE PURPOSE OF THE STUDY?

The aim of this study is to examine the stressors associated with amputation that may affect the dyadic relationship quality and stability in couples where one spouse has at least one amputation.

WHAT WOULD I HAVE TO DO?

You will be asked to participate in filling out the questionnaire one time only after your clinic visit with your spouse. This will only require 3-5 minutes of your time. If you prefer you can complete the questionnaire on the phone at your convenience or take a self-addressed return envelope home. If you are not available at the clinic the questionnaire and self-addressed return envelope will be sent with your spouse, or we can

call you at your convenience. Your participation is voluntary. You do not have to answer any questions you do not wish to answer, and you may withdraw from the study anytime.

WHAT ARE THE RISKS?

There are no foreseeable risks to you as a result of your participation in this research.

Participation in this study will have no impact on any health services that you are receiving or could receive. The disadvantages with your participation are minimal.

Sometimes, mentioning issues like amputation and marital adjustment can leave you feeling unsettled. For most people this is a transient feeling. If you need to discuss your feelings with someone, the researchers can put you in touch with services that may be able to help. Some of these services are free.

WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study there may or may not be a direct benefit to you. If you are in the study because you have been identified as the spouse of a partner who has had an amputation there is no guarantee that this research will help you. The information we get from this study may help us to provide better treatments in the future for patients and spouses following amputation.

There are no direct benefits to participating in the study. The information we get from this study may help us to assist couples in the future in which one spouse has experienced at least one amputation.

DO I HAVE TO PARTICIPATE?

Your participation is voluntary and you may withdraw from the study anytime without jeopardizing your health care. You do not have to answer any questions you do not wish

to answer. Please call one of the researcher numbers mentioned below if you would like to withdraw.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

There are no costs involved.

WILL MY RECORDS BE KEPT PRIVATE?

Only the student researcher, the supervisory team (mentioned above) and the University of Calgary Conjoint Health Research Ethics Board will have access to the records. All personal information that could be used to identify you, such as your name or initials, date of birth, gender, ethnic origin and medical and health-related information will be kept strictly confidential in a secure, locked filing cabinet in a secure, locked research office. Your information will be analyzed using only the ID number mentioned on the questionnaire.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

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Participant's Name

Signature and Date

Investigator/Delegate's Name

Signature and Date

Witness' Name

Signature and Date

This study has been approved by the Conjoint Health Research Ethics Board.

A signed copy of this consent form has been given to you to keep for your records and reference.