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**The Lived Experience of Barbadians with Lower Extremity
Amputation as a Complication of Long-Term Diabetes Mellitus**

Heather Maureen Brathwaite

THE LIVED EXPERIENCE OF BARBADIANS WITH LOWER EXTREMITY
AMPUTATION AS A COMPLICATION
OF LONG-TERM DIABETES MELLITUS

DISSERTATION

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Heather Maureen Brathwaite

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2016

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Abstract

Background: Diabetes is a chronic disease that occurs when the pancreas does not produce enough insulin or when the body cannot effectively use the insulin it produces.

Hyperglycemia may result over time, leading to serious damage to many of the body's systems, especially the nerves and blood vessels. Lower extremity amputation is a very severe complication of *diabetes mellitus*. In general, traumatic lower-extremity amputations occur at a higher rate in those with diabetes than with any other concomitant medical illness. The Centers for Disease Control and Prevention (2011) affirms that the overall rate of lower-extremity amputation is 4.1 per 1,000 persons with diabetes, and about 3 per 10,000 of those in the entire population. Lower-extremity amputations have a profound effect on an individual's quality of life and are associated not only with increased health care costs but also increased risk of mortality.

Purpose: The purpose of this study was to explore, understand, and describe the lived experience of Barbadians living in Barbados with a lower-extremity amputation as a complication of long-term *diabetes mellitus*.

Philosophical Underpinnings: This qualitative study was guided by the hermeneutic phenomenological approach of Max van Manen (1990).

Methods: The hermeneutic-phenomenological approach of Max van Manen was used to guide this study. Guided by the phenomenological method described by van Manen, recordings were transcribed, reviewed, and confirmed with the participants. The theory of transition proposed by Meleis (2010) provided a lens to comprehend further the lived experience of Barbadians with lower-extremity amputations as a complication of long-term *diabetes mellitus*.

Results: Four related themes of *devastating, accepting, adjusting, and transitioning* emerged and represented the participants' lives as amputees.

Conclusions: This research study highlighted the depth of challenges confronting the Barbadian diabetic amputee. A significant aspect of the experience of living as an amputee was searched for meaning, which individuals address as they look to the future.

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DEDICATION

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CHAPTER ONE

Diabetes, a serious and economically devastating illness, has reached epidemic proportions in both developed and developing countries. Diabetes poses a major threat to public health in the 21st century. It was noted to be the seventh-leading cause of death in the United States in 2007 (National Institute of Diabetes and Digestive and Kidney Diseases, 2011). According to data from the National Diabetes Statistic Report (2014), there are approximately 29.1 million Americans (9.3% of the U.S. population) diagnosed with diabetes worldwide, and there are approximately 415 million people diagnosed with *diabetes mellitus* (International Diabetes Federation [IDF], 2015).

Part of a group of metabolic diseases, diabetes is characterized by hyperglycemia, caused by a deficiency in the body's ability to produce or secrete insulin (American Diabetic Association, 2013). This deficiency can be the result of an autoimmune response in the pancreas or when the body is unable to produce sufficient insulin. Insulin is a hormone made by the pancreas, which allows the body's cells to absorb glucose from the blood, and, in the absence of insulin, leads to hyper-glycaemia (American Diabetic Association, 2013). Type 1 and Type 2 Diabetes are the two most prevalent types of diabetes. Type 1 Diabetes is noted when there is no insulin secretion/production by the pancreas, and Type 2 Diabetes results when there is insulin resistance and insufficient insulin production (American Diabetic Association, 2013).

According to the Centers for Disease Control and Prevention (CDC, 2011), Type 2 Diabetes is responsible for the increasing number of comorbidities, such as: cardiovascular diseases, strokes, hypertension, dental disease, kidney disease, blindness,

nervous system disease, impaired immune function, pregnancy complications, and amputations. One of the complications of diabetes is lower-leg amputation. Diabetes-related lower-extremity amputation (LEA) rates are elevated in Blacks compared to Whites in the United States but are lower in African-Caribbeans in the United Kingdom (Hennis, Fraser, Jonnalagadda, Fuller, & Chaturvedi, 2004). It has been suggested that higher rates and risk of amputations occur in Blacks residing in the Caribbean. The purpose of this phenomenological inquiry was to gain an understanding of the lived experience of Barbadian diabetic amputees who are living in Barbados, one of the islands of the Caribbean.

Background of the Study

Global Impact of Diabetes

Type 2 *diabetes mellitus* is a worldwide epidemic, with diagnoses increasing in the past few years. A report from the International Diabetes Federation (2014) estimated that there are approximately 387 million diagnosed diabetics globally, and that figure in the adult population will rise to about 592 million or 7.2% of the global population by 2035. Diabetes was previously ranked as the eighth-leading cause of death worldwide. However, diabetes now ranks fifth, following infections, cardiovascular disease, cancer, and trauma in the 21st century (WHO, 2011).

Non-communicable diseases have a huge effect on the lives and well-being of societies, communities, individuals, and families. China ranks highest in the prevalence of diabetes, with 98.4 million cases, followed by India, with 65.1 million cases, and the United States, with 24.4 million cases (IDF, 2013). It is projected that by 2035, the

prevalence of diabetes will almost double globally (International Diabetes Federation, 2014). In the year 2004, an estimated 3.4 million people died of hyperglycemic complications. The World Health Organization (WHO), an intergovernmental agency, was first established after the Second World War to lead and coordinate health activities worldwide (Holtz, 2008). The WHO has projected that this mortality would double between 2005 and 2030. Most direct fatalities from diabetes occur in low- and middle-income countries (WHO, 2011). Diabetes and its complications have a significant economic effect on individuals, families, health systems, and nations. In 2011, the WHO projected that China would have a deficit of about \$558 billion in income loss between the years 2006-2015 as a result of heart disease, strokes, diabetes, and other chronic non-communicable diseases. The prevalence of these chronic, non-communicable diseases globally has become more challenging and more difficult to treat, often causing unwarranted pain, suffering, and untimely death.

According to Moxely et al. (2011), the worldwide incidence of lower-extremity amputation is high and, even though variations exist, it is often difficult to directly compare rates as a result of heterogeneity in the populations studied. The Global Lower Extremity Amputation Study Group (Unwin, 2000) was conducted after a search of the literature revealed several inconsistencies when comparing amputation incident rates worldwide. This study comparatively examined the rates of lower-leg amputation between different centers around the world. Six centers with populations greater than 200,000 participated in the study. Data collected from Japan, Taiwan, Spain, Italy, North America, and England between July 1, 1995 and June 30, 1997 were obtained by

measuring the incidence of amputations in an entire geographical area, using estimates from an epidemiologically derived method called capture re-capture.

Results indicated that there were obvious variances in the overall incidence of amputations between centers. The Navajo region of the United States (22.4 per 100,000 women, 43.9 per 100,000 men) showed some of the highest rates in that area, while Madrid, Spain (0.5 per 100,000 women, 2.8 per 100,000 men) reported the lowest age-adjusted rates. The age of the amputee significantly correlated to the incidence of amputations in patients over 60 years old. There were more male amputees than females, more major amputations than minor amputations, and the incidence of diabetes accounted for 25% to 90% of the amputees. Recommendations included the need to explore other factors associated with amputations and the need for more access to vascular surgery.

The amputation of a lower-limb as the result of diabetes is one of the most dreaded sequela of this disease process and is associated with incapacitation and a poor quality of life (Schaper, Apelqvist, & Baker, 2008). As the prevalence and incidence of diabetes continues to plague countries globally, the economic burden on health care organizations also continues to expand exponentially (Vamos, Botle, Majeed, & Millett, 2010). Amputations are performed for varying reasons—namely, trauma, musculoskeletal malignancies, diabetes, peripheral vascular disease (non-diabetes), congenital malformations, sepsis, and burns (Cornelius, David, Williams, Joseph, & Daniel, 2013). An amputation can be major or minor. Minor amputations in patients with foot problems have been well documented, and there is still debate regarding what determines successful limb salvage, given the definition of a minor or distal amputation

and a major or proximal amputation for the diabetic population (Nather & Wong, 2013). On November 10, 2002, The ASEAN Plus Expert Group Forum for the Management of Diabetic Foot Wounds (Hasan, Teo, & Nather et al., 2015) made clinical recommendations regarding practice guidelines for determining the nomenclature most appropriate when referencing an amputation due to diabetic complications. It recommended that a minor (distal) amputation should be performed on diabetic patients undergoing amputations for the first time, and a major (proximal) amputation, such as below the knee amputations (BKA), should be performed secondly.

The *International Classification of Diseases, Tenth Revision, Clinical Modification* (ICD-10-CM) uses another method of classification based on the World Health Organization's *Ninth Revision, International Classification of Diseases* (ICD-9). This classification method is the official coding system for assigning codes to diagnoses and procedures associated with hospitals in the United States (Centers for Medicare and Medicare Services, 2011). In 2000, the Global Lower Extremity Amputation (LEA) Study Group defined lower-limb amputations as those involving complete loss/ablation of any part of the lower limb in any of the two anatomical planes: in the transverse plane, proximal to and including the subtalar joint, and in the frontal anatomical plane; a major amputation is done through or proximal to the tarsometatarsal joint. As per Standards of Care, Brigham and Women's Hospital Department of Rehabilitation Services (2011), anatomical levels of LEA include:

- Toe Amputation – the phalangeal or partial amputation of toes involving excision of any part of one or more of the toes

- Transphalangeal Amputation (toe disarticulation) – an amputation done at the metatarsophalangeal joint
- Transmetatarsal Amputation (TMA) – an amputation of the foot in which a dorsal incision is made through the mid- to proximal metatarsal shafts
- Lisfranc Amputations – performed at the tarsometatarsal joint and involving disarticulation of all five metatarsals and digits
- Chopart Amputations – performed at the talonavicular and calcaneocuboid joints and involving disarticulation through the midtarsal joint, leaving only the calcaneus and talus
- Syme Amputation – an ankle disarticulation in which the heel pad is kept to promote adequate weight bearing
- Transtibial Amputation (below the knee amputation) – a very short amputation that occurs when less than 20% of the tibial length is preserved. These amputations may result from trauma and are not usually an elective procedure.
- Knee Disarticulation (through-knee amputation or TKA) – an old and anatomic procedure that does not require surgically cutting through bone or muscular bellies
- Supracondylar Amputation – a surgical procedure in which the patella is left for better end weight-bearing
- Transfemoral Amputation (above the knee amputation) – an amputation that occurs when less than 35% of the femoral length is present
- Hip Disarticulation – loss of the entire femur

- Hemipelvectomy – loss of any part of the ilium, ischium, and pubis

The decision to amputate and the selection of level of lower-limb amputation in dysvascular patients must be carefully considered given the problems of post-amputation. Successful wound healing is important at this juncture and must be achieved quickly to avoid problems with post-surgical rehabilitation (Hunter, 1996).

Impact of Diabetes in the United States

Approximately two million individuals in the United States have lost limbs because of vascular disease (54%), which includes diabetes and peripheral arterial disease. Trauma accounted for 45% of the deaths and cancers were less than 2% (Ziegler-Graham, McKenzie, Ephraim, Trivison, & Brookmeyer, 2008). Between 2009 and 2012, based on fasting glucose or hemoglobin A1C levels, 37% of adults in the United States aged 20 years or older had pre-diabetes, as compared to 50% of adults aged 65 years or older (National Diabetes Statistics Report, 2014). When this percentage was applied to the entire United States population in 2012, it was determined that an estimated 86 million American adults aged 20 years or older had been diagnosed with pre-diabetes. During 2012, the United States had about 208,000 people younger than 20 years old diagnosed with diabetes (type 1 or type 2) and approximately 18,436 million people aged 20 years or older were newly diagnosed diabetics; this number is much higher than the approximately 5,089 people younger than age 20 years old diagnosed with Type 2 Diabetes between 2008 -2009 (National Diabetes Statistics Report, 2014).

The National Institute of Diabetes and Digestive and Kidney Diseases (2010) projected that about 15.1% of American Indians and Alaska Natives have diabetes, compared with 8.7% of non-Hispanic Whites. Non-Hispanic Blacks (13.3%) and Hispanics/Latinos (9.5%) were also disproportionately represented. Although mortality caused by diabetes was lower in the United States than in developing countries, diabetes is still directly accountable for 71,382 deaths and was a factor in 160,022 deaths in 2007 (CDC, 2011). According to the CDC (2011), diabetes contributed to 231,404 deaths out of almost 2.5 million total deaths. These figures are likely to increase, because the lifetime risk of diabetes in the United States was predicted to reach 1 in 3 for children born in the year 2020 (National Institute of Health, 2010).

Lower-limb amputation is one of the most dreaded diabetic complications and is linked to the loss of an individual's mobility and therefore could subject the individual to a poor quality of life (Schaper et al., 2012). According to the National Limb Loss Information Center (2008), roughly 185,000 amputations are performed in the United States annually, and approximately half of the amputees who suffer from vascular complications will be deceased within the first five years of the procedure. These statistics are noted to be worse than the 5-year mortality rates of individuals suffering with cancer (Robbins et al., 2008). Despite the sparse documentation of the occurrence of bilateral amputations, it has been predicted that 30% to 50% of the people who have an amputation associated with diabetes will undergo amputation of the opposite lateral limb three to five years after the primary amputation (Izumi, Lee, Satterfield, & Harkless, 2006).

Island of Barbados

Barbados is an English-speaking Caribbean island located in the eastern Caribbean chain of islands. Spanning 21 miles long and 14 miles wide, Barbados is a very flat island, with a total land area of 166 square miles. Barbados was settled by the British in 1627 and gained its independence from Britain some 239 years later in 1966. Despite its present independent status, the island has maintained close ties to the British as a member of the commonwealth (Inniss, 2007). Barbados is thought to be one of the most densely inhabited countries in the world. In 2013, the population of Barbados was estimated to be 288,725 at a growth rate of .33% (Central Intelligence Agency, 2014). The citizens of Barbados are of African descent, and the ethnic groups include: Black 92.4%, White 2.7%, mixed races 3.1%, East Indian 1.3%, other 0.2%, and unspecified 0.2% (CIA, 2013).

Barbados is an affluent island in the Eastern Caribbean and relishes having one of the highest per capita incomes in Latin America (CIA, 2014). The Barbadian government and its citizens hold education to the highest esteem, making education an important part of the island's development. As a result, the government is continuously and consistently investing a percentage of its revenue to educate its citizens at the primary, secondary, and tertiary levels (Inniss, 2007). The literacy rate for Barbados is 98%, and this prestigious standing is credited to the free mandatory education available to children age 5 to 16 years, regardless of color, creed, or sex (Inniss, 2007).

The health care system in Barbados is known for its top-rated modern medical facilities in the Eastern Caribbean. Barbados has a comprehensive national health care

system that offers free health care at several of its government facilities to its citizens (Inniss, 2007). The Ministry of Health is responsible for regulating, overseeing, and delivering health care services on the island. Currently, there are only two acute care hospitals on the island of Barbados. The Queen Elizabeth Hospital (QEH), one of the island's public hospitals, provides free acute, secondary and tertiary care to all citizens, while Bayview Hospital, a private acute care facility, also renders services to individuals who are financially able to afford the cost of their health care (Hennis, 2011). In addition, there are five government-run district hospitals/facilities that provide geriatric, psychiatric, and rehabilitation services for the physically and mentally disabled. There is also a homeless hostel for individuals diagnosed with AIDS, and eight polyclinics located island-wide, providing free medical services to the citizens (Inniss, 2007).

Despite Barbados's position on education and health care, the citizens of Barbados are plagued by a number of chronic diseases. Dr. Hennis, Head of the Chronic Disease Research Centre in Barbados, estimates that of the 190,000 Barbadians aged 20 years and older, approximately 90,000 are overweight; approximately 38,000 suffer from hypertension or high blood pressure; 19,000 are diagnosed diabetics; and one individual succumbs to a cerebral vascular accident daily (Hennis, 2011). He notes that these alarming statistics are in part due to genetic predisposition and lifestyle behaviors, which include lack of physical activity, intake of high-calorie foods, and the consumption of foods high in fat (Hennis, 2012).

Impact of Diabetes in Barbados

Diabetes mellitus is recorded as one of the leading causes of death in the Caribbean, and a number of studies have documented the high prevalence of the disease. Leske, Wu, Nemesure, and Hennis (2002) conducted a quantitative study to examine the distribution and impact of diabetes, glycemic status, and related factors in a Caribbean population. This study took place between 1988 and 1992 and was reassessed in 1997. The population included 4,709 Barbadian diabetics between the ages of 40 and 84 years. This study showed a high prevalence of diabetes in this population, with increasing mortality in one to five persons. The study concluded that urgent interventions are needed to combat this epidemic. *Diabetes mellitus* had an estimated prevalence of 19.4% in people 40 years and over in Barbados, placing a significant demand on health care resources on the island (Walrond & Ramesh, 1998).

Complications directly related to diabetes add significantly to this problem. For example, the diabetes-related lower-extremity amputation rate was estimated at 936 per 100,000 people in Barbados, making Barbados one of the places in the world with the highest incidence of diabetes (Hennis et al., 2004). The high rate of uncontrolled diabetes meant that the majority of surgical referrals were patients with diabetic neuropathy and peripheral vascular disease who presented with critical ischemia or gangrenous feet. Eighty percent of female inpatients and 50% of male inpatients in the general surgical wards were treated for diabetic foot infections (Walrond & Ramesh, 1998). Due to a lack of radiology and vascular services and resources in Barbados, amputation remains the most common surgical emergency.

Hambleton et al. (2009) conducted a prospective case control study to determine the mortality rate after diabetes-related lower-extremity amputation (LEA) in Barbados. They recruited diabetic amputees and age-matched subjects who were diabetics with no amputations between 1999 and 2001. They followed the group for 5 years as they assessed mortality risk and causes. A total of 205 case and 194 control subjects were recruited for the study. Amputations were classified as minor if they involved the toes or foot, and as major if they were through the tibia or femur. They further categorized major amputations as below-the-knee amputations (BKAs) or above-the-knee amputations (AKAs). Telephone interviews were conducted until July 2007 to assess 5-year survival. Official records verified all deaths, and the death certificates were used to report all-cause mortality.

There were 123 (60%) minor amputations, 47 (23%) BKAs, and 35 (17%) AKAs. Case subjects and control subjects were similarly matched by age as a result of the study design. Case subjects averaged 70.5 years old, and control subjects averaged 69.3 years. Case subjects with a minor amputation were noted to be younger than those with a major amputation (minor LEA 67.1 years; major LEA 75.7 years), and they controlled for this age difference by presenting age-adjusted mortality rates. The average diabetes duration for case and control subjects was 17.8 years and 11.8 years respectively, with no difference between those with minor and major LEA.

There were slightly more male case subjects than control subjects. Case subjects were correspondingly more likely than control subjects to have poorer glycemic control (GHb 11.1 vs. 9.1%). During the 5 years after the index LEA, there were 145 deaths

(112 amputees and 33 control subjects). Survival rates at 3 months, 6 months, 1 year, and 5 years after an AKA were 51%, 49%, 34%, and 10%, respectively, and after a BKA, they were 68%, 64%, 60%, and 28%. Survival rates after a minor amputation were 92%, 86%, 81%, and 59%. Overall survival rates among case subjects were 80%, 75%, 69%, and 44% and among control subjects were 100%, 99%, 97%, and 82%. This study was the first to document mortality rates associated with diabetes-related lower-extremity amputations (LEA) in the Caribbean. The results indicated that the mortality rates for the Barbadian population were above those documented for the American Indians in North America, whose rates were reported as 143.7/1,000 person-years, compared with 205.9/1,000 person-years following a BKA in the Barbadian population. Cardiovascular disease was noted as the primary cause of death following diabetes-related amputation in the developed world.

In Barbados, sepsis and cardiac disease were responsible for a similar number of deaths, as revealed in a single study conducted in West Africa, which suggests the possibility of a different presentation of post-amputation complications in the developing world. These different outcomes were thought to be related to access to health care, social influences, and foot care choices. Patient dynamics and insufficiencies in the health care system may add to the burden of diabetes-related complications. Successful measures to reduce the burden of amputation have been well implemented in other settings to include improvements required in basic techniques for boosting glycemic control, addressing prevention and the detection of foot complications, managing wounds and ulcers, and providing post-amputation support services.

Statement of the Problem

Individuals who experience limb loss are confronted with a wide range of extensive and evolving threats that are challenging physically, psychologically, and socially (Coffey et al., 2009). If left unaddressed, these stressors could have profound consequences on the patient's quality of life and his or her ability to function. Given the large number of Barbadians who are diabetic and the increasing number of diabetics who experience amputation, it is therefore crucial to understand this experience. Areas of concern to the amputee include changes in their occupational status (Schoppen et al., 2001); difficulties with engaging in everyday activities (Halsne, Waddingham, & Hafner, 2013); the loss of personal relationships (Mathias, & Harcourt, 2013), and restrictions in participating in the community and wider society (Gallagher, O'Donovan, Doyle, & Desmond, 2011). Most of the studies conducted on diabetes in Barbados are quantitative in nature, focusing on the incidence, prevalence, and management of diabetes and one of its consequences of amputation. Little attention and interest are placed on individual amputees, their experience, or their quality of life after the amputation.

Purpose of the Study

The purpose of this study was to explore, understand, and describe the lived experience of Barbadians living in Barbados with a lower-extremity amputation as a complication of long-term *diabetes mellitus*. The aim of this study was to give voice to Barbadian amputees, thereby gaining an understanding of the essence of their lived experiences. Understanding the essence of the phenomenon could mean better care outcomes for the amputees.

Research Question

The research question for this phenomenological study is: What is the lived experience of the Barbadian with lower limb amputation as a complication of long-term *diabetes mellitus*?

Philosophical Underpinnings

The process of designing a qualitative study should always begin with the researcher making some philosophical assumptions and taking a position prior to conducting the study (Creswell, 2009). Guba and Lincoln (1994) asserted that the process of formal inquiry should be grounded by a research paradigm supported by a set of beliefs representing the researcher's worldview. This worldview, or paradigm, delineates the nature of the world and the connections that individuals have with the world. Entrenched in the qualitative paradigm are five philosophical assumptions that ground the research and allow the researcher to have a better perspective of the nature of the different realities as they relate to qualitative research (Creswell, 2007).

The *ontological* assumption (the nature of reality) affirms that the nature of reality is subjective and holds many meanings for the study participants and the researcher. The *epistemological* assumption (the relationship between the researcher and the research topic) is concerned with the relationship the researcher has with the participants and the direct knowledge gained as a result of the engagement. An *axiological* assumption (the role of value) incorporates characteristics of the values brought forth by the researcher and the participants to the study.

During the study, the researchers are transparent as they discuss the beliefs that lend character to the narrative. A *rhetorical* assumption (the language of the research) involves the use of linguistics commonly used by qualitative researchers. This casual narration embraces the use of the personal voice and qualitative vocabulary, as the researcher documents the information gathered while in the field. A *methodological* assumption (the process of research) embraces the inductive approach to data analysis. This method involves analyzing specific, unbiased observations and discovering common patterns from the emerging data provided by the participants. After carefully accepting and reflecting on their chosen positions, the researchers are then ready to further develop their research by incorporating a paradigm or worldview as the pragmatic guide to carry out the research (Creswell, 2007).

Qualitative Research Approach

The traditional scientific method of research has enjoyed a considerable and noble reputation as the favored method of inquiry utilized by nurses to address a number of nursing problems. However, a researcher who rejects the traditional approach due to its reductionist approach can find solace in the emerging field of qualitative research (Polit & Beck, 2010). Creswell (2007) affirmed that this continuously expanding research approach presents a number of different frameworks from which to conduct research. Denzin and Lincoln (2011) described qualitative research as:

A set of informational, materials and practices that make the world visible. These practices transform the world. They transform the world into a series of

representations that include field notes, interviews, conversations, photographs, recordings and memos to the self. Subsequently, qualitative research encompasses an interpretive and naturalistic approach to the world. (p. 3)

Qualitative inquiry seeks to uncover and narratively describe how individuals conduct themselves on a daily basis and what their actions mean to them (Denzin & Lincoln, 2011). This perspective is concerned with the “what,” “why,” and “how” questions rather than “how many” (Ritchie, Lewis, Nichols, & Ormston, 2013). The uniqueness of this approach is that the research is conducted in the *naturalistic/interpretivist* paradigm (Polit & Beck, 2011). The *constructivist* paradigm (Guba & Lincoln, 1994) was the guiding philosophy of this study. In contradistinction to positivism, the constructivist paradigm emerged in an attempt to understand and explain human and social reality (Crotty, 1998). It adopted relativist ontology, a transactional and subjectivist epistemology (created findings), and a hermeneutic, dialectical methodology (Guba & Lincoln, 1994)

Interpretivism is referred to as the interpretation and the observation an individual employs when trying to understand the social world and the meaningful nature of people’s character as they participate in both social and cultural life (Ritchie et al., 2014, Chowdhury, 2014). Rooted in philosophical traditions of hermeneutics and phenomenology, *interpretivism* gives credit to the German sociologist Max Weber (1864-1920) as a dominant figure and influence in the tradition (Chowdhury, 2014). According to Weber, the science of sociology attempts to provide an interpretive understanding of social action in order to conclude with a causal explanation of its course and effects

(Crotty, 1998). Weber's primary concern was the understanding of social actions, their causal relationships, and the ability to develop an objective science of the subjective nature of the social world. When researchers choose to work within this framework, they usually take an *ontological* and *epistemological* stance to help them fully understand and answer questions (Munhall, 2007).

The intention of *interpretivism* is to understand the subjective experiences of those being studied; how they think, feel, act, or react in their normal, everyday lives. One of the main tenets is that participants are able to generate meaningful constructs of the social world in which they operate (Scotland, 2012). An *ontological interpretivist* assumption maintains that numerous people see social reality, and these individuals are able to interpret each event differently, while having multiple perspectives and interpretations of the phenomenon. They actively interpret the situations in which they find themselves and act on the basis of these interpretations (Polit & Beck, 2011). An *epistemological interpretivist* assumption asserts that knowledge is gained inductively to create a theory based on personal experiences. The naturalistic inquiry is conducted in the field where the researcher fully understands the unfixed, constructed nature of a participant's realities. The participants see the researcher as an "outsider" who is trying to gain access to their world in order to build a therapeutic relationship with the participant and become "an insider" (Creswell, 2007). In order to obtain the full essence of the phenomenon, the researcher must be flexible, patient, and committed to the process. Both the researcher and participant become fully engaged in the process of data

collection, respecting their relationship as a partnership one that is intimate and reciprocal (Polit & Beck, 2011).

The purpose of qualitative research is not to generalize to other subjects or settings but to deeply explore a specific phenomenon or experience on which to build further knowledge or to develop a more patient-focused practice that is sensitive to the research participants (Thomas & Magilvy, 2011). Subsequently, by gathering the results of several individual and specific exchanges between researcher and participants, a general view of common issues is possible. In other words, going from the specific and individual, a generalized series of conclusions is possible. A qualitative researcher adopts the inductive approach by characteristically gathering an enormous amount of information on one topic, phenomena, or experience to augment his or her desired understanding. This approach of research is more in-depth and holistic than quantitative research and produces rich material on which to base the findings of the research (Polit & Beck, 2011).

In qualitative research, the researcher captures the client's perspective of healthcare, and based on this, enables professionals and providers to understand how clients perceive health services (Bryman, 2001). The time has come for researchers to feel liberated, knowing that there are different approaches that can be utilized when doing qualitative research. However, the researcher must remain committed to the philosophical underpinnings of the chosen method and look for mental models of the world to provide the answers (Munhall, 2007). Qualitative researchers are often able to reflect back on their worldviews and visualize the approach that should be utilized,

depending on the phenomenon of interest. These approaches include: narrative inquiry, case study, grounded theory, ethnography, and phenomenology.

Narrative research is essentially a strategy of conducting research in which the researcher studies the lives of one or more individuals, seeking to uncover the story of their lives (Creswell, 2009). To understand the view of the individual upon which that individual makes assumptions and acts on those assumptions. It is the process of gathering information for the purpose of research through storytelling. The researcher documents the stories and later retells the story in a sequence of events as told by the participant. Case study research is used to look at individuals, a small group of participants, or a group as a whole. These in-depth studies examine the relationship of all variables in order to provide an overall understanding of a condition (Polit & Beck, 2011). The researcher collects data about the participants using the participants' direct observations to determine what is vital to the case and why the participant may have some specific unique mannerisms (Polit & Beck, 2011).

Grounded theory is an approach that researchers use to inductively develop theory from data (Creswell, 2009). In grounded theory, there is no approval or disapproval of a set theory. Instead, the researchers begin the study with a known problem and allow what is relevant to that problem to emerge. Ethnography is the study of individuals as they present themselves in their culture (Polit & Beck, 2011). When conducting this type of research, the researcher is seen as an outsider who needs to gain access to the participant's point of view. The fundamental aim of ethnography is to provide a rich and holistic understanding of people's lives by studying them in their natural living

environment. Phenomenology is concerned with the study of a phenomenon as experienced from the perspective of the individual. The understanding of the lived experience and being able to identify the true essence of the experience is one of the main tenets of phenomenology (Munhall, 2007). Researchers utilizing this method seek to investigate and uncover human phenomenon that has been inadequately reported (Polit & Beck, 2011).

The practice of qualitative research provides the researcher with a practical overview of the research participants' behaviors in the context of their lives (Ritchie et al., 2013). While there are several options from which to choose, all of the traditions discussed share some philosophical and methodological similarities to further enhance understanding, interpretation, and meaning of the phenomenon. A qualitative research approach was chosen for this study because this researcher wanted to explore the lived experience of the Barbadian diabetic amputee in greater detail, due to the paucity of literature written on the topic. Having a clearer qualitative understanding would be a better fit for this topic because the essence of this phenomenon cannot be adequately explained or understood in the traditional quantitative research context. How people describe their lives prior to and after amputation cannot be viewed as separate and apart from how they conduct their daily lives: their psychosocial, physical, and psychological wellbeing are all crucial determinants of their overall survival. All of these underlying principles led this researcher to choose a qualitative tradition for this study. To best explore the lived experience of the Barbadian amputee, a phenomenological approach was utilized.

Phenomenology

The origin of phenomenology lies in psychology and philosophy (Creswell, 2007). Phenomenology is a qualitative research method concerned with the lived experiences of humans and the meaning they give to their everyday lives (Munhall, 1994; Polit & Beck, 2010). The aim of phenomenology is to describe an everyday phenomenon while trying to fully understand its essential structure. It empirically measures what is subjectively felt, whether real or imagined (van Manen, 1990). The purpose of phenomenology as a method of inquiry is to discover how patterns and structures of phenomena are interwoven and lived within the fabric of everyday life (Parse, 2001). Sokolowski (2000) suggested that phenomenology is “a rigorous, explicit, self-conscious enterprise” (p. 53), interested in the world of human beings where truth abides and a science directed toward manifestation and disclosure.

Creswell has elaborated on the four broad philosophical assumptions inherent in phenomenology. The first assumption is returning to the “traditional tasks of philosophy” (p. 58), which originally requires a search for wisdom. Second, it is “a philosophy without presuppositions” (p. 58), meaning that the researcher must somehow put aside pre-existing judgments and biases in order to see the phenomenon through the same lens as the participants see it. This concept is known *as epoche*, bracketing, or phenomenological reduction (Creswell, 2007). The third assumption, “the intentionality of consciousness” (p. 59), refers to an individual’s ability to remain focused on an object. Intentionality of consciousness is important because it allows a person to be able to directly grasp the true meaning of the phenomenon. Fourth is the “refusal of the subject-

object dichotomy” (p. 59). In other words, this is to recognize a relationship between the knower and what is known, and the knower can change perception of reality (Creswell, 2007). Nursing as a discipline is concerned with studying the holistic intricacies of the human condition and the ability to embrace respect for the unique qualities of each patient is an inherent value. Phenomenological nursing research, then, becomes essential to gaining insight into the unique individual interpretations of meaning in life events (Munhall, 1994).

Husserl Descriptive Phenomenology

Phenomenology was first introduced as a movement characteristic of the way European philosophy was practiced in the 20th century (Moran, 2002). Phenomenology is rooted in the work of German philosophers such as Husserl and Heidegger and gained further strength in Europe through the work of French philosopher Sartre and later Merleau-Ponty (Thomas & Magilvy, 2011). Edmund Husserl (1859-1938), who is known as the father of phenomenology, started his career as a mathematician (Creswell, 2007), and later changed his mind from teaching science to pursue his interest and study of philosophy under the direction of Frantz Brentano (dates) (Moran, 2002). Brentano viewed philosophy as an exact science and later restructured Aristotle’s notion of intentionality and mental states to describe the art of one’s awareness (Moran, 2002). According to Crotty (1998), Brentano’s work on intentionality set the stage for this concept as central to Husserl’s philosophical stance. It is Brentano’s work on descriptive psychology that provided the catalyst for Husserl’s refinement of phenomenology.

A more formal introduction to phenomenology was found in the philosophy of Edmund Husserl in his *Logische Untersuchungen* (*Logical Investigations*, 1900-1901) in which he referred to phenomenology as thoughts and the meaning ascribed to those thoughts (Moran, 2002). Husserl's phenomenology was an attempt to abandon the traditional way of engaging in philosophy and constituted a radical re-thinking of its processes. His technique highlights attempts to get at the truth as it presents itself directly to consciousness. He stressed careful description as a means of finding truth (McConnell-Henry, Chapman, & Francis, 2009).

Husserl was well-known for making the statement "back to the things themselves" (McConnell-Henry et al., 2009; Moran, 2002), maintaining a strong conviction that knowledge is derived from careful observation and description of the things themselves, which is the world as one experiences it. This is categorized as "lived experiences." The logical investigation, as detailed by Husserl, was considered a pivotal point in the science of phenomenology (Moran, 2002). Moran (2002) noted that Husserl set about elaborating the full program of phenomenology; not just as the epistemological clarification of logic and mathematics, or even as the *a priori* science of the essential features of consciousness, but rather as a pure *eidetic science*, a "science of essences" (p. 124). Husserl is renowned for the introduction of the concept "lifeworld" (*Lebenswelt*), a world in which knowledge stems from conscious awareness, and the mind is focused towards "objects," whether those objects are real, imagined, in memory, concrete, indistinct, vague, or exist only in language (McConnell-Henry et al., 2009; Moran, 2000), an intersubjective world in which we live and experience each other from different

perspectives (Fisette, 2003), as a discernment of multiple perspectives simultaneously taken, as in the somatic concept of the “atmosphere” or self as center of experience.

Max van Manen (1990) asserts that the lived world is the world of natural, pre-reflective, pre-theoretical attitudes, in which all phenomenological research begins. In 1905, Husserl introduced the idea of phenomenological reduction, the *epoché*, or *bracketing* (Fisette, 2003). This concept of phenomenological reduction is related to our attitude of the world. Husserl spoke of bracketing out objects as seen in the world, putting them aside and not being troubled by them or their presence. Our focus should be directed to the acts themselves (Fisette, 2003). As we turn our attention to the acts, we discover what is known as *noema* and *noesis*, or, as van Manen (1990) refers to it, lived meaning. The *noema* is what is thought, and *noesis* is considered the actual act of thinking (Moran, 2002).

According to Moran (2002), Husserl believed that in our everyday natural attitude we focus just on the object, but the function of suspending the natural standpoint is to focus on the *noema* by a kind of reflection, which Husserl acknowledges is unnatural. Husserl thought that a special kind of phenomenological or philosophical reflection was required to focus on the *noema* differently from our ordinary act of reflection (p. 157). This connection between the *noema* and *noesis* is what allows us to make sense out of our world and is, therefore, a crucial part of intentionality (Moran, 2002).

Heideggerian Hermeneutic Phenomenology

Another prominent philosopher of the 20th century was Martin Heidegger (1889-1976). Heidegger was a student of Husserl who became interested in the philosophical

underpinnings of phenomenology but questioned the approach used by his teacher (Moran, 2002). His reluctance to accept Husserl's epistemological stance, and his desire to articulate his ontological viewpoint of hermeneutic phenomenology, brought about some disagreements between the two philosophers, and they soon parted ways. Heidegger's enthusiasm about his transition from description to interpretation led to many criticisms of Husserl's ideas and writings that addressed dualism, intentionality, and *epoche*, or bracketing (McConnell-Henry et al., 2009). Moreover, Heidegger was more interested in the meaning of being or what he termed being-in-the-world, as he aimed to determine the underlying meaning of experienced phenomena as they manifest themselves to people who construct meaning within their own social contexts (McConnell-Henry et al., 2009; Moran, 2007). This merger of methods in philosophy is what is now known as hermeneutic phenomenology.

Hermeneutics is derived from the Greek verb *hermeneusin*, or *hermeneuein* and the noun *hermeneia*, and means to understand or to interpret (McConnell-Henry et al., 2009). Hermeneutics is also linked to Greek methodology. It is believed that Hermes, a Greek god, was responsible for the delivery of information from the gods to the slaves. The delivery and the dissemination of the information from the gods required that Hermes had to speak a language understood by both in order for his communication to be effective, and to ensure the message was not lost during translation (Rodgers, 2007). Hermes' involvement in this interplay led to what is now known as hermeneutics; to understand or to interpret (McConnell-Henry et al., 2009).

The evolutionary process of hermeneutics took shape in the 19th and 20th centuries (Rodgers, 2007). Historians, such as Von Humboldt, and philosophers, including Kant, Dilthey, Husserl, Heidegger, and Gadamer, also embraced the fast-developing use of hermeneutics (Willig & Staintin-Rodgers, 2007). Friedrich Schleiermacher (dates), a German theologian, was also instrumental in this movement. He defined hermeneutics as the art of misunderstanding, and proposed a two-axial approach to interpretation. The dual axes methodology to interpretation included the grammatical axis and the psychological axis, with interpretation of the text being done simultaneously (Moran, 2000). The grammatical axis maintains that the language used in the text must be reflective and representative of the language/jargon being used by the community, while the psychological axis must be representative of the researchers' history and socio-cultural experiences that create lived experience (Moran, 2007). Schleiermacher maintained that having strong verbal skills was a crucial part of his practice; however, he also advocated strongly for “getting inside the mindset” of the author (Moran, 2007, p. 275). This practice is used as researchers try to immerse themselves in the lived experience of others (Moran, 2007).

One of Heidegger's fundamental beliefs was that, while phenomena are things that reveal themselves, what is revealed might not be accurate or true, so phenomenology cannot solely provide description but must rather rely on interpretation of texts. This is the foundation for his decision to use hermeneutics (Moran, 2000). Heidegger was famous for the use of *neologisms*, or new words, as he continued to imprint his stamp on the world of phenomenology (Moran, 2007). He first used the word *dasein* to describe a

fundamental concept upon which his thinking was grounded (McConnell-Henry et al., 2009). *Dasein* (McConnell-Henry et al., 2009; van Manen, 1990) refers to the distinct features we have as living creatures as we ponder what it is like to be human, and it also allows us to question our “being-in-the-world.” *Dasein* is considered the essential feature of human existence as humans appear in the world, sharing and relating with others in an interpretive manner (Maggs-Rapport, 2001; McConnell-Henry et al.; Moran, 2002).

Understanding the concept of *dasein* can be frustrating to the novice philosopher, given its various interpretations in numerous languages. However, *daesin* might be better understood if there is a basic conceptual understanding of the hermeneutic circle. The hermeneutic circle can be conceptualized as a place where the research strategically is able to uncover the true essence of the experience by utilizing spiral movements as the researchers analyze the data. This constant building, rebuilding, writing, rewriting, looking, relooking, moving from whole to parts and then back to the whole allows the researcher to uncover and illuminate the true essence of the experience and the practice of understanding (McConnell-Henry et al., 2009; Moran, 2007; Rodgers, 2005).

Hermeneutic phenomenology provides the philosophical and methodological underpinning for this inquiry into the lived experience of the Barbadian amputee.

Phenomenological researchers, such as Colazzi, Giorgi, Moustakas, Van Kaam, and van Manen, have all refined, cultured, and modernized the traditional principles of hermeneutic phenomenology, making it the most common qualitative approach used in nursing inquiry since the 1980s (Benner, 1994).

Max van Manen's Approach to Phenomenology

This phenomenological study into the lived experiences of Barbadian diabetic amputees was guided by van Manen's (1990) philosophy. The aim of phenomenology, according to van Manen, is to "construct animating, evocative descriptions of human actions, behaviors, intentions, and experiences as we meet them in the lifeworld" by utilizing the words of poets, artist, authors, and cinematographers (van Manen, 1990, p. 19). To carry out this task, van Manen proposes that the researcher use an overlapping method when interpreting the data. This interlocking interconnectedness of hermeneutics, language, and description is said to yield a richer, more in-depth understanding of the study phenomenon and give meaning to the essence of the experience.

Hermeneutics

Hermeneutics is the theory and practice of interpretation concerned with the nature of understanding and uncovering interpretations of meanings that are not immediately given. In addition, hermeneutic interpretation can only be performed when the researcher is capable of understanding and interpreting the text reflectively (van Manen, 1990). Reflexivity is subjective writing that not only adds to the trustworthiness of the research study but also offers techniques that allow the writer to be creative and innovative (Jasper, 2005). Max van Manen (1990) also refers to reflexive writing as textual practice. Here, he postulates that to understand is to interpret, and interpretation is necessary when trying to seek answers to questions. In this study, this researcher will seek to interpret all text that obtained from the interviews, field observations, and journal

reflections as a means of understanding the lived experience of the Barbadian diabetic amputee.

Language

The qualitative research approach that seeks to describe and clarify experiences as lived, and human science research can prove to be a difficult arena when novice researchers embark on such undertakings (Polkingshorne, 2005). This undertaking requires that the researcher spend long hours in the field with the subjects, and this collaborative effort yields what Polkingshorne (2005) called *language data*. *Language data* is data independent of single words. Instead, it uses interrelated, interconnected words combined into sentences to form dialogues. The textual writing of the documented reminiscent accounts and the stories told by the diabetic amputees in their language, using familiar jargon and semiotics, will all be used as this researcher tries to give meaning to the essence of the diabetic amputee's experience.

Description

There has been much discussion regarding the difficulty some researchers encounter when trying to understand interpretive descriptions. Max van Manen (1990) reminds us that the aim of phenomenological descriptions is to elucidate the lived experience, and those descriptions and interpretations that can be acquired from numerous sources as the researcher uncovers hidden meanings. The long engaged field placement, the interviewing process, the documentation of the engagement, and the analysis of the gathered data lead the researcher to formulate essential themes in the

extraction of the thick, rich data allowing the researcher to fully understand the lived experience of the diabetic Barbadian amputee.



Figure 1. Max van Manen's phenomenological approach: hermeneutics, language, and description (Brathwaite, 2016, adapted from van Manen 1990).

Max van Manen (1990) discussed four existential or fundamental lifeworld themes. van Manen noted that in human experience, the themes are considered separately, even though they exist simultaneously. These four existential themes are fundamental to human life as they “are the themes that are always present in the lifeworld of all human beings” and “represent an intricate unity of the lifeworld that can be differentiated, but not separated” (van Manen, 1990, p. 104). These four existential themes compose the lifeworld: *spatiality*, *corporeality*, *temporality*, and *relationality*.

Spatiality refers to the experience of people whenever they become aware of their surroundings or environment, before language is used to structure and identify what is seen or felt, and refers to how the environment influences a person. “In general, we may

say that we become the space we are in” (van Manen, p. 102). *Corporeality*, or lived body, refers to the experience of embodiment or the experience of the body in the world. Each individual lives within a physical body, and it is from this area that they interact with others and the world. It is through this interaction that the body becomes recognized and what may exist within can be open to possible discovery. Corporeality is therefore seen as being responsible for self-discovery and self-revelation.

Temporality, also known as lived time, is the experience a person has of time, and is thought to be multi-faceted. A good example of this is a person who is not concerned with objective time or clock time. The person is concerned with the here and now and does not allow clock time to impact what he or she is experiencing. Other aspects of lived time could be related to the person’s memory of what took place in the past, what is occurring presently, and what possibilities exist in the future. All these features take place within the lived experience of time and are used by people to form an understanding of their experience. *Relationality* refers to the relationship an individual has with a person or other persons who share the same interpersonal space. Relationships are formed with individuals, families, or community, and these newly formed relationships can add new meaning and value to the individual’s experiences as they are lived.

In order to fully explore the lifeworld of Barbadian amputees, it is important to understand how they attach themselves to the world and how they see themselves in the world. The amputees' lived body is their physical presence and all of the feelings, thoughts, interactions, verbal and nonverbal communication experienced as they learn to

live as an amputee. Their lived space refers to how they see themselves in their home environment, while reflecting on any modifications that were necessary in order for them to feel comfortable in an old space but under drastically altered conditions. This reflective exploration can also allow for the verbalization of feelings, negative or positive, regarding such adjustments to their new life lived day-by-day as an amputee. Lived time to the Barbadian amputee can be captured subjectively and measured or accounted for as time spent in the home, possibly giving an account of how an 8-hour work day can now seem like eternity when an individual is not able to leave the confines of the home.

Caribbean people are often referred to as “social butterflies,” always finding something to do outside the home. The amputation will bring a halt to all past social functions, thus “clipping their wings.” Such firsthand accounts provide the researcher with valuable insights as amputees reflect on life before the amputation, their feelings at the time of the interview, and what, if any, future endeavors are possible. Their lived relationships were explored in the context of their connectedness to others in their homes, neighborhood, or community. While assessing their perception of how they will be received by others, or how others will receive them, given their disability.

The lifeworld of an amputee can be noted as a powerful and truthful word, providing perspicacious depictions of everyday life that no other research tradition offers (Seamon & Mugerauer, 2012). This existential investigation, along with contextual processing and expressions, allows this researcher to capture the true meanings, thoughts,

feelings, and emotions encapsulated and deeply entrenched in the participant's lifeworld (Munhall, 2007). Max van Manen (1990) refers to phenomenological research as the study of essence, a description of the experiential meanings we live as we live them, and as the human scientific study of phenomenon. His manner of conducting this human science research is grounded in *semiotics*, the science of signs and representations, and the essential elements of a phenomenon; those things, which make it recognizable as such. The aim of this type of phenomenological inquiry is to "construct an animating, evocative, description of human actions, behaviors, intentions, and experiences as we meet them in the lifeworld" (van Manen, 1990, p.19).

This manner of conducting human science research was grounded in semiotics, the science of signs and representations. Max van Manen (1990) proposed an approach to qualitative research, which combined hermeneutics and phenomenology. In his scheme, the researcher can recognize his or her earlier experiences, knowledge, and viewpoints and how these may influence the researcher in all phases of data collection, analysis and interpretation. Max van Manen's approach borrowed from Heideggerian's phenomenology using an interpretive approach to study the participants' everyday worlds from the viewpoint of the people experiencing a particular phenomenon. van Manen introduces several overarching interconnected descriptions, interpretations, and language activities to describe the individual's being in the world.

Exploring the topic of the lived experience of the Barbadian amputee as it is related to their *quality of life* (QoL) and functional status is best suited in this context. A qualitative understanding versus a quantitative understanding seems to be a better fit for

this topic, because of the effects amputation could have on the individual's QoL, and the true essence of this phenomenon cannot be adequately explained or understood in a quantitative context. The way people describe their QoL and the effects of being an amputee cannot be separate and apart from their lives and daily activities. Essentially, their respective relationships, work activities, physical and psychological wellbeing comprise crucial parts of their being and how they experience their existence.

Significance of the Study

It is important for nurses to explore the numerous approaches and treatment options available to help deal with the dire global health problem of diabetes and its complications. Community and public health nurses and diabetic educators are all positioned to educate patients and their families regarding the dangers and complications of this non-communicable disease. Without a thorough understanding from those who have experienced the phenomena and the descriptions of their meanings regarding it, nursing would not have the tools and knowledge to provide a basis for culturally appropriate interventions to perform evidence-based practice. Nurses must be emphatically and convincingly involved in identifying those individuals who are at risk for amputation. In addition, healthcare professionals must understand the common denominators that have placed individuals at risk of becoming amputees. The findings of this study may have implications for nursing education, nursing practice, nursing research, and health and public policy.

Significance of the Study to Nursing

Diabetes-related lower-extremity amputations can have a direct and traumatically detrimental impact on a person's quality of life. The individual's understanding of amputation is of importance to nursing science. This study will be helpful in filling the void in the paucity of documentation in the literature. Nurses have a great need to understand the amputee's experience (diabetes related or not) in order to help them cope. The value lies in the fact that this specific group of people gives nursing insight into the amputee's experiences. It is important for nurses to explore the numerous approaches and treatment options available to help deal with the dire global health problem of diabetes and one of its most devastating complications. A phenomenological study of this capacity may provide unique insights into the lives and experiences of those Barbadians who have experienced a lower-limb amputation. There is limited information in the literature about the lived experience of Barbadians as it relates to amputations.

Implications for Nursing Education

The loss of a limb is a traumatic event, and the post-operative care of the amputee could be the most challenging for patients and families. As patients recuperate, they consider the constant presence of nurses to be particularly important to the process of rehabilitation (Royal College of Nursing, 2007). To effectively care for the lower-leg amputee, nurses working in rehabilitation should possess the knowledge needed to address issues related to the physical loss of the limb, the psychosocial stressors associated with the loss, the functional limitations, and the individual's quality of post-amputation life.

As the population of diabetic amputees continues to grow in Barbados, nurses there are faced with the daunting task of teaching and educating patients and families about caring for themselves post-amputation and assisting the patient in reaching his or her maximum level of functioning. The results of this study may influence nursing educators in Barbados to re-evaluate their curriculum to reflect on the advances in treatment options as they relate to the amputee. Persons with disabilities are often seen as marginalized and are faced with many challenges. A physical disability can be perceived negatively by the individual, by those who are charged with providing care and by the community at large.

Furthermore, the stigma associated with the disability can have negative consequences on the care delivered and the care received, leaving some individuals feeling shameful, dehumanized, useless, and dependent on others. Caregivers should be mindful and sensitive of these issues, focusing on respecting and reducing the humiliation of these individuals, trying uncompromisingly to foster an atmosphere of caring and protecting the self-esteem and dignity of the individuals in their care.

Implications for Nursing Practice

Psychological support is essential in every specialty of nursing but particularly when patients experience chronic illness and its complications. Individuals with lower-limb loss can experience significant disruptions in many important life domains, including mobility, occupational status, social relations, participation, and mood (Coffey, Gallagher, & Desmond, 2014). Nurses caring for patients with lower-leg amputations because of diabetes experience many issues with functionality and overall quality of life.

This study provides insight into the challenges the participants experience in this kind of condition. Furthermore, this study indicates strategies that may be developed to assist the nurse in planning and providing care to this population of patients. Understanding the experience of the Barbadian diabetic amputee may provide nurses with the tools needed to assist patients and their families in a better understanding of their life post-amputation.

Implications for Nursing Research

According to Polit and Beck (2010), being a nurse in the 21st century can be challenging, as well as exciting, given the practice arena where nurses are expected to be knowledgeable, extraordinarily skillful and talented, in delivering high-quality, superior care. To accomplish this task, nurses must be able to engage in a systematic method of nursing scholarship designed to develop trustworthy proof and confirmation about pertinent issues related to the nursing profession (Polit & Beck, 2010). This engagement is known as nursing research. Nursing research evidence guides professional practice, an evidence-to-action continuum referred to as evidence-based practice (EBP) (Polit & Beck, 2010). EBP is a lifelong problem-solving approach concerned with the delivery of health care that integrates the best evidence from research studies (i.e., external evidence). EBP is integrative in nature and considers the patients' preferences, their values, clinicians' expertise, and internal evidence gathered from patient data (Spencer et al., 2013). Better outcomes are evident when EBP is delivered in a context of caring and a cultural environment that supports it (Melnyk, Gallagher-Ford, Long, & Fineout-Overholt, 2014).

This merger of nursing research and evidence-based care as practice norms can be utilized as powerful tools in the fight to manage chronic diseases and their complications. This phenomenological inquiry may provide additional EBP facts that can be used to design further studies addressing issues related to caring for the diabetic amputee. There is little research available on the lived experience of the Barbadian diabetic amputee. The findings of this study are intended to fill a void in this research, which consequently may help encourage nurses to become more involved in nursing research. It may allow us to determine shared themes of the lived experiences through studying those unique to the island of Barbados.

Implications for Health/Public Policy

Health policy is intended to address problems or changes that need to be made within a health care system. However, it is crucial that the identification, exploration, and understanding of the problem are the first steps before intervention at the policymaking level (Harrington & Estes, 2008). Brownson, Chriqui, and Stamatakis (2009) further articulated three key domains necessary in health policy process: Understanding approaches that will enhance policy adoption, content to identify specific elements that will prove to be effective, and outcomes to document the effectiveness and impact of the policy. The process by which public policies are created in the United States can be noted as being complex, confusing, dynamic, and even mysterious. Public policies are initiated and introduced at the legislative, executive, and judicial branches of federal, state and local governments, and include all policies that originate at all levels. The three major policy categories are defense, domestic, and foreign. Social policy,

which falls under the umbrella of domestic policy, includes legislation pertaining to health and welfare (Carroll & Estes, 2008).

In Barbados, the Ministry of Health (MOH) is the sole agency responsible for the delivery of health care, and is headed by a Minister responsible for defining policies, providing strategic direction, regulations, norms and standards, as well as indicating political direction. The decision-making is centralized, and there are no local health authorities. The Minister of Health represents the government of Barbados in many regional and international health-related organizations and works collaboratively with the Caribbean Community Market (CARICOM), the Pan American Health Organization (PAHO), and the World Health Organization (WHO) to ensure that programs and policies are implemented to eliminate disease, while trying to improve the quality of life of those served (Pan American Health Organization Health Systems Profile Barbados, 2008). Despite the differences in governments, they all try to improve the health of their people, while working on controlling the cost of health care. Identification and prioritization of resource allocation, as well as assuring that all health care services are equally distributed, and quality of care is enhanced, are of primary importance to these governments (Brodeneimer, 2005).

The International Council of Nurses (ICN, 2012) believes that nurses are key to improving access to quality and cost-effective care and enhancing the health of populations. It is therefore essential that nurses are able to efficiently and effectively influence change at local, organizational, system, national, regional, and international levels. Being knowledgeable about the legislative processes is a valuable tool for nurses

wishing to improve access to care and the quality of health care provided (Harrington & Estes, 2001). It is hoped that the results of this inquiry may influence policymakers in the Caribbean region to focus their efforts on allocating more financial resources at the primary care level, while emphasizing and highlighting services that stress public education, the importance of health promotion, and disease prevention. Government task forces headed by health professionals, educators, and administrators could focus their efforts on implementing strategies to help control diabetes and other chronic conditions. Brownson et al. (2009) concluded that the incorporation of qualitative data could be used as a powerful tool when trying to influence policy deliberations, setting priorities, and proposing policy solutions by telling stories that have an emotional hook and an intuitive appeal. In this case, giving a voice to amputees of Barbados, a voice that otherwise might not be heard. The implication is that a function of nursing is as a proactive advocate for health care reform.

Scope and Limitations of the Study

The scope of this study dealt with the lived experiences of Barbadians with lower-extremity amputation as a complication of long-term *diabetes mellitus*. A purposive sample of diabetic amputees was recruited to participate in one-on-one interviews. All participants must have been able to speak, read, and write English, experience lower-limb loss secondary to the complications of diabetes, and been willing to engage and openly discuss their experience as a diabetic amputee. Participation is voluntary, limited to English-speaking Barbadians age 18 years and older who have undergone a lower-leg amputation, and all participants must be living in Barbados at the time of the interview.

The phenomenological approach of Max van Manen was detailed as each participant described his or her lived experience.

The limitations inherent in this study included the bias of the researcher, the effect of the observer in the environment on the actions of the subjects, the role of perception and memory to recreate history, and the transferability of the findings. As a novice researcher returning to Barbados to conduct research, it proved to be challenging as the participants recognize that the researcher is also a Barbadian and was likely to say what they think the researcher wants to hear. According to Ausband (2006), novice researchers engaging in the process of qualitative research can think of their work as metaphorically like quilting. As quilters begin a project, they think about planning, cutting, sewing, quilting, and binding before initially starting the lengthy and involved project. In qualitative research, the process of planning, data collection, data analysis, and reporting can be viewed as lengthy and time-consuming.

This volume of data makes accurate, discerning analysis and interpretation time-consuming. This limitation can be alleviated by the prolonged engagement the researcher spends with each participant in the field. It is imperative that the researcher follows all the necessary steps in the data-collection process to ensure that data is collected and transcribed accurately and correctly prior to leaving the island. It is desired that the participants will offer honest and genuine responses as they answer the questions for this research study. While the findings of this study cannot be transferred to another population, the rich descriptions might yield commonalities among all amputees everywhere in the world through the specifics of the Barbadian experience. The results

should enable others in similar positions to recognize something of themselves that others are not able to see. This study resulted in rich descriptions of the participants' recollection of their lives as amputees.

Chapter Summary

This chapter provided an introduction to the study, in which background, problem, purpose, and philosophical underpinnings were discussed. In addition, the significance of the study to nursing, nursing education, nursing practice, nursing research, and health and public policy was delineated. The scope and limitations of the study were imparted. Chapter Two will follow with the literature review.

CHAPTER TWO

REVIEW OF THE LITERATURE

Synthesis of relevant literature is vital to research. Popay et al. (2006) communicated that the synthesis, at minimum, is a summary of the current state of knowledge in relation to a particular research question. Therefore, synthesizing and summarizing the results can help determine any deficits or gaps in the literature. The purpose of a literature review is to critically examine segments of a published body of knowledge using classification, summary, comparison of prior research studies, reviews of literature, and theoretical articles. Conducting a literature review reveals what has already been documented on a specific topic, while allowing the researcher to screen and select specific scientific papers that meet the criteria for the research topic. Garrard (2009) and Creswell (2009) described the three procedures used when conducting a literature review in a qualitative report: (a) The literature is used to structure the problem during the introduction to the research study; (b) It is presented in a separate section as a review of the literature, and (c) It is presented in the study at the end as the foundation for making comparisons and contrasting the indications for pertinent further research.

The purpose of this qualitative phenomenological inquiry was to explore, understand, and describe the lived experiences of Barbadians with amputation as a long-term complication of *diabetes mellitus*. A broad search of the literature was conducted to provide the context within which the lived experiences of Barbadians with lower-leg amputations could be studied. Computer databases, such as Cumulative Index to Nursing Allied and Health Literature (CINAHAL), Blackwell, OVID, Medscape, EBSCO Host,

OVID, Science Direct, and ProQuest were used to access pertinent information regarding the phenomenon of leg amputations caused by diabetes. Key words used in the search included: lower leg amputations, diabetes, quality of life of patients with lower-limb amputations, functional mobility, depression, psychosocial factors, amputees, Barbados, and amputee capital of the world.

The key words were used to locate pertinent information about the topic. Citations were limited by subject (i.e., exploring the challenges faced by the amputee), by language (i.e., English), and by time (i.e., 2009 through 2014). The review examined, and critiqued studies related to the psychological impact of amputation; functional and physical impact of amputation; and the quality of life of the amputee. To facilitate a better understanding of the study concepts, this literature search will be organized using key term headings: Historical Context, Physiological Impact of Amputation, Psychological Issues Associated with Amputation, and Quality of Life Issues Related to Amputation.

Historical Context

Amputation is referred to as the surgical removal of part of the lower limb by transection of the leg, the foot or a digit, and necessarily includes the removal of bone (Jeffcoate & van Houtum, 2004). Amputation surgery is a primeval procedure dating back to prehistoric times. Lower extremity amputation is one of the oldest-known surgically performed procedures and has been performed since antiquity for a number of reasons (Magee, 1998). The evolution of amputation can be divided into four time

periods: The Neolithic Period, 1700 BCE and the 1st century Christian Era (CE) period, The 14th to 19th century period, and the 20th century period.

Amputations during the Neolithic period, or New Stone Age, were performed as a result of nonsurgical loss of limbs, disease, congenital factors, frostbite, accidents and rituals or punitive actions. Anthropologists have been able to discover evidence of the practice of amputation depicted in cave paintings in Spain, France, and New Mexico dating back 36,000 years ago (Cantos, 2005). Hand imprints on the cave walls showed the loss of digits, and excavated cadavers have been found with prosthetic devices to replace severed extremities (Kirkup, 2007). It is also noted that during this time it is speculated that individuals mutilated and defaced themselves (even undergoing voluntary amputation) to demonstrate faith and to pacify the gods (Whitelaw, 2005). The amputation of limbs was a common practice among those in the Middle East (Sellegren, 1982). Those who committed crimes lost their limbs consequently, leaving individuals with medical afflictions skeptical and unwilling to have the procedure done for fear of being labeled a criminal. Subsequently, medical certificates were issued to those individuals who received amputations for medical reasons (Sellegren, 1982).

In 1792-1750 BC, The Babylonian *Code of Hammurabi* first documented enforced punitive limb amputations on slaves who were forceful when engaging with free citizens (Mavroforou, Konstantinos, Karachalios, Chatzitheofilou, & Giannoukas, 2014). In 385 BCE, Plato's *Symposium* spoke of therapeutic amputation of the hand and the foot, describing how Hippocrates of Cos (460-380 BC) provided the earliest account of therapeutic amputation in *De Articularis* for vascular gangrene. In 5 BC, Hippocrates

was credited with having performing the first amputations on gangrenous limbs, doing so by cutting through the gangrenous portion of the limb to lessen the pain to the patient (Berger & Bacon, 2009). In the first century CE, Celsus was noted as the first to use a circular amputation procedure and ligatures as means of preventing hemorrhage (Robinson, 1991). His works clearly account the procedure of vessel ligation and proximal division of skin from the bone, allowing a flap of skin to cover the stump (Wooster & II, 2012).

The third period, from the 14th to 19th century, involved the introduction of gunpowder, which dramatically changed the nature of battlefield injuries (Gosselin, 2005). Guns replaced slingshots and arrows, and gunpowder increased the wounding potential during war (Canton, 2005). Initially, concern was expressed that blackening of the tissues by gunpowder, due to obligatory weapon discharge at close range, was a source of "poisoning" (Kirkup, 2007). Removal and neutralization of the poison by simple lavage and later by instilling warm, or possibly boiling, oil was viewed as a key step in management (Wangensteen, Smith & Wangenstein, 1967). In the 15th century, surgeons were becoming more specialized and left the more difficult operations to untrained, crude, and uneducated barber surgeons, who were the sole surgical providers in the dark ages (Wooster & II, 2012). As a result of the barbaric nature of the procedure and technique, the search for new and better techniques was underway. Despite advances and innovations in technique, the high rate of complications involving amputations preoccupied the minds of many surgeons of the time (Wooster & II, 2012). Barbaric surgical techniques of the 16th century were slowly being replaced by less traumatic

practices. Amputation was seen as one of the most challenging operations a surgeon could perform, and, prior to the advent of perioperative anesthesia, it took a barber surgeon three to four minutes to amputate a leg.

Andre Pare (1510-1590), a French army barber surgeon, was the first military surgeon to promote primary amputation for the treatment of gunshot wounds (Hernigou, 2013). Pare's greatest contribution to amputation surgery was during the battle of Turin in 1556. When he ran out of boiling oil, he used a potion made from turpentine, roses, and eggs to dress wounds (Whitelaw, 2005). A day after applying the potion, Pare noticed that the wounds dressed with the concocted balm improved faster than wounds scalded with oil. Pare has received credit for several other major surgical contributions, such as the use of vessel ligation—rather than hot irons—to control hemorrhage (Whitelaw, 2005). He also used a thread-like material to constrict the patient's blood vessels, thus stopping the flow of blood from severed arteries and veins (Hernigou, 2013). In addition, Dr. Pare was the first to identify the link between wound healing and the nutritional status of the patient (Gosselin, 2005), and he is also credited for his invention called the "crow's beak," an instrument that we know today as a hemostat. Pare was instrumental in introducing amputation as a life-saving procedure. His innovative surgical procedures and knowledge of prosthetic science were important contributions to amputation and prosthetics design (Whitelaw, 2005).

There were other significant contributions to the techniques used in amputations in the 17th and 18th centuries. Shortly after Pare's reintroduction of vessel ligation, William Harvey discovered the circulatory system in 1628, setting the stage for further

development and use of the tourniquet (Wooster, 2012). In 1718, Jean Louis Petit, a French surgeon, used a mechanical screw tourniquet to control the pressure by making minor adjustments to the screw (Love, 1978). Petit's tourniquet allowed surgeons to view any residual bleeding vessels without reapplying the tourniquet (Kirkup, 2007). These tourniquets allowed surgeons to more effectively control bleeding, thus reducing the amount of blood loss during surgery.

Prior to the introduction of antiseptics in the late 19th century, a limb amputation was associated with extremely high morbidity and mortality, at 50%-80% (Berger & Bacon, 2009). Patients also continued to undergo amputation without reasonable means of pain relief in what some have termed the heroic era of surgery (Kirkup, 2007). Surgical amputations performed in Europe in past centuries used alcohol or opium as the basic form of anesthesia, whereas in South America, indigenous folk who performed amputations used chewed cocoa and alkali that was released from cocaine as their form of anesthesia prior to an amputation. In 1846, general anesthesia not only relieved the patients' pain but also gave surgeons time to operate more accurately, while pursuing alternative operations that avoided amputation (Kirkup, 2007).

Despite the number of wars that continued to plague the 20th century, this time period is noted for its marked advances in medical/surgical techniques used in amputation (Cantos, 2005) and increased sophisticated computerized prosthetic limbs (Stevenson, 2010). World War I (1914-1918) was noted for its prevalence of anaerobic gangrene that resulted in the increased number of compound fractures requiring limb amputation (Robinson, 1991). By World War II (1939-1945), the number of hospitals and amputee

centers outfitted, equipped, and staffed with physicians, nurses, therapists, and prosthetic personnel to treat wounded soldiers increased (Wooster, 2012). Modern medicine has afforded us the opportunity to witness many improvements and innovations to amputation surgery: the use of tourniquets, improved aseptic techniques, anesthesia, and numerous antibiotics (Whitelaw, 2005). As we continue to make more advances in the 21st century, and as we accept amputation as a restorative effort, the goal of better prosthetic limb fitting and increased functional mobility for the patient should be paramount (Cantos, 2005).

Physiological Impact of Amputation

Lower-extremity amputation is expected to limit physical functioning to some degree. However, as the patient adapts to the amputation and gains skills in utilizing prostheses and other aids, greater mobility and autonomy is possible. Sauter, Pezzin, and Dillingham (2013) conducted a quantitative study examining the effectiveness of rehabilitation received in an alternative post-acute care setting used to improve functional outcomes for 297 patients undergoing major lower-extremity amputation. This prospective study took place between 2001 and 2006 and analyzed the physical functioning and impairment in activities of daily living, 6 months post-amputation.

A survey instrument was developed by the researchers to acquire comprehensive clinical and functional data from patients regarding their baseline, acute post-surgical status and post-acute rehabilitation status. Information was obtained from three main sources: Clinical data was obtained from acute-care medical records, a face-to-face patient interview was conducted, and pre-surgical information pertaining to the patient's

health and wellbeing was gathered. This included their physical functioning 4 weeks prior to the amputation, and a follow-up telephone interview at 6 months post-acute-care discharge. Outcomes were measured using two instruments: the MOS Short Form (SF-36) tool captured physical and mental health, and the basic ADL tool was used to gather information on physical functioning. Both tools were used at the beginning of the study and again at the 6-month follow-up. Levels of amputation were classified into four categories: *foot* (transmetatarsal or above), *unilateral transtibial* (below knee), *unilateral transfemoral* (through or above knee), and *bilateral* amputations (excluding toe amputations).

One hundred and twenty-nine patients (43.4%) received most of their post-acute care in an acute inpatient rehabilitation facility (IRF), while 95 patients (32%) were discharged to a skilled nursing facility (SNF), and 73 patients (24.6%) were sent home. Transtibial amputations were performed more often in this population (45.8%), and the least number of patients received transfemoral amputations (13.8%) and foot amputations (13.8%). Patients who received transtibial amputations were more likely to receive post-acute-care in an inpatient rehabilitation facility (55.0%) or skilled nursing facility (49.5%) compared to home care (24.7%), while patients who were bilateral amputees were more likely to receive post-acute-care in a home care setting (38.4%) compared to a skilled nursing home (18.9%). The patient's socio-demographic profile, amputation level, and health status were all characterized using descriptive statistics.

The research findings revealed that the inpatient rehabilitation setting produced better outcomes for those patients than those individuals who were treated in the nursing

home, or those patients who were discharged to home 6 months post-amputation. These results indicate that there is a positive association between inpatient rehabilitative services and several health-related outcomes for dysvascular amputees. Patients receiving care at IRFs experienced better physical functioning and physical composite scores compared to those discharged directly home. Additionally, IRF patients showed significantly better general health in IRF as compared to SNF or home care. The IRF patients were also less likely to score in the lowest spectrum for physical functioning, role physical, and physical component summary scores in IRF, compared to SNF. Lower ADL impairment was observed in IRF settings as compared to SNF. This study concluded by highlighting the importance of providing patients who undergo major lower-limb dysvascular amputation, the opportunity to have access to inpatient rehabilitation facilities.

Corey et al. (2012) conducted a quantitative study to examine the relationship between the socioeconomic status of patients and 5-year mortality after major lower-extremity amputation in the U.S., using the patients' education level to measure their socioeconomic status. A retrospective review of the electronic medical records of all patients who had undergone an above- or below-knee amputation at the Nashville Veterans Affairs Medical Center between January 2000 and August 2006 was used to analyze the formal levels of education of the study patients. Univariate analysis, multivariate logistic regression, and a standard Kaplan- Meier curve were used to analyze the data. Outcomes were compared between those patients who were high school graduates versus those who did not complete high school. Two hundred and forty-five

primary major lower-extremity amputations (above and below the knee) were performed on 203 patients by the vascular surgery service during the study period. One hundred and ninety patients completed high school, and 83 subjects did not. The level of education of study participants was documented by telephone contact with patients or their families, and the level of education was obtained from the medical record for those patients or families who could not be reached by telephone.

The results of the study showed that patients of lower socioeconomic status, as measured by education level, have increased long-term mortality and were less likely to ambulate with prostheses after major lower-extremity amputation. Of the 135 patients who were alive 1 year after operation, 59 (43.7%) were able to ambulate with prosthesis. Patients who completed high school were more likely to ambulate with prosthesis after amputation (55% vs. 27.3%, $p = .001$), even after adjusting for type of operation among other clinical factors. The 1-year mortality rates after amputation were similar between patients who had completed high school and those who had not (25.2% vs. 33.7%, $p = .259$), and the 5-year mortality rate for patients who had completed high school was lower than for those who had not (62.6% vs. 84.3%, $p < .001$), even after adjusting for important clinical factors (odds ratio for death, .377; $p = .022$). It was recommended by the authors of this study that surgeons must carefully select appropriate candidates for amputations due to their poor prognosis. They also communicated that future research in this area should be devoted to developing risk models that would take into consideration those factors that best predict outcome and mortality after amputation. Such models will

identify those individuals who should not be offered amputation due to their poor prognosis and their predisposition to poor postoperative outcomes.

Livingstone, Mortel, and Taylor (2011) conducted a qualitative study using grounded theory, aimed at providing health professionals with a comprehensive understanding of the realities associated with post-amputation. The study sample included five diabetic amputees and their caregivers. The data were analyzed using the cyclical method detailed by Glaser (1992). Imposed powerlessness, adaptive functionality, and endurance emerged as the three core themes detailing the participants' path to perpetual resilience. All three themes highlighted the physical, social, and psychological consequences of having a lower-limb amputation.

Imposed powerlessness was revealed during the initial diagnostic period as articulated by the participants. Feelings of frustration and lack of trust in the health care delivery system, as well as not being fully informed of the consequences of their diabetes, were of concern to the participants. Adaptive functionality concerned the participants' reaction to the physical aspects of the amputation. Mobility, environmental changes, and the impact of limited social contact were all issues within this theme. Furthermore, with respect to adaptive functionality, participants reported feeling shocked, in disbelief, angry, fearful, and in a state of turmoil immediately following the amputation.

The integration of the three core categories resulted in a chronological pathway that was conceptualized as “The Path to Perpetual Resilience.” This pathway represents the life of the participants as they lived optimistically, while trying to cope with the loss of the limb. The participants' initial voyage began with feeling and reporting a sense of

powerlessness and incapacity. However, they endured, while remaining resilient on their journey, adapting to their disability. The culmination of the journey was met with a sense of healing and acceptance of their limb loss. The authors were able to reaffirm the importance of the amputee moving from feelings of anger, fear, and uncertainty to a more positive adjustment and acceptance of disability.

Norvell et al. (2011) conducted a quantitative study examining factors associated with mobility success during the first year following amputation. A prospective cohort sample of 87 amputees from two VA medical centers was selected to participate in the study. All participants had experienced a first major unilateral amputation surgery. Participants were assessed in person when possible, or by telephone, at four time-points: before surgery, 6 weeks after surgery, 4 months after surgery, and 12 months after surgery. Additional data were gathered via systematic review of the medical records, and information regarding demographics, the index amputations, health factors, and mobility, were provided by subjects prior to surgery or post-surgically, depending upon when they were enrolled.

The primary cause of the amputation and the anatomic level of amputation were categorized as transmetatarsal (TM), transtibial (TT), or transfemoral (TF). The presence of presurgical comorbid conditions was determined using the Charlson Comorbidity Index 11. The VA Large Health Survey assessed smoking status. The Alcohol Use Disorders Identification Test (AUDIT-C) was used to assess alcohol consumption patterns a year prior to the amputation. Satisfaction with mobility at 12 months was determined by the response given to the question, “How satisfied are you with your

current walking ability?” The level of mobility at each time period was measured using the Locomotor Capability Index (LCI-5), and successful mobility was determined when the level of mobility at 12 months was the same as, or greater than, the premorbid mobility level. The Satisfaction with Life Scale (SWLS) was used to measure global life satisfaction.

Results of the study revealed that there was a significantly ($p < .01$) larger proportion of individuals with diabetes in the TM group (100%) compared with the TT (85%) and TF groups (50%), and the percentage of smokers increased with higher levels of amputation. Twenty-eight subjects (37%) achieved mobility success, and 43 subjects (57%) were satisfied with their mobility. Individuals who were 65+ years old who were noted as having an alcohol use disorder, having a history of hypertension, or had been treated for anxiety or depression were less-likely to achieve mobility success. Mobility success was associated with mobility satisfaction and satisfaction with life. Although higher absolute mobility at 12 months was also associated with mobility satisfaction and overall life satisfaction, 50% of individuals who achieved success with low to moderate 12-month mobility function reported being satisfied with their mobility. The authors concluded that it is essential that the individual’s mobility level pre-amputation is considered before being able to measure success post-amputation. These recommendations strongly suggest that the amputee’s psychological, physical, and social states be considered as measures of mobility.

Jayaraman, Deeny, Eisenberg, Mathur, and Kuiken (2014) conducted a case study to examine the use of a GPS unit and a step-activity monitor to quantify community

mobility and social interaction of an individual with transfemoral amputation as a result of dysvascular disease. The subject of interest in this study was a retired 76-year-old African-American woman who lived alone and had a history of smoking, hypertension, congestive heart failure, and coronary artery disease. Three years prior to enrolling in the case study, she developed non-healing dry gangrene in her right foot, which resulted in a transtibial amputation. Ten days following the amputation, she went back to surgery and a transfemoral amputation was performed. She progressed well enough to see the prosthetics for fitting of prosthesis one-year post-surgery.

The patient was examined by a physical therapist and prosthetician prior to being outfitted with the GPS and step activity monitor, and it was determined that this patient was a K2, limited community ambulator. This designation was obtained by using the Medicare Functional Classification Level (MFCL). At the K2 level, a person has limited mobility and may walk for limited periods of time without significantly varying his or her speed. She stated that her goals were to use her prosthesis inside the home as she performed her activities of daily living and household chores. Her outdoor activities included walking from the car in a parking lot to a store, walking inside the store, walking to church, and walking inside the church. The Travel Recorder XT, a small, lightweight, accurate GPS data logger device with a large data storage capacity was used in this study to track the participant's location, and her step activity (accelerometer) was used to track her steps. Data were collected by attaching the monitor to the prosthesis and synchronizing both devices to start recording at the same time.

The assessment plan prior to this case study was to use both standardized patient-report and performance-based tests to determine prosthesis use and ambulation within the home and community, as well as the patient's self-reported perceptions of community mobility and social interactions. She was involved in social activities, such as attending church, and left her home for personal chores, such as grocery shopping. The patient was required to carry a commercial GPS unit and step-activity monitor to quantify her community mobility and social interaction daily for 1 month. The information from the GPS unit and step-activity monitor provided quantitative details on the steps the participant took in and out of the home, her wheelchair use, her prosthesis use, driving trips, and time spent on social and community trips. She performed all of the clinical tests with great enthusiasm and noted that she would not feel uncomfortable wearing the monitor.

The GPS unit was configured to record the patient's location every 10 seconds, and the data were configured in Microsoft Excel and the mapping and spatial analysis software (ArcGIS). Once in ArcGIS, the entire dataset was split into specific days for detailed analysis. A data analyst determined the patient's movements and community destinations each time she left a location and arrived at a destination for each day of the case study. Data was segmented and coded into sections based on the patient's location in the home or community, her mode of transportation (walking, driving, or using a wheelchair), and her transitions to or from the car or community. At the end of the study, the GPS was returned, and the data was uploaded.

Data analysis started with the identification of the days when trips were made outside the home. High speeds indicated car trips. The GPS recognized her leaving from the front of the house and stopped in parking lots. Tight cluster points in the data and low speeds indicated the point of departure and arrival for the first car trip and traveling to and from the car. Determining the destination was the second component of the data analysis process. The analyst used an aerial base map provided by ArcGIS, along with Google Maps, to interface the data, and was able to determine all the destinations for this patient, including identifying whether the destination was commercial, residential, open space (parks or spaces not in or near buildings), mixed use (buildings with mixed commercial and residential uses), or medical (hospital or medical facilities). During the final analysis, the researcher was able to determine the number of days the patient left the house, the destinations the patient visited, the time spent at those destinations, the distances traveled, the modes of travel used, the number of steps taken on walking trips, and the number of steps taken in and out of the home.

The GPS unit was on the patient for 28 days and collected data for about 15 hours per day. The patient left home on 4 of the 20 weekdays and on 6 of the 9 weekend days, spending at least 23.2 hours per day on weekdays and 20.1 hours per day on weekends at home. Most of the patient's time was spent at religious destinations (5.9 hours), followed by other residential locations (2.4 hours), outdoor open space (2.1 hours), and commercial locations (1.1 hours). The most frequently visited destinations were commercial (8 trips), followed by religious (5 trips), medical (2 trips), open space (1 trip), mixed use (1 trip), and other residential (1 trip). Commercial trips were 6.23.3

minutes/1.350.63 miles, religious trips 9.9 1.6 minutes/3.020.2 miles, other residential 111.0 minutes/3.270.47miles, and medical 31.32.9 minutes/10.942.69 miles. The patient used a car to get to all destinations. Traveling from home to any of these destinations was about 3.42.5 miles and took approximately 11.18.1 minutes. The patient walked or used a wheelchair to get to and from the car. Twelve of the 28 pedestrian trips to or from the car were accomplished using a wheelchair, and 16 were accomplished by walking. The patient recorded very few steps when she remained at home, and the average (SD) steps taken during outdoor activity days were 5273 at home and 188,132 outside the home.

In conclusion, the researcher was able to quantify community mobility and social activities of an individual with amputation, by detailing and computing steps, as well as the reasons the steps were taken during the everyday life of the amputee. The findings provided valuable insights into the patient's prosthesis use in everyday life and how use of prosthesis, when worn, could improve mobility and community reintegration for amputees. Limitations of the study included the resolution of technological issues, handling and analysis of large data sets, and the small sample size.

Four quantitative and one qualitative study were synthesized in this section on physical functioning. The results of these studies all support the notion that the ability to return to maximum functional capacity is paramount to the amputee, although it seems that even some degree of improved functioning yields a level of satisfaction by the amputee. All five authors looked differently at the various factors that influence functional outcomes and offered insights into the immediate needs of the amputees.

Norvell's (2011) research addressed mobility success within 1 year of amputation, while Sauter (2013) addressed the importance of rehabilitation in an exclusive rehabilitation center, and Corey (2012) identified SES factors linked to mobility and mortality. The last quantitative study focused on the importance of using technology to accurately quantify the amputee's success at mobility and community reintegration. Livingstone et al. (2011) took a more interpretive approach by affirming the importance of functionality linking resilience, endurance, and mobility; the physical, psychosocial, self-perception and satisfaction to the amputee's desire to be functional.

The paucity of research addressing the diabetic amputee indicates the need for a study that will utilize an interpretive approach to better understand the essence of what it means to be an amputee with some functional capacity. Some limitations of extant research should be considered when interpreting this review. First, four of the studies were conducted in clinical settings, and outcomes cannot speak to the experience of amputees who are not in clinical care. Secondly, the sample size was small in some studies, and thirdly, prospective studies did not explore outcomes beyond 1 year. Finally, each study operationalized functionality differently and utilized different measurement instruments.

Psychological Issues Associated with Amputation

Amputation of a limb can affect all facets of an individual's life, and knowing the psychological state of the individual is very important in understanding the total well-being of the patient (Srivastava et al., 2010). Early assessment and treatment of the psychological morbidities are, therefore, very important in preventing additional trauma

in the amputee. Medical advances have enhanced the quality of life of people living with amputations, by offering procedures such as more localized amputations and making available more highly individualized prosthetic devices. Despite these advances, amputations still carry definite psychological effects ranging from depression, concerns about body image, and the support needed from friends and family (Washington, 2013).

Psychological well-being is the combination of feeling good and functioning efficiently. While every individual experiences ups and downs, an overall mean average of positive outlook constitutes a sustainable sense of well-being. Experiencing painful situations such as displeasure, illness, death, and regret are all normal life stressors, and being able to manage these negative or painful emotions is important for long-term, overarching well-being. Psychological well-being can be compromised when negative emotions are prolonged and impede a person's ability to function (Huppert, Simpson, Nissenson, Liebowitz, & Foa, 2009). The amputation of a limb has a severe impact on all aspects of an individual's life, thus hindering adjustment to the disability and negatively impacting the ability to lead a productive life. Therefore, it is important to address such issues as self-esteem, depression and anxiety, and social support as they relate to the amputee.

Holzer et al. (2014) conducted a quantitative study examining how individuals who undergo lower-limb amputations are impacted by aesthetic factors such as body image, self-esteem, and quality of life (QoL). A total of 298 German patients (149 uni- or bilateral lower-limb amputees and 149 patients with orthopedic conditions) were recruited from three orthopedic/prosthetic rehabilitation centers that provided

postoperative care to amputees within 6 months' post-amputation. Demographic data were collected, and all patients received a questionnaire that included three rating scales: The Multidimensional Body-Self Relations Questionnaire (MBSRQ), the Rosenberg Self-Esteem (RSE) scale and the SF-36 Health Survey (QoL).

The MBSQR is a 71-item self-report inventory that assesses the attitudinal aspects of the body-image construction. The RSE scale is a 10-item questionnaire that assesses a person's general self-esteem. The SF-36 Health Survey (QoL) is a commonly used questionnaire with 36 items covering eight health-related QoL domains that are not specific to age, disease processes, or treatment group. Statistical analysis was performed using student test, and ANOVA was performed using MATHLAB Version 7.9.

The results of the study revealed that all lower-limb amputees had significantly lower MBSRQ scores, compared with the control group, suggesting that a lower-limb amputation significantly decreases the patient's body image perception ($p = 0.001$). Uni- and bilateral lower-limb amputees combined had a slightly higher score in the Rosenberg Self-Esteem Scale compared to patients in the control group. The scores for the SF-36 health survey were significantly lower in patients with uni- or bilateral lower-limb amputation compared to controls ($p < 0.001$). In addition, on the SF-36, the type of amputation showed significant differences in two subscales: role limitations due to physical problems ($p < 0.006$) and the physical component summary score ($p < 0.0028$).

The cause of amputation had a significant influence on several areas noted by the subscales, and female lower-limb amputees were noted as having a significantly lower appearance orientation than male patients ($p < 0.02$). Within the control group, the total

MBSRQ scores were significantly higher in women than in men ($p < 0.001$). Gender differences were noted in some of the MBSRQ subscales: Appearance orientation was higher in women ($p < 0.001$), health evaluation was higher in women ($p < 0.001$), body-area satisfaction scale was higher in men ($p < 0.001$), and lower extremity was lower in women ($p < 0.001$). In the SF-36, female controls had a lower score in some of the subscales: bodily pain ($p < 0.036$), general health ($p < 0.0001$), and mental health ($p < 0.001$); the physical component summary score were all higher in women ($p < 0.04$). There was no significant difference in the Rosenberg scores between male and female controls. The results of this study revealed that patients with lower-limb amputations have poorer body image perception and QoL on multiple levels. Equally, the levels of self-esteem were similar in both study groups. The authors recommend and strongly encouraged health providers to focus on the assessment and treatment of the pain associated with limb loss.

To further articulate the importance of self-esteem, Senra, Oliveira, Leal, and Vieira (2012) conducted a qualitative study to explore adults' experiences of lower-limb amputation, focusing on changes in their self-identity related to their impairment. This sample consisted of 42 adult patients who received follow-up services at a hospital-based rehabilitation center. All subjects were at least 20 years old, had their lower-limb amputation after the age of 18, and were receiving follow-up care at the rehabilitation center's medical unit. Subjects were selected based on their stage of rehabilitation. Those patients who were currently going through rehabilitation, and those who had

already finished rehabilitation but were continuing with services to monitor their health and evaluate their functional progression.

Two face-to-face interviews lasting 45 to 60 minutes were performed with each patient. In addition to the demographic and clinical data collected, core areas of questioning included: the emotional impact of becoming an amputee, adjusting to the amputation, and the relation with external resources—social support and rehabilitation. Data were analyzed using the thematic and categorical analysis recommended by Brandin. Eight themes materialized as a result of the three core categories of the interviews:

- Within Emotional impact of amputation:
 - Reactions and feelings about becoming an amputee
 - Changes in own life
- Within Adjustment to amputation:
 - Self-perceptions in terms of relation with the impairment
 - Relation with the prosthesis
 - Aims related to the rehabilitation and future plans
 - Problems in well-being
- Within Relation with the external resources:
 - Perceived rehabilitation
 - Perceived social support.

When reporting their feelings and reactions about becoming an amputee, about half of the participants verbalized feelings such as sadness, anger, and suicidal thoughts.

Their reaction to the pending surgery included shock, rebellion, surprise, and non-acceptance of the situation. Few participants felt as if the amputation had relieved their pain. Most participants reported significant changes in their lives before and after the amputation, including difficulties with completing activities of daily living (ADL), loss of independence, feelings of inferiority and abandonment, and negative changes in their professional life and achievements.

Several participants responded to the theme of self-perceptions in relation to the amputation. The responses were positive, with respondents adapting to the use of prosthesis and having positive self-talk when referring to themselves as amputees. Most respondents in this category were moving towards acceptance of their situation, but had not yet fully accepted being an amputee. Regarding participants' relationships with their prosthesis, some ($n = 14$) participants spoke negatively about the prosthesis and attributed wearing the prosthesis as a source of pain, while others ($n = 28$) associated the prosthesis with positive improvements in their ability to be independent, in daily life activities, in basic skills, or as being a part of themselves.

Most participants voiced aims related to rehabilitation and future plans, expressing willingness to return to maximum self-sufficiency. A couple of individuals verbalized a desire to return to work as an important goal. Problems with well-being were reported by 29 people, more than half of the participants, and included many of the psychological symptoms often associated with amputation, such as pain, sadness, depression, humor, sleep disturbance, anxiety, and irritability. According to 28 participants, stump pain and phantom pain was not of concern, and those who reported

stump pain felt it decreased their quality of life and impacted their adjustment to the new condition. Perceived rehabilitation, as reported by most patients, was conveyed as positive feelings towards the rehabilitation program, environment, staff, new skills learned, and the likelihood of using prosthesis. The remaining three patients reported inadequacies with the rehabilitation program and thought that the resources provided were insufficient and unsatisfactory. Finally, 27 patients reported feeling satisfied with the social support received from family and friends, and viewed it as a valued resource to improve their adjustment. The other 15 participants described the support received as poor or inadequate.

The research revealed that there were two groups of patients who participated in the study: One group was those who were more aware of their situation, had an emotional response to the situation of becoming an amputee, and were willing to address their feelings and reactions to their impairment. The other group was those patients who did not display any emotional connection to the amputation and its implications and were less aware of their situation. Results also showed that body image, anxiety, and the prospects of a prosthesis, was noted and indicated the start of the adjustment process. The results indicate that most patients addressed their amputation, as a potential break with the past, and with what they anticipated in the future going from familiar to unfamiliar status is frightening and produces anxiety, resulting in hostility. Recommendations included the need for psychological intervention during the rehabilitation and follow-up periods.

Depression is a mood disorder that can cause insistent feelings of sadness and loss of interest. Major depression is also known as major depressive disorder or clinical

depression, which is debilitating with a severe impact on how an individual feel, thinks and conducts the self (American Psychiatric Association, 2013). In 2013, Senra conducted a mixed-methods pilot study with a convergent parallel design exploring whether adult's experiences of lower-limb amputation were related to different levels of depression. When using a convergent parallel design, the qualitative and quantitative data are simultaneously collected, analyzed separately, and eventually merged. This study was the second component of a larger research project on adults' adjustment to lower-limb amputation conducted by Senra et al. (2012). In the first study, the qualitative objectives were met and the findings published (Senra et al., 2012). The second component of the quantitative objective is addressed in this current study.

Forty-two adult male patients were recruited from a hospital-based rehabilitation department where they received follow-up care. All participants were at least 20 years old at the time of data collection, and all of them reported that their amputation of the lower limb was performed after the age of 20 years. The majority of patients ($n = 25$; 59.5%) had had the surgical procedure performed between the ages of 40 and 64 years. A total of 26 patients (61.9%) had undergone transtibial amputations, and 16 patients had undergone transfemoral amputations. Twenty-nine patients had their amputation up to 2 years before joining the research, and thirteen patients had undergone amputation more than two years before joining the research. Half of the patients ($n = 21$) were at the rehabilitation stage, and the other half ($n = 21$) were at a follow-up stage.

The Centre for Epidemiologic Studies Depression Scale (CES-D) was used to assess the depressive levels. The CES-D is a self-rating scale that gives final scores

ranging from 0 to 60. Scores above 23 indicate clinical depression. Statistical analysis for this study included Pearson's Correlation Test, the student *t*-test, and Cohen's *d*. The results of the study indicated that 31% of the patients scored 23 or above on CES-D. There was no significant correlation between depressive levels (CES-D) and the time of post-amputation (0.84; $P = 0.595$). There were varying degrees of significance between the differences in the CES-D scores among patients in terms of clinical history and experience of amputation, and the corresponding effect sizes. Cohen's *d* showed a medium to large effect on self-awareness and a large effect on other variables for which significant differences in depressive levels were found. Depression in this population occurred at a similar frequency (31%), when compared with previous studies addressing depression. The second significant association was found between the main variables related to the experience of amputation and depressive levels. Patients who reported having a greater self-awareness of their impairment, a lower self-identification with the impairment, inadequate social support, and poor well-being showed higher depressive levels. Recommendations included the need for long-term psychiatric and psychotherapy follow-up, as well as longitudinal studies to assess the relationship between the experience of amputation and depression.

Similarly, Williams et al. (2011) conducted a retrospective cohort study to investigate the association between diagnosed depression and the incidence of non-traumatic lower-limb amputations in veterans with diabetes. Medical records of 531,973 veterans from a Diabetes Epidemiology Cohort, from 2000-2004, were obtained from a national U.S. Veteran Affairs (VA) registry. Subjects were divided into two groups:

those diagnosed with depression and those without depression using the International Classification of Diseases, Ninth Revision (ICD-9) coding for depression. Depressed participants had had at least one inpatient or outpatient hospitalization or were prescribed a Selective Serotonin Reuptake Inhibitor (SSRI). Amputations were defined using diagnostic and procedural codes, and in this study, amputations associated with cancer or trauma were excluded. Incidence of amputations for this cohort was calculated and a Cox Regression Model was used to determine the hazard ratio and confidence interval for incidents of non-traumatic lower-limb amputations, when compared to patients with and without a diagnosis of depression. The study found 624,968 veterans diagnosed with diabetes in 2000 and 531,973 patients eligible to participate in the study. Of those eligible patients, 63,615 veterans had depression codes, with the most common diagnoses being depressive disorder, not otherwise specified (68.0%); major depressive disorder, recurrent episode (22.6%); dysthymia (20.6%); and major depressive disorder, single episode (16.4%).

Sociodemographic analysis revealed that the sample population was mainly elderly and male. The depressed group was younger and included more female, Caucasian, Native-American, unmarried, homeless, and disabled veterans as compared to the non-depressed group. The depressed group was noted as: using more insulin, having more diabetic complications, experiencing more hospitalizations, having more outpatient visits, and experiencing higher medical and mental health comorbidities. There were 3,830 incidents of lower-limb amputations over 4.1 years post-amputation. Three thousand one hundred and eighty seven amputees were evaluated as non-depressed, while

643 amputees were identified as depressed. Veterans with diabetes and a diagnosis of depression had a 15% higher risk of any lower-limb amputation, and a 38% higher risk of major amputation, compared to those without a diagnosis of depression. There were no significant interactions between depression and age, gender, race/ethnicity, or Post Traumatic Stress Disorder (PTSD), and there was no increased risk of minor amputations associated with diagnosed depression. Depression was associated with a 33% increased risk of incident non-traumatic major lower-limb amputations, but no increased risk of minor amputations. These results support the need to address the relationship between depression and amputation and to determine if depression screening would decrease the amputation rate.

Social support is the perception and/or observed reality that a patient receives emotional care and assistance and that she or he is incorporated into a social network. Social support is known to exist along several dimensions, such as emotional, tangible/instrumental, informational, appraisal, and companionship. Good social support is known to improve health outcomes, by buffering the effects of stress (Cohen & Hobrman, 1983). In 2009, Unwin, Kacpersek, and Clark conducted a quantitative study examining how demographic, amputation, and psychosocial variables influenced positive psychological adjustment outcomes for lower-limb amputees. This prospective study was conducted at a regional outpatient mobility and rehabilitation center in the U.K., and the participants were new referrals with lower-limb amputation. A total of 99 patients was recruited for the study and provided data at two time points during the study. At the start of the rehabilitation sessions, and 6 months following the start of rehabilitation.

Age, gender, and level and cause of amputation were recorded independent variables. The predictor measures included: The Hope Scale, which was used to assess hope; the Multidimensional Scale of Perceived Social Support (MSPSS), which was used to assess the level of social support; and The Trinity Amputation and Prosthetic Experiences Scale (TAPES), which assessed the amputee's quality of life with regard to pain, adjustment, restrictions, and satisfaction with the prosthesis. Outcome measures included the Positive and Negative Affect Scale (PANAS), which assessed positive mood, and general adjustment was assessed using the total scores from the TAPES. Descriptive statistical data for the variables was examined, and multiple regression analyses were used to determine the contribution of demographic/amputation factors, versus psychosocial factors to adjustment outcomes.

The results of the study revealed that hope at the beginning of rehabilitation was correlated to having a positive mood ($p < 0.001$) and hope and social support were related to overall adjustment ($p < 0.01$, $p < 0.001$) at the 6-month follow-up period. There was no relation between the demographic and amputation factors and psychological adjustment outcomes in this study. The findings of this study are demonstrative of how psychosocial variables can be an indication of positive adjustment to lower-limb amputations.

To further emphasize and highlight the need for a strong social support system, Olugbemi, Tolulope, and Adesoji (2013) conducted a quantitative study examining the role of social support and the need for achievement on psychological well-being of below-the-knee amputees. The study was conducted at three hospitals in Nigeria. A

convenience sample of 78 below-the-knee amputees took part in the study. Demographic information included the participant's age, gender, educational qualification, marital status, religion, and ethnic group. Perceived social support was measured using The Multidimensional Scale of Perceived Social Support (MSPSS). The MSPSS is a self-report Likert scale tool used to measure perceived support from friends, family members and significant others. The need for achievement was measured using The Need for Achievement Scale. Stronger agreement reflected high achievement needs, and low agreement reflects lower- levels of achievement needs. Psychological well-being was measured using The Ryff's scale of Psychological Wellbeing. This 54-item scale measures six areas of psychological well-being, which included, autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance. The data was analyzed using SPSS version 15.00.

The results of the study concluded that social support has significant influence on psychological well-being. Participants with a high need for achievement reported higher psychological well-being than their low-need for achievement counterparts. Gender was noted as having no significant influence on psychological well-being, and the social predictors used (age, gender, educational qualification, marital status, religion, and ethnic group) had no significant relationship jointly or independently in predicting psychological well-being in this population. The authors, therefore, recommended that families, friends, and significant others who engage in the lives of the amputees should provide them with as much needed social support as possible. Another recommendation was for health clinics and establishments that provide services to amputees also provide

family members with pre- and post-amputation information and education, targeting issues related to anxiety and the adjustment to a disability.

Overall, these six studies in the U.S. and abroad highlight significant psychological issues related to amputation. Research showed that self-esteem is lower among amputees and may be mostly associated with functioning abilities and body satisfaction. Patients who feel greater freedom and set personal goals seem to experience better self-esteem. Inadequate social support seems to be closely linked to depression in this population, with more females reporting depressive symptoms. Depression may actually precipitate amputation; one study of diabetes patients found that those with depression had a greater incidence of amputation.

This systematic review of the literature underscores the importance of identifying and addressing these psychosocial issues within the amputee population to achieve improved health outcomes. However, these study populations could present some bias due to the choice of the sample setting. All participants in these studies were in rehabilitation or in hospital-based rehabilitation centers, which could indicate that they were afforded rehabilitation services. If the subjects were recruited from clinics and non-rehabilitation facilities, the results could prove more generalizable. At present, there are no studies addressing these issues in the lived experience of the Barbadian population, hence the need for this study. Exploring the lived experience of the diabetic Barbadian amputee may provide insights into much-needed psychosocial interventions.

Quality of Life Issues Related to Amputation

In past years, it was fair to say that the cost of human suffering could not be quantified; however, this statement may no longer be true, given the fact that there are now reliable measures to do so (Mendlowicz & Stein, 2014). One approach to understanding and measuring human suffering is to use the concept of “quality of life.” This social science concept was first developed and applied in medical practice to see if cancer patients’ survival time and improvements in their well-being were related to specific cancer treatments (Mendlowicz & Stein, 2014). Since its introduction in the medical literature in the 1960s, the term “quality of life” has become increasingly popular in recent decades, and was introduced in 1975 as a key word in medical literature databases (Post, 2014).

In 1991, The World Health Organization Quality of Life (WHOQOL) project was initiated, with a primary focus on developing an international cross-culturally comparable quality of life assessment instrument. This subjective instrument measurably assessed how individuals perceive their culture, value systems, personal goals, standards, and concerns. It is currently available in more than 40 languages (Vahedi, 2010). The two instruments used are the SF-36, a multi-purpose, short-form health survey, and the WHO gold standard (WHOQOL) instrument. Five quantitative studies were reviewed to explore the quality of life of the amputee as associated with other variables.

The first study, conducted by Sinha, van den Heuvel, and Arokiasamyin (2011) was a quantitative, cross-sectional study assessing factors affecting the quality of life in lower-limb amputees in India. The purpose of the study was to identify important

background and amputation-related factors that affect quality of life in these participants and to compare these quality of life study participants to that of the general population. The amputees were selected from a rehabilitative center, a limb-fitting center, and four limb-fitting camps in rural India. The quality of life study in the general adult population was conducted in 2006, following purposive sampling. The data was then used to compare the quality of life profiles of both general and amputee populations.

A total of 622 amputees and 186 non-amputees from the general population were included in the study. The MOS short-form health survey (SF-36) was used to measure quality of life. This multi-purpose short-form health survey is a 36-item questionnaire. The patients' background and amputation characteristics, as well as quality of life issues were ascertained from the questionnaires. The amputation characteristics included reason for amputation; the level of the amputation; skin-problems related to the stump; stump pain; and phantom-limb sensation. These characteristics were all noted as important factors when determining health outcomes in lower-limb amputees.

The SF-36 measures health status in eight dimensions. The first four dimensions comprise the Physical Component Summary (PCS) scores and include physical functioning (PF), role limitations due to physical health problems (RP), bodily pain (BP), and general health perceptions (GH). Mental (MCS) Component Summary scores include subscales that address vitality, energy, and fatigue (VT); social functioning (SF); role limitations due to emotional problems (RE); and general mental health covering psychological distress and well-being (MH).

The PCS and MCS scores were obtained from the eight SF-36 scales using a correlated physical and mental health factor model. The quality of life scores of the amputees were compared to those study clients from the general population, and were used to measure the impact of amputation on QoL. There were a total of 381 (63%) traumatic amputations. One hundred and thirty-five (22%) amputations were due to diabetic/vascular complications, while 88 (14%) were due to other causes, such as cancer and leprosy. The average time since amputation was 9.9 years.

The prevalence of different amputation-related factors and comorbidities with reference to the level of amputation was also significant. Seventeen percent of amputees reported stump skin problems, and 28% reported stump pain. Two-thirds of the lower-limb amputees, were bilateral amputees (72%) and reported phantom-limb sensation; however, the total overall report of phantom pain was only 22% and was reported only by the lower-limb amputees. Use of prosthesis was reported by 66% of amputees, and almost half of the amputees (44%) used canes or crutches.

Fifty-two percent of them were unemployed at the time of the study, and 80% of the study participants reported being employed prior to amputation. Eighty-two percent of the unemployed amputees reported loss of employment as a direct consequence of amputation. This suggests that the amputation was directly related to employability and should be the focus of those involved in vocational rehabilitation and job training. Two-thirds of the study population was male. In India, the male is traditionally the primary earning member of the family, and the unemployed status of a male member can have a direct impact on the family's income and living standards. This might explain the

important role of employment status in determining QoL among these amputees, as unemployment is stressful and affects mental functioning, as observed in this study. The study also found that prosthetic use positively impacted physical health more so than the mental health component of QoL.

Other documented studies also report the importance of mobility on physical functioning, while suggesting that the use of canes and crutches negatively impacted the PCS and MCS scores. Phantom limb pain affected the physical health component more negatively than the mental health component of QoL, and it appeared to obstruct mobility, as well as the psychological and mental state of the amputee. Despite these findings, phantom-limb pain needs to be addressed adequately during treatment and after discharge. This study revealed that these lower-limb amputees had worse QoL outcomes, as compared to the general population, a crucial point that has been substantiated by other studies; these results indicate that amputation is a major life-event affecting an individual's QoL for many years post-amputation.

The most important factor in this study found to influence the physical health component was the use of prostheses, while medical comorbidities were found to significantly influence the physical health component of QoL. The employment status of amputees and their comorbidities was noted to significantly impact the mental health component of QoL. The use of prosthesis, comorbidities, phantom-limb pain, and lingering stump pain were also found to be other significant factors affecting QoL. The authors recommended that a holistic reintegration plan should include addressing all

these factors during the initial treatment phase, the rehabilitation phase, and post-surgery after the individual is discharged from the hospital.

Similarly, Cox, Williams, and Weaver (2011) conducted a quantitative study using variables such as age, gender, and amputation level to determine the QoL and functional independence of Jamaican lower-limb diabetic amputees 1 to 3 years post-amputation. The exploratory study took place in Jamaica at the St. Ann's Bay Hospital. A review of the physiotherapy records from 2006 to 2009 identified 87 participants (35 males and 52 females) eligible to participate in the study. Participants were selected from a group of surviving male and female amputees, who had received rehabilitative services at the physical therapy department of a local hospital. Inclusion criteria consisted of diabetic participant ages from 40 to 90; those who had either a below-knee or an above-knee amputation at least 1 to 3 years prior to the study. The World Health Organization Quality of Life Scale (WHOQOL-BREF) and the Functional Independence Measure (FIM) were used to determine outcome variables. The data were analyzed using SPSS Version 12.00.

The participants' ages ranged between 43–86 years with a mean of 62 years. Sixty-four participants had below-knee amputation and 23, above-knee amputation. Male participants with below-knee amputation were in the older age groups (60 to 70 and 71 to 86 years), and female participants were in the younger age groups (43 to 59 and 60 to 70 years). The results of the study revealed that amputees with below-knee amputations recorded higher QoL scores, compared to those with above-knee amputation ($p < 0.05$), and their functional independence measure scores were also higher ($p < 0.0001$) than

their counterparts. Female participants had significantly better QoL and FIM scores ($p < 0.0001$). Both sexes recorded higher mean scores within the domain of physical health on the QoL outcome measure (8.43 and 10.04, respectively) and lowest mean scores were observed within the social relationships domain (5.09 for males and 9.06 for females). A greater number of females in the 43- to 59-year-old and the 60- to 70-year-old age groups reported high to average QoL, respectively ($p < 0.0001$), while the majority of males' ages 60 – 86 years reported lower quality of life scores. A positive correlation was noted between QoL and functional independence ($r = 0.5999$, $p < 0.0001$). The authors concluded that the female amputees, despite having their amputations at an earlier age than the males, coped and had better physical functioning with their lower limb amputations, while those female amputees with below-knee amputations were shown to have higher levels of functional independence and demonstrated better QoL than their male counterparts, as demonstrated in higher QoL scores.

Karami, Ahmadi, Nejati, and Masumi (2012) conducted their quantitative study evaluating Iranian veterans with lower-limb amputations and their health-related quality of life. The cross-sectional design compared 38 male lower-limb amputee veterans with 50 normal, healthy male subjects. The mean age for the amputee group was 43.91, and the mean age for the healthy subjects was 43.66. The mean duration of time since amputation was 24.55 years. Quality of life was assessed using the SF-36 Form, and component summary scores were calculated to provide a global measure of physical and mental functioning. The Physical Component Summary (PCS) and the Mental Component Summary (MCS) scores were derived from the eight multi-item scales.

Results of this study showed that these amputees had significantly lower scores than normal subjects in role physical ($p < 0.01$); significantly better scores than normal subjects in vitality and mental health issues ($p < 0.01$); a higher grade in mental summary component of quality of life ($p < 0.05$); and a lower grade in physical component of quality of life ($p < 0.01$). It was also noted that those living with an amputation for more than twenty years had grown accustomed to their situation, and the adjustment had less of an impact on the subjects' reduced physical role for their bodies, thus reflecting a higher score on physical role performance than the healthy individuals. The authors concluded that there is a significant difference in the mental and physical factors that influence an individual's quality of life and improvements in the handicapped individuals' mental health state directly impacts an enhanced quality of life.

In a similar study by Akarsu, Tekin, Safaz, Göktepe, and Yazicioğlu (2013) conducted a quantitative, cross-sectional study comparing the QoL and functionality of patients with bilateral versus unilateral lower extremity amputations. The study enrolled fifteen bilateral and 15 unilateral lower extremity amputees, ages 21 years to 43 years, who were receiving services at a Turkish Armed Forces Rehabilitation center in 2010. Survey measures included The Turkish-validated version of the SF-36 Health Survey to assess QoL, and the Satisfaction with Prosthesis Questionnaire (SAT-PRO) was used to evaluate satisfaction of patients towards their prostheses. The Turkish-validated version of the Amputee Body Image Scale (ABIS) assessed the patient's feelings and perceptions about their body experience, and the Houghton Scale (HS) to evaluate the use of the prosthesis with respect to proportion and duration; places travelled (indoors and

outdoors); supportive ambulatory aids, (such as wheelchairs, walkers, crutches) and how well the amputee navigated various outdoor ground types (plain, slope, broken). In addition, functionality was assessed using the 6-minute and the 10-meter walk test (10MWT) with sufficient resting time between walks.

The use of prosthesis was found to be positively correlated with improved QoL, by providing normal body image and increasing physical abilities. The authors found that physical function and subscales (role physical and role emotional) were significantly better in the unilateral group. It was assumed that the differences in scores were related to the increased activity and the motivation level of unilateral subjects, when compared with the bilateral amputee subjects. Bilateral amputees scored worse than those of unilateral amputees on QoL issues, and there was a positive correlation between the amount of time the prosthetic was used and reported QoL, except for the pain subscale of that measure. Subsequently, the bilateral (above-knee) amputees used wheelchair and crutches, while those with bilateral (below-knee) amputation did not need those ambulatory devices in order to independently ambulate.

Furthermore, overall prosthesis use was observed in the unilateral amputee group who also performed better in the walk tests. Other observations included: Physical capacity of bilateral lower extremity amputee patients was lower than the unilateral amputee patients; satisfaction with prosthesis and body image were not related to amputation level. The QoL and the patient's satisfaction with the prostheses increased when compared to the use and wearing of the prostheses. Prosthetic use was noted to improve the QoL by increasing the amputee's physical abilities, as well as providing an

improved normal-body image. The authors recommended the need for larger study populations focused on comparing other parameters, such as energy expenditure or social status of unilateral versus bilateral amputees.

To finally stress the importance of QoL issues, Adegoke, Kehinde, Akosile, and Oyeyemi (2012) conducted a quantitative study, assessing the QoL of Nigerians with lower-limb amputation, by exploring how clinical and socio-demographic variables impacted their QoL. This descriptive study enrolled 47 individuals with lower-limb amputation recruited from rehabilitation centers/clinics in Oyo, Lagos, and Kwara states of Nigeria. The researchers documented the participants' age, gender, marital status, time since amputation, level of amputation, affected lower-limb, use of prosthesis and occupation. Their QoL was then assessed with the WHOQOL-BREF questionnaire. All data were analyzed by SPSS Version 15.0.

Thirty-one (66.0%) participants were male; 83.0% of the participants were using prostheses; 57.4% had dominant lower-limb affectation, and 61.7% had below-knee amputation. The majority (51.1%), were engaged in a skilled occupation, (57.4%) had been amputees for less than 24 months, and only 8.0% of the participants had been amputees for more than 6 years. The findings revealed that there was no significant difference ($p = 0.78$) between the ages of male and female participants, and there was also no significant difference ($p = 0.06$) between time since amputation. The majority (51.1%) of amputees were ages 40-59, and trauma was the leading cause of amputation, accounting for 43.0% of all cases.

There was no significant difference in the QoL scores for participants based on their occupation. Individuals with lower-limb amputation wearing prostheses scored significantly higher than those not wearing prostheses in the overall health ($p = 0.033$), physical health ($p = 0.015$), psychological health ($p = 0.008$) and environmental domains ($p = 0.011$); however, there was no significant difference noted in the two groups in overall QoL and social relationship domain scores. There also were no significant differences ($p > 0.18$) between the overall QoL, overall health, and domain scores of participants with dominant and non-dominant lower-limb amputation. The QoL scores did not differ significantly from those with above-knee amputation, or those with below-knee amputation. Time since amputation and age group did not significantly influence participants' QoL scores. In conclusion, the findings of this study suggested that the QoL of individuals with lower-limb amputation in Nigeria is moderate and male lower-limb amputees had considerably higher scores in physical health, social relationships, and overall health than female amputees. The only factors noted as having a significant influence on some QoL domains were gender and use of prostheses. Female lower-limb amputees and those amputees not wearing prostheses required special attention.

The review of this existing literature shows that there are many factors that need to be considered due to their influence on an amputee's quality of life. Some of these factors include the use of prostheses; issues related to stump pain; level of amputation; the amount of time post-amputation; and general health and mental health of participants. Overall, the studies indicated that people with lower-limb amputations adapted,

responded, and coped differently following the traumatic experience of having a leg surgically removed.

All available studies were quantitative, using the WHO BREF assessment tool or the MOS Short-form Health Survey (SF-36). Both tools are effective and known to have good validity and reliability. However, the SF-36 is a short, 36-item questionnaire used to measure health-related quality of life (HRQOL), and may not be inclusive enough to address all relevant areas of interest to the amputee. Similarly, the WHO BREF is also a short, 24-item version, as part of the more extensive WHOQOL 100-item questionnaire. This condensed version only addresses certain aspects of the individual's quality of life. The use of these short-itemed tools could miss some valuable information related to the amputee population. Despite the studies' use of these short forms, they provided a much-needed assessment of patients' perceived health, physical functioning capacity, social relations, psychological adjustment, and environmental support. It is, therefore, recommended that clinicians continue to utilize these screening tools before, during, and after the surgical removal of a limb.

The strength of this literature lies in the array of geographic regions examined. Many outcomes may be generalized to other developing nations. Still, some limitations are important to consider. First, there was misrepresentation of females in the available studies. Second, all studies were conducted in rehabilitation centers, indicating motivation for treatment and clinical support. Finally, none of the studies in the literature explored or attempted to discover the lived experience of the amputee population and how their quality of life may be affected. This gap in research supports the need for more

qualitative studies of amputees' lived experience as a beginning step to understanding the phenomenon of this population.

Experiential Context

In qualitative research, the experiential context is the forum in which the researcher has a chance to validate why the proposed study is valuable; why the researcher is fully vested in the study; and what prior connections he or she may have to the study. Munhall (1994) notes that experiential awareness can provide significant insights, as the researcher attempts to bracket layers of interpretation. In 2011, a colleague informed this researcher that the Chronic Disease Research Centre (CDRC) confirmed that Barbados is, in fact, described as “the amputation capital of the world,” and diabetes and its complications were blamed for the alarmingly high-rate of amputations on the island. This report was personally significant, given the fact that this researcher had been diagnosed with morbid obesity and *Type II Diabetes* in 2003.

Maintaining a healthy weight has always been a struggle for me. As a child, I remembered hearing family members and friends asking my parents if they only fed me and neglected my siblings. Dieting as a young adult was very commonplace and a part of my daily existence. Joking about my weight-loss struggles with colleagues in the mental health profession was always related to my perception of myself as an addict. I told them that my weekly dieting could be related to an addiction to food, and I compared myself to individuals plagued by substance abuse and alcoholism. Finally, in 2003, after being on numerous diets and failing, this researcher decided to enroll in a double-blinded weight loss study, thinking that it could be a means to an end. The initial sign-on process was

successful, and seen as a joyous beginning to a lifelong struggle. Study materials were provided, and this researcher was well on her way, not knowing if her vial contained the study medication or the dreaded placebo.

Three weeks into the study, this researcher received a call asking her to present to the clinical site and return all of the study supplies. The clinical staff informed me upon my arrival that my fasting glucose was 165, and my continued participation in the study had to be discontinued due to strict study protocol criteria; immediate follow-up with my primary care physician was recommended. The day my physician delivered the news and the numerous diagnoses was a day that would forever be etched in my mind. My diagnosis included morbid obesity, diabetes, lower-leg neuropathy, sleep apnea, a hemoglobin A1C of 11, and a body mass index of 35. This researcher's decision to undergo gastric bypass bariatric surgery was received by others as a "quick fix and drastic," but to a person who recently received what was perceived as "a death sentence," the benefits outweighed the risk, and drastic measures were more appealing. Bariatric surgery is viewed today as a way of providing substantial, sustained weight-loss and major improvements in glycaemic control in severely obese individuals with Type 2 diabetes. In retrospect and reflection on my medical state, and the challenges of having some of the comorbidities associated with diabetes, I cannot stop thinking of how my life might have been if an amputation was to be the end result of my diabetes.

Qualitative methodology is increasingly used within the field of social science research as a means to connect and explore the lived experience of the participant (Tufford & Newman, 2010). While these opportunities allow us to engage our subjects

and gain insights into their phenomenon, this exercise can result in subjective research bias and the transfer of feelings, thoughts, and judgments. In an attempt to minimize and hold these thoughts and judgments in abeyance, the researcher is encouraged to employ bracketing, a term used in mathematics, and a fundamental methodological principle of Husserlian phenomenology. The researchers' preconceptions are held in abeyance to ensure they do not shape the data collection, or impose their understanding and construction of the data (Polit & Beck, 2010). Bracketing prevents the researcher from having any influence on the participants' understanding of the phenomenon.

One way the researcher can achieve bracketing is through reflexive writing that is keeping a reflective journal to document thoughts, feelings, and perceptions throughout the research process. Mentally having an awareness of an individual's position on issues as they arise can prove to be a valuable tool when conducting qualitative research. Reflexivity allows the researcher to remain accountable to all involved in the research process. Regular journal entries detailing any methodological issues can be used as a tool if the researcher wants to discuss findings with dissertation committee members. This collaboration is seen as adding integrity to the research. As a psychiatric nurse practitioner, this researcher often employs an empathetic process when engaging her patients. Empathy, like bracketing, involves setting aside all judgments an individual may have about the patient as he or she tries to understand the patient's underlying issues. By using bracketing, the researcher can temporarily set aside all assumptions and revisit them to gain a deeper understanding of the phenomenon.

Chapter Summary

This chapter provided a literature review on the historical perspective; physiological and psychological issues related to the amputee, and the quality of life aspects of amputation. The literature revealed that lower-leg amputations had a major physiological and psychological (van Manen, 1990) and impact on the lives of amputees. Despite the vast number of studies reporting negative findings as the individuals adjust to their disability, there were some positive adjustments among individuals with lower-leg amputations. These positive findings indicate a move toward a better understanding of the predictors influencing functionality and quality of life. The experiential context is further highlighted in Chapter Three, which will follow outlining, detailing, and discussing the methodology adopted for this study.

CHAPTER THREE

METHODS

The purpose of this qualitative phenomenological inquiry was to explore, understand, and describe the lived experiences of Barbadians with lower-extremity amputation as a long-term complication of *diabetes mellitus*. This chapter details the research methodology, sample, setting, inclusion and exclusion criteria, data collection, data analysis, and ethical considerations. The hermeneutic phenomenological process as outlined by Max van Manen was used to explore the day-to-day lived experience of Barbadian diabetic amputees. This researcher sought to uncover and capture the essences of their experiences.

Research Design

Creswell (2009) referred to the research design as the blueprint or proposal to conduct research that involves the researcher's worldview, the strategies that relate to that worldview, and a set of procedural steps allowing the researcher to translate the approach used into practice. Researchers are more inclined to use a qualitative research design when there is no relevant data known about a research area and when the main purpose is to understand or describe a particular phenomenon of interest (Miles & Humberman, 1994). A hermeneutic phenomenological research design provides the philosophical, as well as methodological underpinning for this inquiry into the lived experience of the Barbadian amputee. Hermeneutic phenomenology is based on Heidegger's philosophy and seeks to interpret the lived experience of participants. This method seeks to find the essential meaning of the experience being studied (Polit & Beck, 2010).

Phenomenological researchers such as Giorgi, van Kaam, Moustakas, Colazziand, and van Manen have all refined, cultured, and modernized the traditional principles of hermeneutic phenomenology.

Rationale for a Qualitative Study

Qualitative description is a method used as a preface to statistical inquiry when there is limited information available about a subject, or when the information provided needs clarification or refinement before it can be measured (Ritchie, Lewis, Nicholls, & Ormston, 2013). According to Denzin and Lincoln (2011), qualitative research can be seen as an endeavor that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world by turning it into a series of representations that can be found in field notes, interviews, conversations, photographs, recordings, and memos to the self. In addition, Creswell (2007) articulated that there are several reasons for choosing a qualitative approach; however, the principal reasons for undertaking a qualitative study should begin with the nature of the research question, followed by a need for the topic to be explored. Other reasons for choosing a qualitative approach include the need to provide detailed interpretation of the topic and the need to study individuals in their natural habitat (Creswell, 2007).

The qualitative design was strongly indicated for this study because little is known about the Barbadian diabetic amputee, and this researcher was able to explore the lives of the participants while gaining an in-depth subjective view of their experience in order to fully understand the essence of the phenomenon. This design allowed the

researcher to delve deeper during questioning, while remaining respectful of the participants and their responses. Furthermore, a researcher interested in this approach is also engrossed in writing in a literary style that involves storytelling, while seeking to clarify, as well as understand, the complex nature of the study. There are many approaches to qualitative research; however, the chosen qualitative approach depends on the research question and purpose (Creswell, 2007). This researcher used the hermeneutic phenomenological approach of Max van Manen (1990) to guide this study because the researcher was interested in understanding and interpreting the lived experience of the Barbadian diabetic amputee.

Rationale for a Phenomenological Study

The objective measurement and analysis of health, health care and the healthcare delivery system can inform decisions that maximize health as a social good; however, to subjectively address these phenomena that are implicit, enacted, and experienced by humans, there needs to be a better understanding of the multidimensional nature of humanity (McWilliams, 2010). These insights into human consciousness, and the subjective and intentional nature of individuals, are valuable facets that, if explored, can lead to the optimization of the quality of healthcare, health services delivery, and, ultimately, the health of individuals, communities and society at large (McWilliams & Bailey, 2010). The use of hermeneutic phenomenological research is, therefore, posited as addressing these humanistic objectives.

The history of phenomenology is situated in the philosophical tradition launched back in the first half of the 20th century by Edmund Husserl (1859–1938), a German

philosopher known as the founder of transcendental/descriptive phenomenology. Subsequently, Martin Heidegger (1889–1976), Jean Paul Sartre (1905–1985), and Maurice Merleau-Ponty (1908–1961) extended this methodological approach from questions of epistemology, or how we know something, to questions of ontology; the nature of existence (McWilliam, 2010). In recent years, a number of schools of phenomenology have emerged with varying similarities and differences to their methodological approach.

Colaizzi (1978), Giorgi (1985), and van Kaam (1966) are phenomenologists from the Duquesne School of Phenomenology, and their approaches are based on the teachings of Husserl. Colaizzi's method requests that the researcher return to the study participants for revalidation of the data collected. Giorgi's method relies solely on researchers, as he rejects Colaizzi's methodology, and van Kaam's method requires that the researcher find peer researchers or experts in the field to revalidate the data (McWilliams, 2010). The Utrecht School, another school of phenomenology, utilizes the Dutch approach to phenomenology by merging the characteristics of both descriptive and interpretive phenomenology. van Manen (1990) is a prominent Canadian phenomenologist from this camp, and his human science research method is one example of how this approach of combining description and interpretation can allow researchers to fully understand the essential meaning of the experience being considered. His work is noted for its greater sensitivity to the personal and intersubjective roots of meaning, and the complex nature of relations among language, experience, and culture (McWilliams, 2010).

van Manen's (2000) approach to human science builds on the hermeneutic approach articulated by Heidegger, and his concept of human science is focused on the explanation of the meaning of human phenomena and at understanding meaning in the lived experience; it is a reflection on the text of lived experiences as described by the participants. van Manen's (2000) method of phenomenological research is centered on the assumptions that phenomenological research is: (a) a study of lived experience, (b) an explication of phenomena as they present to the consciousness, (c) a study of essences, (d) a description of experiential meanings, (e) a human scientific study of phenomena, (f) a "poetizing activity," or an attentive practice of thoughtfulness, and (g) a pursuit for what it means to be human (van Manen, 1990, p.13). van Manen (2000) describes hermeneutic phenomenology as descriptive, paying attention to how things appear, providing a creative description of one's position in the lifeworld, and reflecting on experiences as they are lived rather than experiences that are conceptualized or theorized. Novice researchers using van Manen's method seek to find the essence of meaning, as they explore the life experiences of participants in their research. To accomplish this, researchers must clearly and systematically follow skillful modes of questioning, reflecting, focusing, and intuiting in order to gain enough text content that will eloquently articulate the meanings embedded in the participant's lived experience.

The art of skillful writing is a requisite when utilizing van Manen's method in hermeneutic phenomenology. When the researcher is fully engaged in reflexive writing, he or she is able to measure the depth of things and have some sense of their personal feelings (van Manen, 2000). Writing, according to van Manen (2000), is a measure of

our thoughtfulness that removes us from what we know while moving and aligning us with what we know. In addition, writing has a tendency to move us more away from the lifeworld, while drawing us more closely to the same lifeworld. It removes our thoughts from practice, while also returning thoughts to meaning, it abstracts our experiences of the world, yet concretizes our understanding of the world, and finally, by writing, we are able to put our thoughts in print, while gaining a concrete understanding of something that preoccupies our thoughts.

Max van Manen (1990) suggests six activities for conducting hermeneutic phenomenological research. These six activities, if executed correctly, provide the framework for interpretation of the phenomenon of interest. These overarching interconnected descriptions, interpretations, and language activities are used to describe the individual's being in the world. The first activity is to look at an occurrence, which seriously interests us and binds us to the world. It is at this juncture that the researcher formulates the phenomenological research question. The second activity is to study experience as lived, rather than theorized. The third activity concerns reflection on essential themes, which characterize the phenomenon. The highlight of this step is in analyzing data generated from interviewing. The researcher in this activity interprets the text and engages in the member-checking process to capture the essential meaning and fundamental essence of the lived experience in question.

The fourth activity is to describe the occurrences through the art of scripting and rephrasing. In this process, the researcher engages in a number of rewrites that make visible the feelings, thoughts, and attitudes of the participants. The fifth activity is to

remain steadfast and focused on the pedagogical relationship with the phenomenon. The researcher should attempt to maintain focus on the research question, without allowing outside influences to compromise the research. The researcher must understand the way the themes connect to the interview, the contextual interpretation of the sections, and how it relates to the overall data collection. The sixth activity is to balance the research context by considering the parts and whole. The researcher concludes the research process by assessing the general aim, design, and plan of the study against the entire structural process.

While these six activities appear to be chronological, van Manen (2000) cautions against the use of these steps in this manner. This non-chronological use makes it possible to employ memory, reflection, and reinterpretation as research begins, the process of analysis and unfolding themes as data is examined, is engaged, re-examined, scrutinized, and analyzed. The researcher must remember that there is no set entrance or exit to this process. This approach should be viewed as intermittent or simultaneous to the research processes.



Figure 2. Conceptualization of van Manen's six research activities (Brathwaite, 2016, adapted from van Manen,1990).

Sample and Setting

In qualitative research, the researcher is required to carefully chose and use a small sample of a given population for the study. The objective of the study and the makeup of the study population determine who to select and how many of those selected will actually be needed for the study. According to DePoy and Gitlin (2011), one of the main purposes of sampling is to choose a subgroup that is accurately representative of the population being studied. Two commonly used types of sampling procedures used in qualitative research are *purposive sampling* (judgmental sampling) and *snowball sampling* (DePoy & Gitlin, 2011).

Purposive sampling, or judgmental sampling, is the most utilized sampling technique. It involves deliberately selecting participants based on their knowledge about the phenomenon in question (Creswell, 2007). Quota sampling is a type of purposive sampling frequently used in market research (DePoy & Gitlin, 2011). This type of sampling informs the study design to determine how many people possess characteristics respective of the study. *Snowball sampling*, also referred to as networking or nominating sampling, is used when the researcher has difficulty gaining access to the population and solicits selected participants to help in the process (Munhall, 2007; DePoy & Gitlin, 2011). Munhall (2007) further asserts that the qualitative researcher is not concerned with figures; his or her goal is to seek and select participants who will add meaning to the phenomenon. This researcher has relied on purposive and snowball sampling in conducting this research study.

There are no set guidelines to determining the number of subjects needed for a research project. According to Polit and Beck (2010), the sample size is determined by data collected, the research question, and informational needs. Redundant, repetitive, large datasets should be avoided when conducting qualitative research, and, to ensure that this does not occur, the researcher must select samples that are large enough to reveal and expose the most important phenomenon (Mason, 2010). Subsequently, if the researcher is diligent and adheres to the tenets of conducting qualitative research, the size of the sample should be reflective of the concept of saturation (Mason, 2010).

Data saturation is achieved when the researcher makes the independent determination to stop interviewing additional participants, knowing that new data will not

provide new information or insights for developing categories/themes (Creswell, 2007; van Manen, 1990). Morse (2000) emphasized that reaching saturation is dependent on several factors. Polit and Beck (2010) noted that a researcher may need a larger sample of participants if the scope of the research question is too general, while a smaller sample is sufficient if the informants are able to clearly articulate their experiences. Creative, fictitious, and imaginative sources can also be a source of samples when conducting interpretive phenomenological studies (Polit & Beck, 2010). These sources, such as diaries, journals, novels, and poetry can provide a more intimate look at the text, while allowing the researcher the opportunity to uncover and better understand the phenomenon being investigated (Polit & Beck, 2010). For this study, the researcher sought a maximum of 20 participants or until data saturation was achieved.

All study participants were asked to select a time and a place convenient and appropriate for them to meet with the researcher. The study purpose and the aim were addressed with each participant, giving him or her the opportunity to continue or withdraw from the study. Emotional distress was also discussed with the participants at this time, and if any participant became too distressed and unable to continue the study, the participant was allowed to withdraw from the study. This researcher made available the crisis hotline telephone number to Samaritans of Barbados and provided a referral letter for free psychological services at the Black Rock Psychiatric Hospital. This information was explained to each participant at the beginning of each interview to be used in the event of emotional distress during or after the interview process.

Access and Recruitment of the Sample

Permission to conduct the study was sought from the Institutional Review Boards of Barry University, the University of the West Indies, Barbados, Cave Hill Campus, and the Ministry of Health in Barbados (see Appendix A). This researcher strictly followed the guidelines set forth by these entities. A recruitment flyer (see Appendix D) was distributed upon Barry's IRB approval and clearly indicates that the researcher is a doctoral student at Barry University in Miami, Florida, and includes the researcher's name and local and long-distance contact numbers. It indicates the purpose of the research, the inclusion criteria, the research advisor's name, contact information, and the contact information for the Barry University IRB. These flyers were placed in polyclinics located throughout the island and also the Tropical Medicine Research Institute and the Chronic Disease Research Center. Snowballing or chain-sampling was used. When contact was made with the participants, the researcher determined eligibility, briefly discussed the study, and arranged to meet the participants at a mutually suitable location and time.

Individuals who have the authority to grant or deny access to research participants are referred to as *gatekeepers*. These overseers are charged with protecting the individuals being studied, while ensuring that all protocols are followed correctly and there is no threat to the study participants. Gaining access to the study population in Barbados required the researcher to gain a letter of support prior to the start of the project (see Appendix C). The University of the West Indies, Barbados, Cave Hill Campus, and the Barbadian Ministry of Health are the gatekeepers for this project. Creswell (2009, p.

178) recommends that six pieces of information should be given to gatekeepers prior to gaining access to the participants:

1. Why was the site chosen for the study?
2. What will be done at the site during the observation?
3. How much time will be spent at the site by the researchers?
4. Will the researcher's presence be disruptive?
5. How will the results be reported?
6. What will the gatekeeper, participants, and the site gain from the study?

The researcher must be able to answer the above questions in the event the gatekeeper should have any concerns, and are outlined in the University of the West Indies, Barbados Ministry of Health Research Ethics Committee (REC)/Institutional Review Board (IRB) Human Subject research application.

The research was conducted in Barbados, West Indies. The researcher worked with the University of the West Indies (UWI), Cave Hill Campus, and the Ministry of Health on this project. The Tropical Medicine Research Institute and The Chronic Disease Research Center was contacted and asked to be an additional referral source for this research. The Tropical Medicine Research Institute (TMRI) was established on October 1, 1999, by UWI, in an attempt to increase viable research in major areas affecting the health of people in the region. The Chronic Disease Research Centre (CDRC) is a collaborative effort by the School of Clinical Medicine and Research, UWI, Cave Hill Campus, the Ministry of Health, and the Government of Barbados, in response

to the prevalence and high incidence of chronic diseases (hypertension, diabetes, obesity, and their complications) in the Caribbean and its regions.

Inclusion Criteria

The inclusion criteria for this study consists of Barbadians ages 18 years and older who are identified as diabetic lower-extremity amputees. Participation is voluntary and limited to English-speaking Barbadians who have undergone a lower-limb amputation. All participants must have lived in Barbados for at least 1 year at the time of the interview, and are willing to engage the writer in open discussion regarding their experience as a diabetic amputee.

Exclusion Criteria

Exclusion criteria consists of Barbadians ages 18 years and older who are identified as amputees and who have suffered lower-limb loss by any means other than the complications of diabetes, as well as amputees who are unable to read English.

Ethical Considerations/Protection of Human Subjects

Western organizations and companies frequently conduct health care research involving human subjects in developing countries where there are ethical concerns, notably issues related to culture and socioeconomic status (Igoumenidis & Zyga, 2011). Some of these researchers have been known to engage in unethical research practices without adhering to policies and procedures set forth to protect those involved. As a result of these practices, various codes of ethics have been established here in the United States, as well as globally, to set guidelines for researchers conducting human subject

research (Polit & Beck, 2010). Researchers must consider several important ethical principles when conducting research that involves human subjects.

Nurse researchers are often faced with challenges due to apparent blurred lines when considering nursing practice and data collection methods (Polit & Beck, 2010). Creswell (2007) also affirmed that a number of these ethical issues are usually apparent during field engagement, data collection process, and at the conclusion of the research activity when the analysis, dissemination, and the writing of the report is in progress. According to Munhall (1994), phenomenological researchers have an ethical obligation in describing the experiences of study participants. Munhall further communicated that it is important for researchers disclose their research aims and ethical means, be truthful, and maintain an obligation to be as authentic as possible when interpreting data while the phenomenon unfolds. The most important ethical concerns guiding this study include informed consent and confidentiality.

A human subject research protocol for this study was submitted to two Institutional Review Boards: the IRB at Barry University and the IRB at the University of the West Indies, Cave Hill, Barbados. This review process ensures that all appropriate steps are followed by this researcher to protect the rights and welfare of all study participants. After receiving approval from the Barry University IRB (see Appendix A), the University of the West Indies, Cave Hill IRB (see Appendix A) and the Ministry of Health, Barbados (see Appendix A) and upon being granted access to potential participants (see Appendix C), the researcher provided each participant with a consent form and verbally reviewed the information about the study. The informed consent form

(see Appendix B) explains that their participation is voluntary and that it will offer a clear description of the study, the purpose of the study, their role in the study, and how the information gathered will be used and disseminated upon completion. The participants were given an opportunity at that time to ask any questions pertaining to the study before the start of the interview. All participants who met the inclusion criteria and who agreed to willingly participate in the study were asked to sign the consent form.

Confidentiality was maintained by asking the participants to select a pseudonym or a non-identifying name used on all written records during the study, when discussing the participants and when reporting the findings at the end of the study. Only the researcher will have access to the actual names, addresses, and phone numbers of the participants, and this demographic data will remain in a locked, secure cabinet in the researcher's home office while in Barbados, brought back to the United States at the completion of the study, and destroyed 5 years after the completion of the study.

The risk to participants in this study was minimal. According to van Manen (1990), study participants may experience feelings of anxiety, guilt, self-doubt, and irresponsibility, while others may report feeling hopeful, along with experiencing increased awareness and a sense of liberation. If the participant became distressed during the interview while discussing the stressful event, a referral letter for free psychological services at the Black Rock Psychiatric Hospital, was made available and given to each participant at the beginning of each interview to be used in the event of emotional distress during or after the interview process. The researcher informed participants that there was no direct benefit from this study. A \$25 gift basket was offered to the participants after

their taped interviews were completed as a token of appreciation for their time. The token of appreciation was also offered to any participant who withdrew from the study before completing the taped interview.

Data Collection Procedures

Creswell (1998) outlined and described phases of data collection as circles of activities, or a series of “engaging activities that include but go beyond collecting data” (cite title of work p. 109). These collection activities include: (a) locating a site and an individual, (b) gaining access and establishing rapport, (c) purposeful sampling, (d) collecting data, (e) recording information, (f) resolving field issues, and (g) storing data. The cumulative goal of these activities is to collect a substantial amount of information sufficient to answer the emerging research question. Data collection commenced upon approval from the Institutional Review Boards (IRB) of Barry University, the University of the West Indies, Cave Hill, and the Barbadian Ministry of Health (see Appendix A).

Potential participants who verbalized an interest in the study were contacted by phone, and eligibility was determined based on the inclusion criteria. After agreeing to participate in the study, the participants were asked to select a mutually agreed-upon location and time convenient for the interview. At that time, the researcher encouraged each participant to reflect on his or her experiences of living as an amputee in preparation for the first interview. The purpose, risks, benefits of the study, and the length of the interview were also addressed.

Participants were afforded the opportunity to ask questions and have any issues clarified before this researcher provided them with the consent form. They were

informed of their rights, and their right to refuse to answer any questions as well as the right to remove themselves from the study at any time without any penalties. The participants were informed that they could request to have the audiotape turned off at any time during the interviewing process. While the tape is off, this researcher requested permission to continue the interview process by recording verbatim what is being said. At the end of the interview, the participants were given the opportunity to ask additional questions or share any additional insights.

A demographic questionnaire (see Appendix E) followed the end of the initial meeting. Participants were asked to select pseudonyms instead of their real name for all study documents that pertain to them. The pseudonym ensured confidentiality and was used throughout the investigation and for reporting study results. The nature and meaning of living as an amputee was explored through face-to-face interviews with each participant to produce real-life accounts of their experiences. These face-to-face interviews lasted about 1 hour and were audio taped.

Two audio tape recorders were visible and on hand during the interview process in case of equipment malfunction. Prior to each interview, the researcher addressed bracketing, by creating written journal entries on personal pre-conceptions and goals of the interview, to establish trust and confidence in the interview results. To facilitate a more informal, flexible conversation this researcher used semi-structured interviewing. This researcher used a set of prewritten interview questions (see Appendix F) to guide the interview. Each question was asked in an open-ended and non-directive format in order to fully ascertain the participants' insights and experiences. After the conclusion of the

initial interview, participants received a gift basket worth \$25 as a token of the researcher's appreciation for their participation in the study.

This researcher transcribed the interaction immediately following the encounter by making detailed notes about the experience, paying special attention to thoughts, feelings, and any nonverbal cues noted during the interview. Environmental determinants were noted during this process, because they might have an impact on the interviewing process. The transcripts were reviewed line-by-line with the audiotape for accuracy by the researcher. A second interview was scheduled with the participant to review and verify the transcripts. This process is called member checking and allows the participant an opportunity to verify the data as identified by the researcher. This second meeting lasted approximately one-half hour. All audiotapes were stored in a locked cabinet in the researcher's home office in Barbados, brought back to United States at the end of the study, placed in the researcher's home office, and destroyed by the researcher 90 days after returning from Barbados.

Interview Questions

Qualitative interviewing offers a meticulous method for collecting rich, detailed information about how individuals experience, understand, and explain events in their lives. These interviews allowed the researcher the flexibility to obtain countless details that provide needed depth and breadth absent when using standard surveys and insights into how individuals understand and recount the various facets of their lives as they relate to the phenomenon (Ritchie et al., 2013).

Qualitative researchers seeking to gain access to participants and conduct interviews need to recognize that the questions that asked are meaningful, allowing the researcher to remain close to the experience as lived by study participants (van Manen, 1990). van Manen (1990) and Munhall (2007) both address the specific purposes for interviewing participants for a hermeneutic phenomenological study. They see the interview process as one that is explorative in nature, gathering first-hand detailed accounts of data that may be used to develop a deeper, more profound understanding of the phenomenon of interest and, secondly, the interview may be seen as a catalyst that allows the interviewee to expound on the meaning of the experience. Questions should be open-ended, easy for the participant to understand, and stated in such a way that the participant is able to immediately grasp what is being asked.

Open-ended questions were used to guide the participants as they respond to questions, so that they are encouraged to elaborate on their responses as they expand and clarify others. This process allows flexibility in gathering information from the participants (Polit & Beck, 2012). The aim of utilizing this process is to illuminate the participant's perceptions of his or her life as an amputee without the writer imposing any personal assumptions. The purpose of this interview method is congruent with what van Manen (1990) described as a vehicle to develop conversational relationships with participants about the meaning of the experience. This researcher used initial social conversation and icebreakers as ways of creating a relaxing, trusting atmosphere prior to the start of each conversation.

Demographic Data

Each participant was asked to complete a demographic questionnaire developed by this researcher (see Appendix E) after signing the informed consent document (see Appendix B). This process took at least 15 minutes. Information from the demographic questionnaire was combined to describe the study participants, including age, gender, marital status, children, support system, ethnicity, their age when diagnosed with diabetes, the date when the physician informed them of the amputation, the date the limb was amputated, and any other information related to the nature of the amputation. This demographic data assisted the researcher in describing the participants while identifying commonalities among each participant.

Data Analysis

Many qualitative researchers utilize an approach to analyzing qualitative data called “constant comparative analysis.” These procedures were originally used in the grounded theory method as articulated by Glaser and Strauss (Noble & Smith, 2014). A researcher operating from the naturalistic inquiry employs thematic analytic and interpretive description methods that depend on the constant comparative analysis processes as they seek to understand the human phenomena within the context they are experienced (Thorne, 2000).

Phenomenologists such as Colaizzi, Giorgi, van Kamm, and van Manen restructured the phenomenological analysis process into a set of manageable working steps to better-fit questions pertaining to the lived experience. Their refinement of the Glaser and Strauss process has allowed many phenomenological nursing researchers to

utilize their methods when conducting qualitative research (Noble & Smith, 2014). Van Manen's approach consists of creating protocols, or texts full of narrative stories, using hermeneutic reflection and engaging in the grueling process of writing and rewriting in order to develop themes, while listening for the essence of the phenomenon. Van Manen's (1984) human science method of hermeneutic phenomenology was used for analysis and interpretation of transcripts in this study. Therefore, this researcher was engaged while using the three approaches advocated by van Manen (1990) to discover themes.

As a novice researcher, this researcher's challenge is to ensure that the quality and rigor of the research is held to these standards. The utilization of van Manen's three thematic methods: the holistic approach, the selective highlighting approach, and the detailed line-by-line approach, along with his six research activities, provide the guidance needed. Van Manen (1990) suggests the use of "structures of experience" (p. 79) as ways of decrypting themes characteristic of his methods. The *holistic approach* is concerned with highlighting the meaning of the text/data source, the *selective approach* uncovers the text/data source, and the *detailed line-by-line approach* is a way of dissevering each sentence while methodically looking for themes and other nuances about the phenomenon of interest.

Van Manen (1990) suggests six activities for conducting hermeneutic phenomenological research. These six activities, if executed correctly, provide the framework for the interpretation of the phenomenon of interest. These overarching interconnected descriptions, interpretations, and language activities are used to describe

the individual's being in the world. This researcher transcribed each tape recording in its entirety as soon as possible after the interviews, listening attentively to pauses and vocalizations (Creswell, 2007; van Manen, 1990). The analysis of data began during the interview and continued through the transcription process. Transcripts were individually analyzed, giving this researcher the opportunity to familiarize herself with each participant's account by reading and listening to each one a number of times. This process allows the researcher enough time to assess for recurrent ideas indicative of reaching data saturation. Margins on each side of the page provided space to record notes, jot down anything thought-provoking or significant to statements made by the interviewee. At this juncture, the researcher paid special attention and documented perspectives, connections, similarities, differences, and contradictions. During data analysis, the researcher employed reflective journaling to record characteristics of the interview and personal reflections. This practice of journaling aids the researcher's efforts to hide any prior beliefs about the phenomenon. Munhall (2007) also affirms that journaling places the researcher in the lifeworld of the study.

Research Rigor

Research rigor must provide irrefutable evidence of credibility, dependability, confirmability, and transferability. When a researcher decides to embark on a project of investigation, whether qualitative or quantitative, one of the biggest challenges is how to assure the accuracy, quality, authenticity, and trustworthiness of the research. Activities such as retaining field journals, mounting safeguards against common distortions, conducting debriefings, triangulating data, and developing an audit trail are all ways to

ensure that the research has some degree of trustworthiness. Many have debated this issue; hence, the parallel perspective as proposed by Lincoln and Guba (1985) is now regarded as the gold standard for assessing trustworthiness in qualitative research (Polit & Beck, 2010). This standard, or framework, parallels methods used in quantitative research to test reliability and validity (Polit & Beck, 2010). The framework initially articulated by Lincoln and Guba (1985) contained recommendations to use credibility, dependability, confirmability, and transferability as the criteria for assessing rigor in qualitative research (Polit & Beck, 2010). Nine years later, the authors explicated yet another concept to their framework in response to critics of their previous framework, which include the notion of authenticity congruent within the naturalistic paradigm (Polit & Beck, 2010).

Credibility

Credibility refers to the value and truthfulness of the data collected and is similar to internal validity in quantitative research, the element allowing others to recognize experiences contained within the study through interpretation of participants' experiences. The researcher is, in this context, perceived as credible by checking for the representativeness of the data as a whole. Accordingly, this researcher has reviewed all individual transcripts, while meticulously looking for similarities among the study participants in terms of what they have experienced. To establish credibility, the researcher must include reflexivity, member-checking, and peer debriefing or peer examination. Reflexivity refers to the researcher being aware of the study in a way that honors and respects the site and participants (Creswell 2007; Polit & Beck, 2010).

Member-checking, also known as informant feedback, involves returning to the persons from whom data has been generated (a qualitative term for data collection) to ensure that the interpretations (reported as categories and themes) of the researcher are recognized by the participants as accurate representations of their experiences.

Peer debriefing constitutes an external check on the research process between the principal investigator and a person uninvolved with the research study (Creswell, 2007; Lincoln & Guba, 1985). This person can ask questions about the methods, meanings, and interpretation of the data, allowing the researcher an opportunity to express her feelings (Creswell, 2007). The consideration of multiple interpretations between this researcher and the peer debriefing produces study results that are believable interpretations of the amputee's experience. This researcher provides thick, rich description, researcher reflexivity, and member-checks along with peer-debriefing to achieve credibility.

Dependability

According to Polit and Beck (2010), dependability refers to the stability and the reliability of the data over time and under diverse conditions. This process is accomplished by providing a detailed report of the data collection and data analysis process within the study. Maintaining an audit trail is important because it allows an auditor or second party familiar with the study, its methodology, findings, and conclusions the opportunity to appraise the research processes and confirm its findings. According to Sandelowski (2010), a study's findings are auditable when a peer reviewer can follow the decision trail detailed by the researcher in the study. The peer reviewer should be able to arrive at the same or comparable, but not contradictory, conclusions

given the researcher's data, perception, and position. This researcher provides in-depth details of the research design, using van Manen's approach to hermeneutic phenomenology, as the phenomenon of the Barbadian diabetic amputee is revealed. This researcher also provides detailed descriptions of the data-collection process and thick, rich descriptions of the study findings, which will collectively strengthen the consistency and stability of the study.

Confirmability

Confirmability, which is similar to objectivity in quantitative terms, occurs when credibility, transferability, and dependability have been established. Polit and Beck (2010) articulate that in order for confirmability to be attained, the research findings must be reflective of the participant's voice and the circumstances of the investigation. The researcher's biases, motives, and presumptions must be addressed so that research findings are not compromised.

The qualitative researcher must be reflective, maintaining a sense of awareness and openness to the study and unfolding results. Like reflective practice (Johns & Freshwater, 2009), reflective research allows a big picture view with interpretations that produce new insights, allowing for developing confirmability of the research and, overall, leading the reader or consumer of the research to have a sense of trust in the conduct and credibility of findings leading to its applicability to the study. To achieve confirmability, this researcher keeps detailed field notes documenting any observations, slang words, and metaphors used by the participants. The clarification of the researcher's bias is

established at the beginning of the study, with the researcher articulating in writing her biases and perceptions of the phenomenon.

Transferability

Polit and Beck (2010) defined transferability as the extent to which the findings from qualitative research can be transferred to other settings. It is the ability to transfer research findings or methods from one group to another. Furthermore, this can also include “how one determines the extent to which the findings of a particular inquiry may be applied in other contexts or with other subjects/participants,” equivalent to external validity in qualitative research (Lincoln & Guba, 1985, p. 290). The basis for transferability is the thorough description of the participants, observations, and processes, providing the reader with information necessary to understand the research findings (Lincoln & Guba, 1985). To achieve and enhance transferability, this researcher provides thorough descriptions of the participants, the methodological approach used, and the thick, rich descriptions of the phenomenon.

Chapter Summary

This chapter summarized and discussed how the researcher has executed the study. It highlighted the methodology used to design this qualitative study, the qualitative paradigm, and the reason the researcher chose this method. A description of the study population, setting, access and recruitment of the sample, inclusion and exclusion criteria, ethical considerations, the data collection procedures, and data analysis plans were also incorporated. The researcher also discussed research rigor in reference to this study. Chapter Four follows with the results of this inquiry.

CHAPTER FOUR

FINDINGS OF THE INQUIRY

The primary research question of this study, “What is the lived experience of Barbadians with lower-extremity amputations as a complication of long-term diabetes mellitus?” considered the sensitivities conveyed by Barbadian diabetic amputees. The aim of this study was to contribute to current scholarly literature and provide a deeper understanding of individuals who have undergone an amputation because of *diabetes mellitus*. This chapter outlines the findings of the lived experiences of 16 diabetic amputees. Demographic representations and individual descriptions will be presented for these participants. The essence of the participants’ lifeworlds, thoughts, and feelings are described. The participants’ stories elucidate the meaning of their lived experiences. In addition, the data analysis process and thematic depiction reflecting the amputee’s lived experience are provided, as well as a summary of significant findings.

Permission to conduct this study was received from Barry University, The University of the West Indies, Cave Hill, and the Ministry of Health, Barbados. The first 2 days on-site proved to be the most challenging, as the Queen Elizabeth’s Hospital rehabilitation department had not been made aware of the researcher’s date of arrival by their administrative staff. The researcher reached out to the Ministry of Health and the parties who initially had given permission, and another day passed with no participants to interview. Finally, word arrived that the researcher was permitted to conduct the interviews, and the rehabilitation lead physiotherapist and the attending rehabilitation physician were made aware of the researcher’s presence, and permission was again

granted. Feeling frustrated and bewildered, this researcher returned to the hospital on day number three, prepared to conduct interviews with any potential participant. Despite these challenges, the participants were willing and eager to engage this researcher.

The phenomenological framework of van Manen (1990) directed this inquiry and guided the researcher to discover the meaning of this phenomenon and provided specific particulars and thick, rich descriptions of the phenomenon for the diabetic amputees' belief that phenomenology is aimed at gaining a deeper understanding of the meaning of everyday experiences. Through the personal accounts of these participants, the researcher was able to illuminate, describe, and give meaning to the lived experiences of Barbadians with lower-extremity-amputation as a complication of long-term *diabetes mellitus*. The data collection and analysis were directed by van Manen's six activities. The researcher collected, transcribed, and analyzed the data over a period of 3 months.

According to van Manen (1990), phenomenology as a qualitative research method cannot be used to generate theory or to explain or control the world. However, phenomenology describes that which is of the world, and brings one directly in contact with the world. This method is not based on experimental science, it cannot be used to generalize findings, and it does not problem solve. However, this research method allows the researcher to gain a profound understanding of the individual's experience of the phenomenon, without abstraction or classification of the experience that is their lifeworld (van Manen, 1990).

Consequently, the aim of phenomenology ultimately is to tell a story, while discovering and exposing an aspect of human experience. This researcher wanted to

learn more about and construct meaning of what it is like to be a Barbadian diabetic amputee. This was completed by focusing on the amputee's experiences through their lifeworlds. The researcher interpreted accounts of the participant's lifeworld by conducting in-depth interviews. These interviews allowed this researcher to become immersed in the everyday lived world of the participants, seeing firsthand and interpreting what was said and how it was said. van Manen (1990) communicated that phenomenology is the study of the lifeworld, the world in which we live, a world that is void of words, and somewhat difficult to explain, the study of the essences of an experience as we attempt to understand it. Phenomenology can be seen as the vehicle used to gain a better understanding of the world of human beings, the methodical attempt to uncover and describe the core meaning of the structures of lived experiences (van Manen, 1990).

The data assimilated through the interviewing process led to the evaluation and critique of other studies looking for similarities, parallels, and variances. Each transcript was gleaned over several times, as the researcher listened attentively to the audiotapes. This chapter contains the findings of this phenomenological study in which the lived experience of Barbadians with lower-extremity amputations as a complication of long-term *diabetes mellitus* were revealed through audio-taped interviews and reflective journaling. Four core themes emerged: *devastating*, *accepting*, *adjusting*, and *transitioning*.

Demographic Representation

The study included 16 diabetic amputees, all of whom were from Barbados. Table 1 provides the demographic characteristics, name, age, marital status, amputation site, and the event precipitating amputation for each participant. Fourteen of the research participants were recruited from the rehabilitation services department located at the Queen Elizabeth Hospital (QEH), and two of the participants were referred to the study via snowball sampling. The QEH is a 600-bed complex, located in Bridgetown, Barbados. It was originally constructed from 1963-1964 and officially opened on November 14, 1964.

Table 1

Study Participants Demographic Characteristics

Pseudonym	Age	Gender	Marital Status	Amputation Site	Precipitating Event
Kofi	65	Male	Married	Bilateral BK ^a	Toe injury
Kwami	62	Male	Married	Right AK ^b	Callous infection
Akosua	80	Female	Single	Right AK	Toe injury
Adwoa	61	Female	Single	Bilateral AK	Toenail injury
Abena	82	Female	Single	Left BK	Acupuncture
Kwasi	44	Male	Single	Left AK	Wound
Kobby	75	Male	Single	Left AK	Wound
Yaa	69	Female	Widow	Right BK	Toe injury
Lariba	53	Female	Single	Left AK	Heel crack
Ekua	53	Female	Single	Left AK	Poor circulation
Akua	62	Female	Divorced	Right BK	Toe gangrene
Afia	67	Female	Widow	Left AK	Ingrown toenail
Ama	60	Female	Single	Bilateral AK	Bruised toe
Lahari	80	Female	Single	Right BK	Toenail removed
Sibri	82	Female	Single	Right BK	Needle stick
Esi	79	Female	Single	Right AK	Injured foot-fall

^a Below knee (BK) ^b Above knee (AK)

Characteristics of the Participants

The researcher remained committed to the research process, with the intent to gather generous amounts of rich data reflective of each participant's lived experience. The participants were asked by the researcher to select a pseudonym, and each pseudonym was used throughout the study to maintain confidentiality. The pseudonyms used in the study are representative of the names the Akan people of Ghana name their children. Each name represents the day of the week an individual is born. These "day names" are thought to hold meanings concerning the soul and character of the person. All participants were intrigued by the researcher's choices. None of the participants had any issues with the name selected. Participants' description of their journey was carefully deciphered from the audio tapings and then transcribed.

The interviewing process proved fruitful and highlighted the participants' enthusiasm as they reflected and detailed their stories as diabetic amputees. The interviews, field notes, and additional anecdotes from the researcher's reflexive journal were edifying, enlightening, intriguing, and generated sufficient information to describe each participant. Both researcher and participants were appreciative of the opportunity to share information in a reciprocal manner, and each detailed interview provided a perspective articulating the mental state of each participant. All participants met the inclusion criteria for this study; a brief description of each participant follows in the next section.

Kofi – Friday

Kofi is a 65-year-old married male diagnosed with diabetes at age 55 years. He is a retired engineer by profession and is married and has three children. **Kofi** lives at home with his wife and daughter, and he is one of the founding members of Barbados Amputee, Rehabilitation and Enabling Society (BARES). He appeared eager and willing to have a dialogue with this researcher regarding his life as a diabetic amputee. **Kofi** received his first BKA in January 2014 and his second in 2015. The interview was conducted in his home at his request. The dining area of the home provided the privacy needed for the researcher to conduct the interview. **Kofi** reported frustration and disbelief when he was told that his leg had to be amputated. He stated, “Well from the first outset to have your leg amputated is disappointment, frustration and unbelievable. It is unbelievable, you know. One wouldn’t imagine that he would lose a leg.”

Kwami – Saturday

Kwami is a 62-year-old married male diagnosed with *diabetes* in 1994. He is a retired teacher, married, and has two children. **Kwami** received his amputation in 2015. His interview took place in the home of his very close friend **Kofi**, at the request of both participants. **Kwami** is also one of the founding members of BARES, and he reported that he felt comfortable speaking openly in the presence of his friend **Kofi**. He lives at home with his wife and his daughters, and he also appeared very eager to tell his story. **Kwami** spoke with enthusiasm as he reminisced about his days as a youth with two legs. He stated:

Well, at first it was most unsettling because I consider myself a fairly active person. I used to do lots of walking and I played games. I played volleyball. I played football as a youngster. I played volleyball in my 20s. So I went from as a youngster, as a teenager I played lots of football. In my 20s I took up volleyball and played lots of volleyball, and in my 30s I coached volleyball to my school team. Having lost a leg then I obviously then would miss it because I couldn't play the sports I liked anymore.

Akosua – Sunday

Akosua is an 80-year-old female who is retired. She was diagnosed with *diabetes* at the age of 50 years, and had her right leg amputated below the knee in 2012. **Akousa** is a high school graduate, and she has eight children. She was a very mild-mannered elderly lady with motherly qualities who reports living alone. **Akousa** shared:

Having a leg amputated is very hard for some people that is true. When I see a man with his leg off it hurts my insides and I did not know that I was going to get mine cut off same way, but praise God I am alive. And I ask God for help and strength and all who help me, I thank them.

Adowa – Monday

Adowa is a 61-year-old female who is single, never married. She mentions that she is retired, has two children, and her recollection of her diagnosis of *diabetes* is poor; she admits that she cannot remember the specifics of when she was diagnosed with diabetes. **Adowa** is a bilateral BKA amputee who had her left leg amputated in 2012, and her right leg amputated in 2013. During the interview, she was very descriptive as

she told her story, providing insights into the first time she realized something was wrong with her leg. “Well, my leg amputated in 2012 was a real hard to take it. I had to get some friends and they help me along with some of my family.”

Abena – Tuesday

Abena is an 82-year-old female who is single and has no children. She is a high school graduate now retired, and admits to a history of *diabetes* dating back some 15 years ago. **Abena** had her left leg amputated below the knee in 2015, and during the interview, she kept referring to the amputation as “still new for me.” She admits to feeling surprised when she was told that her leg was going to be amputated and again feeling surprised after the amputation. “It is very difficult. It was not painful but surprising, surprising when they took it off.”

Kwasi – Monday

Kwasi is a 44-year-old male with a high school education and is a general contractor. He is single, has no children, and resides with his mother. **Kwasi** was diagnosed with *diabetes* in 2008 and had his left leg amputated above the knee in 2015. He spoke openly about his amputation, his limitations as a person with a birth defect that has left him physically challenged, and how he is managing and coping with a second disability. During the interview, **Kwasi** spoke in high regard for his mother, who is a registered nurse. He admits to being grateful for her as his mother and for the nursing care he received from her after the amputation. He explained:

Losing a leg is like losing a part of your body that you did not plan for. You really do not know what to expect. Well lucky for me my mother was a nurse so she understands somewhat what has to happen.”

Kobby – Tuesday

Kobby is a 75-year-old male with a high school education, single, has three children, and shared that he is retired at present. He cannot remember when he was diagnosed with *diabetes*; however, he indicates that he noticed something was wrong with his foot back in 2012. **Kobby’s** left leg was amputated above the knee in 2016. He refers to himself as a bachelor and jovially told the researcher that he has elected to be a bachelor because he can do all of the things that a wife does for her husband. He had a perplexed look on his face when speaking of his feelings and what it is like to have a leg amputated. **Kobby** shared:

I really don't know this is the first time for me. A lot of people I see in there, that are diabetics and they have their foot off too, but some of them foot off by the part, the toes. So I really don't know. This is a first time for me. I really don't know how to think, but I have a feeling like I still have the foot. A doctor pass and he ask me a question and tell me that it gine [going to] feel that way for now so I said well that sound strange.

Yaa – Thursday

Yaa is a 69-year-old widowed female. She is retired and communicates that she was diagnosed with *diabetes* in 2000. **Yaa** admits to having her right leg amputated below the knee in 2010. She was very excited to see the researcher as this researcher’s

aunt referred her. The interview took place in her living room, and she was very welcoming, as she provided details of her position in the home, her family, and her life as an amputee. **Yaa** lives with two of her children and spoke openly about her physical limitations, what she is able to do for herself, and what she needs in the way of assistance. She speaks of herself as a “social butterfly” who continues to enjoy life despite her challenges. **Yaa** mentioned:

Well, sometimes you find difficulties in getting around; sometimes it doesn't really bother me. I accepted everything that happened because it is a long time I had it. I still get around, Mrs. Lasscel's will tell you, I went to a fair up to May Day, I go all about I go out pun dat [on that] pasture pun [on] a Friday evening with some friends and sit down and enjoying myself. I can get down the ramp, but I can't get back up, and if I could, I would come out by she regular. However, she can't push me back up the ramp, so I stand home. But if I have somebody who wants to bring me back up the ramp, you know, I would.

Lariba – Wednesday

Lariba is a 53-year-old single female who is a high school graduate. She was diagnosed with *diabetes* in 1997 and had her left leg amputated above the knee in 2015.

Lariba appeared very dismayed when reliving the moment; she found out that she had to have the amputation. She stated:

Well, it's a hard thing. It's like real depressing. You can't really do nothing much for yourself. You always got to depend on people and I guess what I can say, it's depressing, it's heartbreaking to lose a limb and then you can't really get around.

You always got to depend pun [on] people. Well, I guess after your feet get amputate, a lot of them just sit around. You can't work now so it's... people here ain't really loving or caring in particular, you're on your own then. So, to me they ain't really care too much about my foot amputate or how we would get along. They would just say, oh, well you had, you will get little pension from the government and so they live in a house where you got to pay rent, and then they must wait 3 months, 3 months before I can get money come to me, a little national insurance.

Lariba lives with her son, and she praised him for his role as caretaker when she initially went home. She recalled:

Well, it is very hard because where I live I got my bedrooms upstairs and I cannot get up 14 steps to get to my bedroom. I had to get my son to bring down a bed and I had to transform my living room, half of my living room into a bedroom so that I could stay there, and I could use it as a bedroom because I cannot –with just his own, help me up the stairs to am thing. So, I can't even get a proper bath because the bathrooms are on the upstairs.

Ekua – Wednesday

Ekua is a 53-year-old single female who has one child. She has a high school diploma and worked as a supervisor prior to her amputation. **Ekua** was diagnosed with *diabetes* in 2009, and she had her left leg amputated above the knee in 2013. She lives alone and appeared angry at her landlord for lack of empathy towards her situation,

noting that no effort was made to modify her home and make things more accessible following the amputation. **Ekua** expressed:

Well, well I'm renting, so I explain to the lady and everything and she never suggested anything, so I try to get by as best I possibly can. I don't have any hand grips or ... If anybody's taking me out, we take mostly wheel chair and there's a fairly tall ascending, but it is all right 'cause I get accustomed to it now, and all I want to do is learn to walk. So, I will be jumping over that same thing.

Akua – Wednesday

Akua is a 62-year-old divorced female with no children. She was diagnosed with *diabetes* 20 years ago and had her right leg amputated below the knee in 2015. **Akua** describes herself as a God-fearing woman who was independent prior to her amputation, and reports that she will continue on a trajectory of being self-sufficient. She lives alone and reminded this researcher of this throughout the interview.

Oh, well, not very good. I say make the best of it. It's something that you must live with now, you have no choice, so you make... at first, I had find a little difficult accepting it, but I never really after that had any problems. I try to cope with everything.

Afia – Friday

Afia is a 67-year-old widow and mother of three children. She admits to being retired and is dependent on her pension to financially sustain herself. **Afia** has a primary school education and admits to a diagnosis of *diabetes* about 25 years ago. In 2013, she had her left leg amputated above the knee. **Afia** is a proud woman, who reports that she

worked for many years, taking care of herself following the death of her husband. She is presently residing with two of her children and cringes as she describes how it has been for her as an amputee. She said:

It is very awful to have a leg amputated, especially above the knee because it is uncomfortable, it is not comfortable. Everything got to do with the right foot. It got to stay up on the right foot, to jump in the bathroom, jump up on the toilet.”

Afia explained that she feels that her children did not accept the news of her amputation well. “They had it hard, cause up to now, I had my foot off in 2013 and up to now my daughter ain’t see it yet. It hit my daughter so hard. My daughter cannot face it up to now.

Ama – Saturday

Ama is a 60-year-old single female with four children. She communicates that she was employed as a laborer for many years up until the time of her first AKA amputation of her left leg in 2012. **Ama** later had her right leg amputated above the knee in 2013. She is presently in a relationship, and she remarked that her male companion is very supportive of her, and he is very useful around the house. She further added that her children are also supportive; however, she has a son with whom she is estranged, and this bothers her at times. **Ama** expressed that an amputation for her meant disruption and dis-equilibrium:

Well, it is very disruptive to me because when you have one off and the other one on, then I move, and you might be able to get along a little better, you know, but certain things you cannot do as you wanted to do in life. At home, I sit down on

my bed all day and cry, cry, cry. My son came home and said, “What are you crying for?” I said because I would like to get up and do things and I can’t manage it now. So that was my biggest midpoint.

Lahari – Sunday

Lahari is an 80-year-old single female with three children. One child is deceased, one lives with her, and the other child is married and lives with his family. She is educated at the primary school level and is retired. **Lahari** has a left leg below the knee amputation since 2005, and she appeared upbeat and hyper talkative during the interview, welcoming the researcher to the rehabilitation center, while pointing out a few of the staff members who she described as “gems.” **Lahari** appears feisty in her response to the questions and uses many hand gestures as she exclaims her points. She reported excruciating pain to her leg and telling the doctor where and how much of her leg he should remove. “Well I did say I wanted it off because I was in so much pain, I marked where I wanted it to come off, yes, I tell him that there is a certain amount I want you to cut off.”

Sibri – Saturday

Sibri is an 82-year-old single retired female who admits to having a primary school education. She has nine children, including one male child who is also a diabetic amputee. **Sibri** was diagnosed with *diabetes* about 15 years ago, and she had her right leg amputated below the knee in 2015. The interview was conducted in her home, and the writer was made comfortable throughout the interviewing process. **Sibri’s** daughter,

her granddaughter, and her amputee son all reside in the home. Her granddaughter was present for the interview and added collateral information that her grandmother could not recall. **Sibri** spoke openly about her journey as a diabetic amputee and some of her challenges.

Esi – Sunday

Esi is a 79-year-old single female with a primary school education and is presently retired. She has six children and admits to a diagnosis of *diabetes* approximately 20 years ago. **Esi** had her right leg amputated above the knee in 2014. She is the sibling of **Sibri**, and they both reside on the same street, two houses apart. **Esi** resides with one of her sons and his family. The interview took place in her living room, and her son was present for the interview. He made the interviewer feel at home by offering a cold beverage. **Esi** admits to being an avid gardener who spent countless hours in her garden, planting and harvesting what she so passionately refers to as “greens and thyme and tings [things] like that.” She admits that she was forced to make some changes to her hobby because of her amputation. “The ... It ... I don't let it worry me, but it ... by accustom, working in the garden, doing things, you know, it set me back.”

Sixteen Barbadian diabetic amputees participated willingly and fully, openly sharing their journey. All participants provided valuable insights about their diabetes, their amputation, and subsequently their life, living as diabetic amputees. The researcher provided participants with the opportunity to share their story, while providing privacy and showing empathy. Each participant was afforded the opportunity to engage and as

such provided the researcher with countless detailed descriptions of their phenomenon, which led to the capturing of the true essence of their experience.

Themes

Eleven interviews were conducted in an office located in the Rehabilitation Physiotherapy department at the Queen Elizabeth Hospital, and five interviews were conducted in the participants' homes. The interviews conducted at the hospital provided a safe and private location for the researcher and the participants, and the home interviews provided the researcher and the participants the same level of privacy and quietness for each audiotaped interview. All participants who met the inclusion criteria were approached by the researcher during their clinic visit and were informed of the study and the interview. On the day of the interview, the researcher discussed the terms of consent in detail and allowed each participant the opportunity to ask questions or request clarification of the interviewing process. Real names were not used, and each participant could choose a pseudonym prior to the interview for confidentiality.

Semi-structured interviews, and audio-recordings were utilized to examine the experiences of the Barbadian diabetic amputee. According to van Manen (1990), it is difficult to learn about a lived experience through collateral accounts (books, journals, or discussions); thus, the phenomenon must be investigated (1990). Semi-structured, in-depth interviews were used because they supported the study and the phenomenological approach that underpinned the study. The researcher conducted the interviews, which allowed for the gathering of thick, rich narrative textual data that would provide a deeper understanding of the phenomenon. Participants told their stories in their own words, thus

promoting an atmosphere of trust and empathy between the researcher and participant. Leading questions allow for flexibility and are an advantage when utilizing semi-structured interviews. This tool allows the researcher the opportunity to include new and additional information from each participant. This one-on-one is direct and immediate (coexisting time and space), which is the same kind of empowerment for qualitative exchanges between an audience and a performer even though it is implicitly understood that a performance art is an “illusion;” it still must be psychologically valid to be believable, engaging both the story-teller and the listener.

Each individual interview lasted between 45 and 90 minutes, and upon completion of the interview, each participant was given a gift basket worth \$25 U.S. Immediately following each interview, the researcher wrote detailed notes and reflected on the atmosphere, tone, and verbal and nonverbal cues. The researcher first listened to each audio recording several times, and each transcript was also read numerous times to achieve adequate understanding. The researcher performed bracketing and self-reflection to examine personal beliefs regarding the experience of the Barbadian diabetic amputee. This was done at several points in the data collection process. The researcher also completed a journal prior to, during, and after data collection to ensure any presumptions or biases did not influence or alter data collection or interpretation. The researcher then immediately transcribed the audiotaped interviews verbatim. The researcher transcribed all the interviews immediately for transcript verification and ensured member check because of the researcher’s limited stay in Barbados. Each participant was asked to review their transcripts for clarifications, discrepancies, and additions. Along with

clarifications, discrepancies, and additions, it was requested that each participant ensure that the interview accurately and realistically depicted their experience. Participants were asked to make necessary changes and return the transcripts to the researcher. None of the 16 participants had additions or corrections for their respective transcripts. Saturation occurred after the tenth interview; however, the researcher continued the data collection process for confirmation with another six participants.

The transcripts were thoroughly read and reread to capture the overall meaning and essence of the experience. Each sentence and sentence cluster were also read carefully, and phrases were highlighted in an attempt to reveal the nature of the phenomenon. The four lifeworlds: lived space (*spatiality*), lived body (*corporeality*), lived time (*temporality*), and lived human relation (*relationality*) existentials provided guidance as the researcher reflected on the amputee's experience. The researcher used van Manen's 1990 method of "free imaginative variation" (p. 107) to corroborate themes directly related to the phenomenon. This process required the researcher to examine the data as a whole, and question whether the phenomenon still exist without each individual defining theme. The researcher was then able to clearly identify those themes that were mutually fitting to the phenomenon. Four themes emerged as a result of the inquiry.

According to van Manen (1990), themes are like a constellation of stars that make up the cosmos of meaning we live through, and by the light generated from these themes, we can explore and maneuver through each cosmos. It is through these themes or structures of experience that we can fully analyze and understand the phenomenon.

Themes can also be viewed as intransitive (p. 87) short-lived moments of a narrative, "the

knots in the webs of our experiences.” (p. 90). The researcher began the data analysis by reviewing each transcript, reading and rereading the narratives, and organizing the statements into groups of meaning that best characterized each participant’s words. Field notes and journal entries were used to associate the researcher’s observations to each transcribed interview, and this process allowed the true essence of the phenomenon, to emerge, the core and spirited meaning of what life is like as a diabetic amputee.

Four major themes emerged from the thematic analysis: (a) *devastating*, (b) *accepting*, (c) *adjusting*, and (d) *transitioning*. These themes were representative of the existential lifeworlds of the Barbadian diabetic amputees, accentuating their lived space, lived body, lived time, and their human relation to their amputation. *Figure 3* is the schematic representation of the researcher’s conceptual thematic representation of the lived experiences of Barbadians with lower-extremity amputations as a complication of long-term *diabetes mellitus* as described by the study participants. Although the themes are listed separately and appear to be linear, they are entwined and interwoven throughout the inquiry, and their inter-connectedness can be seen as each research participant gave their account of their personal lived journey. The themes can then be individuated and understood at any time in the amputee’s experience, and then be brought back into the whole as new developments or challenges presents themselves. Max van Manen’s (1990) phenomenological method provided the guidance and analysis for this inquiry, “What is the lived experience of Barbadians with lower extremity amputations as a complication of long-term diabetes mellitus?”

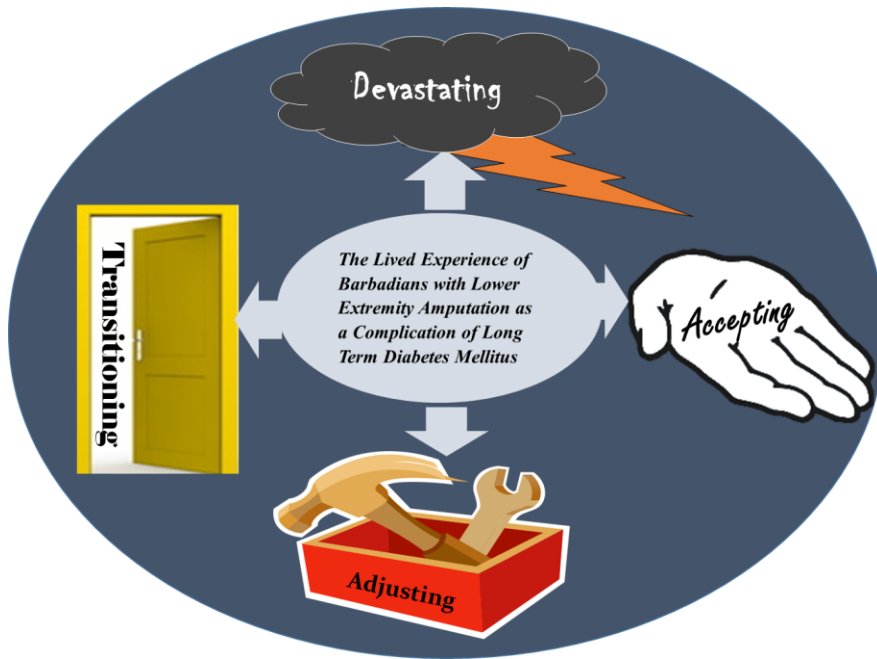


Figure 3. Brathwaite's conceptual thematic representation of the lived experience of Barbadians with lower-extremity amputations as a complication of long-term diabetes mellitus. (Brathwaite, 2016).

Devastating

To devastate is to cause emotional suffering and to destroy (Merriam-Webster Dictionary, 2016). This was the first theme that emerged from the data. Every individual participant overwhelmingly described and zealously relived the day they realized that something was wrong with their foot, and the time before the amputation.

Kofi communicated that he can still vividly recollect the day he noticed something was wrong with his foot, and that disconsolate day when the doctors informed him that his foot needed to be amputated. He recounted:

I actually, as far as I remember a couple of days before that, at the edge of the bed I used to keep my PC or electronics or something. And there is this radio down there and I hit my foot onto it. I remember that distinctly in the toe. There is after about 2 or 3 days after an evening I noticed that the top of the toe had a clot, like a blood clot, but that would have been actually when things started to gangrene, and it was black... like it was dark.

Several months later, he was told:

Kofi we hate to have to tell you, and I am sorry, but it seems like this gangrene thing is on the move and it's getting higher and we have to amputate as soon as possible. Otherwise, it would possibly go and shut down your system and things.”

Kwami's affect changed as he recalled visiting his sister in New York and remembering having plumbing problems that created an issue in her shower. He appeared perplexed as he describes how that incident started his troubles and

subsequently devastated his life. In October 2014, he spent some time with his sister in New York. While there, **Kwami** recalled:

Her sewer system backed up, and I put slippers on and went in the bathroom to bathe and the water came over the slippers and I had a callous on the right foot. I stood in the thing and I took my bath and I got an infection in the foot, but I didn't know.

In 2015, he stepped on a nail, and that started the deterioration of his foot. **Kwami** stated:

He examined the foot and he told me he was going to take the two toes that were badly infected, so you have to take off your two toes. So I was like, if you're taking the toes to make this pain go away or stop the foot from hurting like it's hurting, take them off. Go ahead. So he continued examining and then in the next few minutes he said he was going to take off all the toes. So I was thinking, well, I've seen people with four toes. At least they would still be able to walk. So take the toes. Get on with the toes. So he continued examining the foot, pressing here, pressing there, squeezing it, and then he said he was going to take the foot.

Akosua remembered going home from church and taking a look at her feet. She also acknowledges that she often checked her feet because of her diabetes; however, she cannot recall why she elected on that unfortunate day to pay special attention to her feet.

Akosua recollected:

I came from church one Sunday and sit down and I look at my feet, all cracked and torn, and I see that between my toes it was black and red. That part was

blood. I went to the clinic on Monday, and my doctor tended to me. He said I will try to save these toes for you cause it ain't too bad, but I knew that the diabetes was good with it." The infection worsened and the doctor informed her: "Mom, I have got to schedule the surgery for Tuesday. The bad circulation is traveling too far." I said, "Are you trying to kill me?" He said, "No mom I am not going to kill you, I am going to save your life."

As the interviews continued, each research participant's demeanor changed as they described in details what some of them so dearly called the day of remembrance, a day that will be forever etched in their mind, a day that will always bring about reflection. **Adowa** recounted when she looks back on that day when she saw Dr. Carrington in his office. She reported a crushing feeling in her chest, a feeling of doom when she was sent to the hospital. **Adowa** shared:

The first thing that happened to me was my left big toe that get dark, dark and the nail came off. So I had to go to clinic that same day, December 23, 2011. That same day I had to go and see Dr. Carrington at the Warren Clinic, and she ordered me from there straight to hospital because she didn't like how my toe did look, and they did trying, trying, but with my foot being sore afterwards the toe got dark, dark, so they had to take it off. The other four got dark so they tell me the best thing now to save my life, the foot would have to go. If I want the foot, then it would take me then, so I said, Well, they have to take my foot and I will be here. I let the foot go, and I am still here.

Abena also appeared very baffled as she spoke of attending an acupuncturist and fearing that a needle injured her. She stated:

So I went to get them checked. What yah does call the people now? When you does put the pins in yah, Acupuncture, and probably I got stuck in one veins.” I was all well I say “I it gotta go. I gotta go” 'cause it used to be very painful. I couldn't sleep. I couldn't eat; bear pains, so you had to decide in your mind to do something and to save your life. Because after I had that, I didn't know that I had thrombosis too because as it wouldn't heal – It healed good, good, and dry up good, and the doctor said that I could go into the sea going to sea and I mind her and went in the sea. Yeah, I pick up an infection, a bad infection in the sea, so when I come out de sea, it was yellow like a yellow flower. That was a Sunday, and I had to rush to the doctor on Monday, and he dropped down in a chair and asked me, "What's going on?" and I say, "You tell me to go to sea. And I went in the sea, and this is what happened." And everything break down from there.

Kwasi, the youngest participant, spoke of feelings of disgust, anger, and eventually feeling mortified. He recalled that he had a wound on his foot, and it appeared to be healing, and then “all of a sudden he telling me that he gine teck [going to take] off the foot.” **Kwasi** mentioned:

I had a wound and I went to the doctor, and I realize it was starting to hurt a little more, and then last year it kind of broke back open. Honestly speaking, when the doctor called in the morning and I talked to him and he told me that I had to take it off. I didn't take the decision. The problem in Barbados is that the doctors in

Barbados don't really talk to you like they ought to, so you will wait here wait there and then you don't want to lose the leg, but then you decide it has to go.

Kobby also appeared angry as he spoke of the moderate construction work that was being done on his home. His voice rose as he spoke of the careless mason, and attributes his injury to the negligence of the mason. **Kobby** recalled:

Well a mason man, he said he was a mason; he did not round up the edge of the step. He just let it rough. So a day I was coming out and I get the rough part grater my foot, and then I say well this man is a mad man, he did not round up this step. So from there I started to feel problems in the foot, and then I decided to get some alcohol and bathe the foot, but a man tell me man listen, look, you is a diabetic, that foot rotting. I said, foot rotting, so at the same time I did not hesitate, I come straight to the hospital and everything was happening down dey [there].

Thus far, the responses were all in keeping with the feelings associated with sudden loss. **Yaa**, was calm and admitted to the feelings of being "caught off guard" by the news:

Well it had a few, what do you call...? Spots? No, it was on the side of the foot. And from there then my private doctor sent me. She gave me the information to come down to the hospital. It wasn't frightening, but it was surprising, because the foot wasn't hurting per se. Because I was still getting around and everything. Would I be cut off from doing things for myself and so on, because I am alone all the time. This was what I was thinking as he was talking to me.

Lariba said she felt that something catastrophic was going to happen to her. She looked down at her stump as if it was still there, and she started to describe the pain and anguish that she was experiencing before receiving the “earth shattering” news. **Lariba** stated:

Well, I realized the leg start getting like really painful to walk and things like that. I was telling the doctor; I keep on telling her that my foot was like hurting very bad. She just look at it. She didn't actually give me nothing for it so I just had to live with all this pain all that time. I didn't really know it was bad circulation and blood didn't actually going down to my leg. Well, I came into hospital just with one small crack on my heel and they look at it and said it want debriding and they just debride it a bit and the debriding, how they realize that it was bad circulation is the debriding get worse. The doctor and they said they couldn't do nothing more until I probably have to get the angioplasty so it can get blood going down to the feet because I couldn't get the surgery then because it's going to get worse. So and then I came into hospital. I then had to wait like six weeks to get approval to get the angioplasty done so that I could actually get blood going down to the feet. Then for them to do the surgery. Pain coming up and the pain was gangrene. I really didn't take when them den teck [then take] notice of it although I was complaining about this pain coming up. I actually then had to get above knee amputation.

Most of the participants reported a myriad of emotions that were evident when they received the news about their amputation. Some participants felt the need to blame

others as in the remarks made by **Kobby**, and the intense anger at the physician as reported by **Kwami** when the physician kept pressing on his leg during an assessment. Others felt guilt, anger, depression, hopelessness, and helplessness.

Akua stated:

In March of 2013, I was walking, and I notice the left leg it was like what we call the shinbone or the upper calf. It was very, very painful and I'd run to the bathroom, turn on the water thinking that would help. No, but that's better. I mean anything major. Before it used to hurt casual like the other foot, like the right foot you know but nothing major. But I never got any tests or anything. Nobody never gave me any tests.

She remembered the pain:

Well, it was very rough because I guess it was getting so bad, it become septic so I really know what was going on. I remember when it was hurting; my son took me to a private doctor. And she didn't give me a lot of satisfaction anyway. She told me that if I got worse, I should go to the QEH hospital.

Ekua recounted lying in bed, with little attention from the staff:

My sister came, my sister she went to look for me. Three, four days I was still in the socks and when we went to the hospital I didn't have the gangrene. My feet were clear like any other. But they took so long to attend to it, okay, if you have a patient in a bed, it's quite obviously the person have to be sponge, they have to be clean. So, in cleaning they should take the socks off to clean between the toes and everything. And my sister say that she had to take the socks off and when she

took the socks off it was real black. And they didn't have a choice then but to amputate my foot.

Akua also spoke of frustration as she recalled her initial wound treatment schedule, the travel to and from the clinic, and feeling like “all of that was in vein, cause they still had to chop it off.” She stated:

It's just that I realized that the nail was not right and I went to the doctors right away. And as I say, he took it out. I was supposed to go and see the foot doctor to get it done but it started bleeding so he took it out. And I was attending the clinic for like nine weeks, three days a week and then the end of nine I was between seeing the clinic and seeing the foot doctor, the podiatrist. Right. And then they tell me that the toe had gangrene after nine weeks. I mean that had me, I can't tell you. That took a toll on me more than knowing that had to get cut off. That's the truth. Cause I mean every day and practically some mornings because I could never walk properly anyway. I had a little problem with this foot after I had cancer and – yeah, so then I been to the doctor and I had to get – they want to take off a little bit to bottom. And then if it was, 'cause the flow wasn't properly. So I said no, I said if you're gonna cut me, cut me below my knee and I don't wanna be cut twice because I had to get cut twice in my neck already, the thyroid cancer, and I didn't think I could handle that.

Afia's recollection of what she calls “Doomsday” and **Akousa's** unbroken spirit, were filled with humor and dramatization despite their memory of the day they received information about the amputation. **Afia** remembered joking with the physician about not

being able to kneel and pray for him, using the most reverend position that shows respect to “the almighty.” She stated:

I used to tend to the doctor with that ingrown nail. He get rid of that. That got better. Then I was walking on heel. I had a corn on the heel. He get that dey. But then he give me the health stocking to put on and I put on his stocking for one day and then take it off the evening, all the blood was clotted to the back. So he send me here to clear the blood. I don't know what went on. In two days' time de foot turn black, black and he said I catch a infection 'cause it was only my heel, he said get infection and it was a cut below the knee, but when I came out of the surgery I saw above the knee. And said the doctor I thought you was cutting my leg below but he cut it above. I said, but you cut it that I cannot pray for you. I have to lay down and pray for you can't kneel down and pray.

Lahari, likewise, received her dire prognosis with humor. “So he admitted me to the hospital. She remembers telling the doctor: “Well I did say I wanted it off because I was in so much pain. Yes, and I marked where I wanted him to cut it off.”

Ama and **Esi** are both avid gardeners who smiled as they reminisced about working in the field planting cucumbers and the like. Both women were devastated at the news of the amputation. **Ama** reminisced:

I was working and I was molding some cucumbers so a rock got underneath my socks in the shoe, and I worked on that the whole day. It felt okay to me because of not having sensation or anything. So I took off my shoe and I see this rock come out. So I stand up and my foot felt a little funny to me so I tell my son to

check it for me and see, and he tell me mummy I see a round stone bruise underneath it. I said, “Oh my god!” at this time. So then I came home and I just got a bath and I went to the hospital.

She remembered that day in the hospital:

It was very, very embarrassing. I cried actually to this because I didn't want to lose my feet. Because every morning they would come and look at my feet. I said to the nurse, “Nurse, I don't want to lose my feet at all. I don't know how I can get around.” She said it is coming it look pink and it looked good and all that, so all of a sudden it just went down here wire.

The *devastating* feelings continued to resonate in **Ama's** mind even when she returned home. She struggled emotionally as she recalled returning home:

At home I sat down on my bed all day and cry, cry, cry. My son came home and said, “What are you crying for?” I said because I would like to get up and do things and I can't manage it now. So that was my biggest midpoint.

Esi's further stated:

I used to still work my garden and so on, but I didn't know the circulation in the leg was so poor. But I was in the garden one day and then leave, and I went by a friend just down the road dey, and she said she had some eggs for me, and then I coming up the steps, I... these shoes I had on my feet slide, and I went down, and cut the... scraped the... not near the bone, just near the bone, and I came in and put a little something for... you know. ...Dr. Armstrong... And I used to turn around and do everything, and then it start bleeding – the bruise I had, wouldn't

heal, and the doctor used to tend it and so on, but then he said, “It should be healing” and he gave me a letter to take to the hospital to get X-ray and things. And then I went there to the hospital. This lady doctor gave me a X-ray and said like a vein did break and that is what stop the blood from going to the wound.

Esi remembers many weeks of trying to correct the problem and then:

So they tell me it's my choice 'cause I had a young doctor no blood at all ain't going in to that one, and you know, gangrenous come on very quickly and it works through your body. They say, "It's up to you." I say, "Well, if it's to save my life, I will live without it.

Sibri clearly remembers the day she got stuck in her foot with a needle. She stated:

I get a stick with a needle on the leg, a needle, I was in the mat. I didn't know it was in the mat, so it stick me. I went to the doctor and after it was swollen and the doctor transferred me to the hospital. So it caught gangrene.

She recalled telling the doctor, “Well, if a ting ain't no use to you, well you take it off.”

All 16 participants clearly articulated their feelings of devastation when they received the news that their legs had to be removed. The prognosis of amputation had a profound impact on their wellbeing, including their physiological, psychological, and psychosocial perspectives. The diagnosis not only impacted the individuals, it also had a significant impact on their families and friends, and at times resulted in the loss of support from family and friends due to the stigma attached to being an amputee. The

responses from the participants clearly indicate that there is a significant amount of emotional trauma associated with this phenomenon.

Accepting

The second theme revealed was *accepting*. Acceptance refers to nonjudgmentally embracing and experiencing inner states (thoughts, feelings, and physical symptoms) without attempting to avoid, change, eliminate, or control them (Prevedini, Presti, Rabitti, Miselli, & Moderato, 2011). In rehabilitation, acceptance might refer to a variety of reactions, such as *accepting* the presence of a medical condition/illness, the uncomfortable emotions, and physical discomfort associated with the presence of a medical condition.

Elizabeth Kübler-Ross (1969) acknowledged five stages of grief/loss. The fifth stage of grief is acceptance and is characterized in this context by comments indicating realistic acceptance of a changed reality and hope for a better future. According to Kübler-Ross, acceptance occurs when the individual has processed his or her initial grief emotions and is accepting that the loss has not only occurred but is also undoable. These individuals are therefore able to plan for their futures and re-engage in daily life. According to the research participants, receiving word that an amputation was inevitable left them bewildered, lost, shocked, and feeling catapulted towards *accepting* of the demise of the leg. **Kwami** recalled:

There was no talk about taking measures to try to heal the foot, get the infection out, or nothing like that. The decision was to take off the foot. So here I was on the bed sitting down, laying back, crying of course, 'cause I didn't go expecting

the foot to be taken off, amputated. So I admit freely I cried. I told them, "You cannot take the foot. What do you expect me to do?" The guy told me then, the doctor told me then, "You are relatively fit, so you can be fitted with a prosthesis and you should be able to walk again. You should be able to drive and all those kind of things that you were accustomed to doing. You should still be able to do those things." So the decision was made there and then to take off my foot.

Kobby remembered a friend telling him that his foot was rotting, and when he arrived at the hospital, it was as if the amputation had already been done, so he accepted his fate. He states, "Well to me you can't get along as you would like, but you still got hopes, as papa Davis said, 'life can be beautiful.'"

Abena described the intensity of the pain and suffering she endured as the result of the wound allegedly caused by acupuncture, and why she almost immediately accepted her fate. She stated, "I was all well I say, "It gotta go, It gotta go" 'cause it used to be very painful. I couldn't sleep. I couldn't eat. Bear pains. So you had to decide in your mind to do something and to save your life." **Akousa** joked of her *acceptance* of limb loss by giving the doctor instructions as to where she felt he should amputate. "Well I did say I wanted it off because I was in so much pain. Yes, and I marked where I wanted it to. Yes, I tell him that there is a certain amount I want you to cut off. **Lariba**, with a grimace on her face, and holding her stump, describes her circumstance, her lengthy hospitalization, and her *accepting* of the amputation. She mentioned:

And at that time it was just only dealing with like the feet down to the bottom, near down to the ankles but it seems over time to get worse and it come to a point

then after like spending six months in a hospital. It get to a point then that it get worse and I actually had pain coming up and the pain was gangrene. I really didn't take notice of it although I was complaining about this pain coming up. I actually then had to get above knee amputation.

Sibri was also *accepting* of her amputation when she was informed that the limb had become gangrenous. Her sentiments were dramatized as she used her hands in a chopping manner towards the amputated leg. She said:

I went to the doctor and after it was swollen and the doctor transferred me to the hospital. So it caught gangrene. How it feel to me? Well, if a ting aint no use to you, well you take it off.

Kofi spoke of desperation and pondering before the *accepting* of his misfortune. He too felt the need to resort to the Bible for guidance, mentioning that most of the members of BERES are Christians, and many of them often uses quotes from the Bible to accentuate their statements.

At that time, I didn't really have a window really to sit down and study anything. At that stage my state of mind was that this was desperation, it was a matter in life or death, so... The first thing is if something offends you, you have to cut it off. I planned to cut it off it is. I think I remember asking him, "So, when you amputate, does it mean it would stop the infection from going any further?" He said, "Yes." That is the reason why we have to cut above it." I said, "Okay." and I hardly wasted any time in signing it at that point. But in the back of my mind is going from a toe to having the majority of the limb amputated.

Lahari, with her eyes closed, recalled her moment of *accepting* when she felt calm, and she finally surrendered. She explained:

He carry me and put me, and I lay down in my bed very comfortable and I look up. I say father me and you and all who will look at me. I asked him to direct their path clearly so is my body. After that I felt a cover come and cover me, and say **Lahari**, I gine [going to] carry you safe cause you in the house of God already. From the time I say thank. the hand let go sweetheart, and I aint see that hand since.

One by one, each participant recalled so vividly the moment they surrendered in *accepting* the medical team's recommendations, and decided to have their limb amputated. For some it was a decision that was instantaneous, and for others it took some time to contemplate their decision. For **Akua**, her decision was all hers. She stated: As far as my family is concerned, I was in this by myself. I didn't involve because I didn't want anybody say oh, you couldn't do it yourself and I didn't sign nothing for you to cut off your foot. You know, I handle everything myself, and the doctors can tell you that.

Kwasi's moment of reality and his decision in *accepting* his amputation was initially met with defiance and anger, as noted in his tone of voice. He shared:

Honestly speaking, when the doctor called in the morning and I talked to him and he told me that I had to take it off. Initially, I didn't take the decision. The problem in Barbados is that the doctors in Barbados don't really talk to you like

they supposed to so you will wait here wait there and then you don't want to lose the leg, but then you decide it has to go.

Akua, Afia, and Adwoa all recall the color of their toes, the swiftness of the tissue death, and the urgency of the surgery, and their *accepting* life without their limb. **Akua** remembered her sister being concerned that her socks had not been taken off her feet for a few days, she stated:

So in cleaning they should take the socks off to clean between the toes and everything. And my sister say that she had to take the socks off and when she took the socks off it was real black. And they didn't have a choice then but to amputate my foot. They had to do it in emergency that it's life and death. And I start to become septic. Because it was gone too far.

Afia's tone of voice changed as she remembers being "ok" with the amputation and consenting and *accepting* the surgery, however, she so bluntly expressed her disbelief. She expressed:

In two days' time de foot turn black, black and he said I catch a infection 'cause it was only my heel, he said get infection and it was a cut below the knee, but when I came out of the surgery I saw above the knee.

Adwoa also recalled *accepting* the physician's recommendations, *accepting* her fate, and living her life without a leg in order to save her life. She divulged:

When I finish now, the other four got dark so they tell me the best thing now for to save my life, the foot would have to go. If I want the foot, then it would take

me then, so I said, “Well, they have to take my foot and I will be here. I let the foot go, and I am still here.”

In the study, all the participants, who were diabetics, described candidly how their diabetes and its chronicity resulted in the loss of their limb/limbs. They were clear in their articulation of how profound the progression from diabetes to amputation was for them. *Diabetes* is a chronic disease, and having a long-term, or chronic, illness can cause disruptions in the individual’s life in many ways not clearly understood by immediate family, caregivers, and even providers. While living with an amputation is challenging and can affect the amputee’s quality of life with deep ramifications, physiologically and psychologically, overcoming these challenges and achieving a sense of balance is cardinal as the amputees move toward a more promising future. The themes that emerged from the participant’s narration in the study, described the experience of *accepting*, of their new lifeworld.

Adjusting

The third theme became more obvious as the participants described their surgical procedure, their return home, and the shift in their thinking as they tried to cope with their life as an amputee. In psychological research, *adjustment* is discussed as an accomplishment or result, and as a process (Fathi, 2015). As an achievement, psychological adjustment represents the individual’s positive mental health, their state of mind and overall well-being, and as a process, psychological adjustment depicts whether an individual is able to cope effectively with their environmental stressors and the changes brought about by the varying environmental circumstances (Fathi, 2015).

Adjusting, according to the participants, was difficult, and this theme loops around psychologically, and physiologically how the loss of a limb is restrictive and presents limitations that are obvious, yet sometimes unobserved.

Kwami communicated:

Initially at first it was not all that good because my thing is that I didn't want to be hospitalized. I didn't want to be in there. I felt uncomfortable in the hospital, but I think when I was discharged from the hospital I was not fully prepared for life out because I was chair bound and I had to be moving from the chair to bed, from bed to wheelchair, from wheelchair to bath, and those kind of things, and obviously I felt very scared about falling and hitting the foot because I almost fell when I was in the hospital. I left my bed to go to the toilet, bathroom, and not being trained on crutches, I took two crutches they had, got on them, and I went to the bathroom.

Abena so passionately recalled going home and being alone in the home while others were at work. She stated:

I fall down, too. I forget that I had the leg, but that is what I does tell my children, my children at work. So I gotta get realistic. I gotta learn to get around. I learned to help myself. Is – I does wash something, but I gotta get somebody to hang them out. And cook, you see? I cook. I can't make up my bed though because it's got on a tight fitted sheet, the doctor tell me that I am one in a thousand I put myself in this position, that my children ain't here, and I got to do for myself, 'cause if anybody had to rush here to look for me like you come, I

should be all prepared, I should not have to rush here and there to put on this and that, I should prepare myself.

Adjusting to their new condition was met with trepidations as the participants' spoke of mobility issues, their role as caregiver to being cared for, restrictions inside and outside the home, and coming to terms with their transformed surroundings. Lariba return home with increasing anxiety as she describes transforming her living room to a bedroom, a home that was now difficult to navigate. She shared:

Well, it is very hard because where I live I got my bedrooms upstairs and I cannot get up 14 steps to get to my bedroom. I had to get my son to bring down a bed and I had to transform my living room half of my living room into a bedroom so that I could stay there and I could use it as a bedroom because I cannot –with just his one help me up the stairs. So I can't even get a proper bath because the bathrooms are on the upstairs. On the upstairs so I just have a toilet down bottom and a face basin and a tub, a washing tub and I have to be using that as a temporary bath and it's not easy. It's terrible.

Ekua felt disappointed because her property owner made no modifications to the home prior to her arrival. She explained:

Well, well I'm renting, so I explain to the lady and everything and she never suggested anything, so I try to get by as best I possibly can. I don't have any hand grips or, If anybody's taking me out, we take mostly wheel chair and there's a fairly tall ascending but it is all right 'cause I get accustomed to it now, and all I want to do is learn to walk. So I will be jumping over that same thing.

Akua also spoke of *adjusting* to her home that allowed her to have more contact with the outside world. She mentioned:

Most of all getting into the shower and I'm working on that. I can get in there myself now but still have to do something. And my most thing is getting out of the house. I had to build a ramp and sometimes they use, sometimes they don't use it. They get me out very well is the choice. But I wish I could get out more. The house is okay. I can go the big balcony. I can wheel myself out there. I can see people and I talk to people every day. And share a joke or whatever or some people come and look for me. It is a challenge, tell you truth because when you think of things that you could get up and go, I got to tell myself you cannot get up. I think it would help me a great deal. I like helping myself. I think I am very independent so that's why at home, anybody can tell you, oh, she don't want any help. She does everything herself. I cook myself. I do everything. I try not to use the oven too often because then the heat come back on my feet. So I try not to do that very often, but I cook. I can hand myself.

Adjusting takes time, and for some, the adjustment period is long, and for others, it could seem like a lifetime. **Afia's** *adjusting* took her 3 years. She recounted:

Yeah, it is a long journey cause it is since 2013 and it's only now that I try to do things on myself. It's only this two-week now that I making up my bed but every now and then somebody had to make it up for me. Cause I tell myself you see me, I gotta learn to do things on myself. And I hop up on the bed and sit down,

when I tell my daughter I use for sheets on my bed, she said, "Mom, you cannot."

I say, "Yes I can, I got on all four."

Kofi reported:

Well, after the operation, like I said I was thinking a lot about what I would normally do, thinking about how I would go about trying to do these things. My biggest fear or anything was not so much me, but like my wife and immediate people, my kids ... They were so overprotective that I was more worried about that, Right? And sometimes what would happen is that I might sound as though I didn't want anybody to help me or anything, but at the same time I didn't want to be leaning on any person or anything like that and I wanted to be as self-sufficient as I can be, as close as possible back to where I was... Yeah, and I am happy to say that there isn't anything that I used to do before that I can't do now even with my 2 limbs. I mean, even sitting in a wheelchair without these limbs, I can still do a whole lot. Even including reaching up there to part the curtain or whatever, I can do that! I can reach it. I can't get my height yet. Getting to the bath and all that.

Lahari and **Yaa** reported *adjusting* very well to their new surroundings. **Lahari** eagerly showed how she maneuvers her way around the house when she stated:

Well sweetheart, I manage real good at home. You see this? I walk with this. I does swing bout with this, in my front house, my bedroom, my kitchen, with my chair. The only thing I don't do is to go to town because I don't have any money.

And I don't send nobody for nothing for me. You see God let it happen that I buy everything that I need before the amputation.

Yaa used her wheelchair to show how she is able to lock the wheels and pull herself up in an effort to be self-sufficient and industrious. **Kwasi** felt that his return home meant that his life was going to be an open book:

Well it kind of impact me because at one time I would get up and go but now I have to wait on people, people have to know a lot more about my personal business, you find that you have to open up to society.

The research participants clearly articulated that the process of *adjusting* proved challenging, and dependence and/or independence was a factor that determined how well they adapted to the change in their environment. They reported significant impairment in their ability to care for themselves, and some shared role-reversal thoughts of feeling helpless.

Transitioning

Transitioning is the fourth theme elucidated from the data. According to Schlossberg (2011), a transition occurs if a situation or incident results in an individual making changes in the way they perceive themselves, their behavior, and the way they interact with others. Schlossberg views transition as uninterrupted segments that require continuous processing, assessment and integration as individuals move into, through and eventually move out of it. This theme emerged as some participants described their transition from having two legs to their new prosthetic limb or ambulatory aid, in preparation for their return to normal life. All of the participants reported significant

challenges as they tried to adjust and transition to their life as an amputee, indicating that the return to normal life was progressively slow, but they had to overcome the physical limitations caused by the amputation. Most of the amputees reported their transition with the new leg as a positive move towards adjustment, noting that the prosthesis or ambulatory aid made it easier for them, as it increased their mobility.

Kwami remarked:

Well, the prosthesis allows me to move around, so I am mobile. I can walk on it. It is not the most comfortable thing. It has its advantages and disadvantages. Advantage is I can put it on and I can walk and I can go wherever. I can drive and those kinds of things. I don't drive with it, but I can get to my car and transport myself. Wearing it is uncomfortable, but it's better than having no foot at all.

Kofi and **Kwasi** both admitted that they were happy and pleased with their prosthesis and the positive adjustments they were able to make with the prosthesis. However, both men alluded to the fact that a prosthesis in this century was necessary for positive adjustment. **Kofi** also offered insights into the Barbadian economy and the cost of the prosthetic leg. **Kofi** explained:

I would think is a good step, but the prosthesis in this day and age is a good implement for anyone who has because in the earlier days there weren't these fancy things. People had to shuffle on peg legs and all that, because I knew a gentleman who was like that. The thing about it is that prostheses are expensive; very expensive. And an island like Barbados which is an economy up-scale. Of

course you know you have a lot of people that would be sidelined and things like that. The access to these tools is worrisome for other people because you know some people would love to be able to walk like you. But they don't have to beware at all. And so I think that that rear train is seeking to address.

Kwasi shared his thoughts:

Well, I decided at the time when I decided to take off the leg that I would have to get a prosthesis, because I wanted to be mobile still. The prosthesis is still artificial but I am still getting to learn it, that is the only way I could see an amputee surviving, is a prosthesis.

The thought of a prosthesis is merely a thought for some amputees who have no financial means, and for others it can be as if they hit the lottery.

Kobby spoke of feeling grateful for the opportunity if he could be the beneficiary of a leg. He uttered:

Well, I'd be able to get around. The way I see it, a couple days, actually I see a fella come in hey [here] one day with one, I don't know what the problem was, but he said if it gave him a big problem so he come back to get it look after I think I would get around. He spoke so enthusiastically and was filled with such excitement when he saw a young man with what could have been a newer prosthesis similarly to the blade runner. Yeah. I see a little fella hopping around and he jumping up and he got one, and I say wait this could be right, this man, this little fella like it got springs, right in this same hospital I see he and he mother

dey, and he jumping up. I have this wheelchair, and I have a walker at home, and I am able to get around pretty good with them.

Lariba spoke of the cost of the amputation as financially burdensome and costing approximately \$10,000.00 Barbadian dollars. She feels that without finances, the incessant task to even start the process, will limit the time it takes her to transition to her new life. **Lariba** expressed:

No, there's not. It just have to build it, disability unit and they're saying they don't have money to take the cost of everybody prosthesis and it's like a long waiting to get things to... I have to just keep writing politicians, dealing with my parliamentary. I was trying to see how they can help. Up to this date I haven't get a answer from them if they would really help with it or not. So my boss said he would help with half, but then I don't know how we would get my other half to add to be with it. The prosthesis would help me to get around a lot, but for now I have a wheel chair and two walkers.

In contrast, **Ama**, spoke of her amputation and how she was able to secure the finances to afford her prosthesis. **Ama** stated:

So Mr. Codeer told me what to expect and not to expect. He wanted to put me back on my feet and what's not. But then my boss man had give me some money to put down, but I had was to find the rest of the money.

Then I was finding it hard to find the rest of money. My boyfriend then was only working and he work get chop in half. My son, well he work get chop in half. One son well I don't hear him or see him, but the other two

they will help me out. So Mr. Codeer call me and say well **Ama** I want you to come and see me tomorrow. So I came the next morning at 6 o'clock and (I can't remember the man name, but I think he came from Canada or something, and his wife come here). So they donate this one and finish off this one for me. He said it was God.

Although the prosthesis is seen as a "God send" to some, it initially posed numerous problems for others. Feelings such as frustration, feeling let down, and "throwing in the towel" were the sentiments of some during their *transitioning* process. The task of obtaining the funds to purchase the prosthesis was also challenging initially, and some unforeseen problems were initially not apparent. **Afia** verbalized her initial disillusion and discontent with her prosthesis and so did **Ekua** when she stated:

Had I know it was so much trouble I would not because I don't know, I can't walk. I see my son walk but because it aint getting on, I really put on weight but you know doesn't matter. I pay \$8,000.00 for that. I had to beg, beg, beg but I can't beg no more. You know I gotta buy back a piece not the whole leg. I have to get a stump. Where the money gonna come from I don't know. I will continue to work on it until I get it.

Ekua recalled feeling like she could use her prosthesis and fly like a bird:

No, not as it should be. I know that the above the knee cut is more difficult but I've seen people do it. You understand, it takes a bit longer but somehow I get this illusion during a journey. The guy Mr. Codeer that does the prosthetic leg, he say I was so enthusiastic and his therapist always said if you had a below the knee cut

I know you'd be flying right now when you walk in. Somehow, along that journey I lost interest. I don't know if it was too much to walk in it. The stump start to get fat, I start to get fat, and everything. And it just I would still practice but not like before. I don't have anybody home to help so I will have to continue to go to therapy in order to get it right.

Adowa smiled as she remembers the days of hanging by the rum shop with the men, the fun times, and the constant reminders from her male friends of her presence in the shop. She feels that the prosthesis will be that tool to get her back on the road to a life she so longs for. She shared:

My thoughts on having the prostheses is I know I will have to learn to walk and thing and if I want to get back on the road. I is a girl that don't stay quiet, I used to be up and down, all to tell you the truth, my friends are more men than women and I can make a joke so long as it is a man, I can make a joke with him. Cause you know you have some men like we, I don't do with them, I like to I like to be around, I don't drink the rum, I like to be in the shop and around the crowd and them talking, about the good the bad and the indifferent, so dat [that] is the way how I like it and how it is.

Abena spoke with determination as she recalled all of the ambulatory aids that she has tried, and the issues with each aid. She demonstrated for this researcher, her ability to use the prosthesis, walker, and wheelchair, and how these aids are important for her *transitioning*. **Abena** explained:

Yeah, I can't use it because of the...it heavy, I is a big woman. So it's gonna be heavy. Hers would be light because she's small. But like me, or you or Ms. Lascells, it would be a bit heavy so I can't use it, because when I have on the prosthesis, I have to use the walker. So you know the walker you hold it here, you gotta put it on the two fronts and go, and you gotta jump, my crutches. because he says under the arms is carry some fine veins and to use the crutch have the crutch up in the arm no matter if it padded, it rubs, and it will burst one of the veins, and it's dangerous. So I don't do the crutch. I only use the walker now.

Transitioning from two legs to one leg or no leg proved to be physically and mentally challenging. Every participant's recount of their experience resonated their desire to be mobile and productive as they looked forward to some sense of normalcy. The use of prosthesis or an ambulatory aid was noted as the positive variable that made the process of *transitioning* smoother for some participants.

Connection to a Theory

The themes that emerged from this study can be connected to transition theory, a mid-range nursing theory conceptualized by Afaf Ibrahim Meleis (2010). As such, this theory applies to the lived experience of Barbadians with lower-extremity amputations as a complication of long-term *diabetes mellitus*. This theory suggests that transition is initiated by certain events, and the events become the catalyst for transition, whereupon this new undertaking is viewed as a progressive move towards stability (Meleis, 2010). This theory allowed the researcher an opportunity to review the transcripts of the

participants and highlight the statements that indicated how participants planned for their future.

According to Meleis, four different types of transitions exist: *developmental*, *situational*, *health-illness*, and *organizational*. Meleis also identified patterns, properties, conditions, and patterns of the transition response. The five properties of transition; awareness, engagement, change and difference, transition time span, and critical points/events will be addressed in greater details, in Chapter Five since these in particular support the themes that emerged in this study.

Chapter Summary

Chapter Four provided a plethora of information from the narratives obtained from the participants. This information afforded the researcher the opportunity to listen to their voices, illuminate the essence of their lived experiences as amputees, and note the impact of the amputation on their lives. All of the stories recounted how the devastating news of the recommended amputation was for them. The devastating news of the amputation required them to swiftly move to accept, adapt, and transition to their new life and new world. While there appears to be a sequential flow in their presentation, the essential themes are interwoven and in motion. This gives ground to the themes of *devastating*, *accepting*, *adjusting*, and *transitioning*. Chapter Five provides the interpretative analysis of the meaning of this study.

CHAPTER FIVE

DISCUSSION AND CONCLUSION OF THE INQUIRY

The purpose of this study was to explore the lived experiences of Barbadians with lower-extremity amputations as a complication of long-term *diabetes mellitus*. The aim of this study was to contribute to the current body of nursing knowledge and provide a deeper understanding of individuals who have undergone an amputation because of *diabetes mellitus*. Van Manen's (1990) approach to hermeneutic phenomenology was used as a philosophical lens to guide this study. An interpretative analysis of the themes that emerged from the study is presented in this chapter, as well as a discussion of the relationship between the findings of the study and the theory of transition. The implications of the study for nursing education, practice, research, and health/public policy are presented. Strengths, limitations, and recommendations for future studies are also addressed.

Exploration of the Meaning of the Study

According to van Manen (1990), the main pursuit of phenomenological research is for meaning. Phenomenological research allows the researcher to grasp the true meaning of being human, existing in the world, and ultimately, how we find ourselves in the world (Vagle, 2016). This phenomenological study began with a personal interest and a burning desire to discover something important about this population's experience with this phenomenon that has not been explored. The rationale for this study is supported by the paucity of nursing literature regarding the lived experience of the

Barbadian diabetic amputee. In this phenomenological study, the researcher asks the research question, “What is the lived experience of Barbadians with lower-extremity amputations as a complication of long-term *Diabetes Mellitus*?” van Manen’s hermeneutic phenomenological approach was used to excerpt meaning from the data. His doctrine and six activities were methodologically used in this study to elucidate the fluid nature of the lifeworlds and interpretive flow (Vagle, 2014) detailing how this researcher was able to discover the true essence of this study pertaining to the lived experiences of the Barbadian amputee.

This researcher was able to extricate meaning and gain understanding of the nature of this phenomenon by showing empathy and listening attentively as each participant provided rich descriptions in their narratives. These narratives provided a clearer, more vivid understanding of life and the “in-ness” (Vagle, 2014) of being an amputee. Activities such as bracketing, journaling, and reflecting were all strategies utilized by this researcher as she searched for deeper meaning and the overall essence of the phenomenon. Literature, poems, music, and films were critiqued in search of unearthing words that could clearly represent the essence of phenomenon. The researcher uncovered significant meanings and challenges faced by the participants as they tried to navigate through their lifeworlds.

Participants were asked to describe their experiences and lives as amputees. All of them adamantly evoked how *devastating* the experience was for them; however, they all moved quickly towards an attitude of acceptance and felt hopeful about their new lives. This astounding facet of the experience of living as an amputee resonated with all

the participants who seem to be motivated to be at ease with themselves, looking forward to the future as they live without a limb. Many participants spoke of acceptance in the context of returning to some degree of normalcy of their pre-amputations state.

Qualitative research as a methodology is often reproached for its lack of scientific rigor and poor explanation of the methods adopted, lack of transparency in the investigative procedures and the findings of the study are thought to be a collection of personal sentiments subject to researcher partiality (Noble & Smith, 2015). The process for evaluating qualitative research is therefore essential if the findings are to be applied in practice and incorporated into care delivery. Therefore, when assessing the study findings for credibility, researchers are required to question the authenticity of the research relative to the application, the study's appropriateness, and the integrity of the final conclusions (Noble & Smith 2015). The soundness, strength, and trustworthiness of qualitative research are appraised by *credibility*, *dependability*, *confirmability*, and *transferability* (Lincoln & Guba, 2000).

Throughout the research process, this researcher made a concerted effort to ensure that the trustworthiness of the study was maintained. To achieve credibility, the researcher spent long hours engaging the participants in the field, and equally as much time was spent in the collection of data, observation, and interviews, immersing herself in the data in order to gain in-depth knowledge. Guba and Lincoln (2000) suggested that a study is credible when it presents such a vivid and faithful description that people who had that experience would immediately recognize it as their own. Member checking also supports credibility. The participants were presented with a typed copy of their transcript

and were asked to review the transcript to provide critical feedback regarding the truthfulness of the data that was translated from the audiotapes. In addition, this researcher consulted throughout the research process with her dissertation committee members who are experts in this field.

Dependability is the assessment of the data collected and the method used to analyze the data. The researcher provided thick, rich details of the study findings and the research design and accurately documented all facets of the final report. The audit trail describing the research was detailed so that if someone read the study, they would be able to replicate it. *Confirmability* indicates that the study findings are supported by the data collected. The researcher kept a paper trail and linked the participants' words to the themes. This researcher bracketed personal ideas and knowledge as it relates to the phenomenon under investigation, and thoughts and participant observations were recorded in the researcher's reflexive journal to reduce bias. The researcher also reviewed the analyzed data through member checks by consulting with committee members to further reduce researcher bias.

The extent to which the findings from of one study may have similar meaning to other studies in similar context, is referred to as *transferability* (El Hussein, Jakubec, & Osuji, 2015). Transferability was obtained through purposive sampling, data collection, and the analysis process. The thick, rich descriptions of the data including the study's purpose, method, sample and settings, the inclusion and exclusion criteria, number of participants, length of the interview sessions, methods and time-period over which the data were collected, add to the criteria needed for this study to be transferable. This

detailed “paper trail” thereby provides opportunities for replication and transferability of results. Reflections were documented as non-verbal cues of each participant during the interview, preventing the researcher from interfering with the process of data collection or analysis. Thus, trustworthiness is achieved when the findings reflect the meaning described by the participants (Lincoln & Guba, 2000).

Interpretative Analysis of the Findings

The interpretative analysis of the findings was accomplished by meticulously reading and rereading the transcripts several times to capture the true meaning of the experience. The researcher scrutinized the field notes, margin notes, and the transcriptions line-by-line, highlighting and identifying categories and codes in preparation for thematic identification. After removing the initial codes from interviews, codes were reviewed and summarized several times, then classified, based on similarities and congruence. Next, by further reviewing and comparing the levels, their inner meanings were identified as initial themes emerged.

The themes revealed included: *devastating*, *accepting*, *adjusting*, and *transitioning*. The overall impact of having an amputation did not differ greatly among the participants, and all of the participants struggled to find meaning and a sense of purpose as they prepared themselves mentally for each phase of their journey. Each research participant candidly provided detailed accounts as they moved fluidly from *devastating*, *accepting*, and *adjusting to transitioning*. Poems, music, literature, and religious quotations were used as the researcher interpreted and analyzed the findings, and linked the relationship of the findings to the theory of transition. The implications of

the study for nursing education, practice, research, and public policy, and the study limitations are discussed.

Themes

Devastating

Lower-limb amputation is one of the most dreaded diabetic complications and is linked to the individual having a poor quality of life, and a severely compromised level of physical functioning (Schaper et al., 2012). As a result of diabetes, diabetic foot ulcers (DFU) have made their mark in societies worldwide, with the prevalence of diabetes being four times higher than all cancers combined (McInnes, 2012). Infected DFU results in prolonged hospital stays and are responsible for more than 9/10 of non-traumatic lower-limb amputations (Tiwari et al., 2012), and this accounts for more than a million amputations per year worldwide (Peter-Riesch, 2016).

Participants in this study conveyed experiences that were recognized as *devastating* as they laid out the trajectory of their life as a diabetic with DFU and other vascular complications. When the study participants received the news that an amputation was imminent, it was perceived as being very *devastating*. The devastation was manifested as shock, disbelief, feeling overwhelmed, sadness, depression, anger, helplessness, and hopelessness. Many of the participants struggled for years with the sequela of diabetes and foot problems, but none of them were prepared mentally for the *devastating* news of the amputation.

Hoban et al. (2015) conducted a quantitative study to evaluate the effect of foot problems on mental health in diabetic patients and their caregivers. Forty-seven diabetic

patients with foot problems, 49 patients without foot problems, and 21 caregivers of patients with foot problems, completed the outcome surveys. Foot problems included ulcers (41 patients), osteomyelitis (nine patients), and Charcot foot (eight patients). The results of the study showed that foot problems are associated with mental health symptoms in diabetic patients and caregivers, and these symptoms affect the treatment in the foot clinic, outcomes, and quality of life. The data also supports the hypothesis that foot problems in patients who have diabetes are associated with worse mental health; including greater average depression, pain, and suicidal behavior scores. These emotional issues of patients with diabetic foot problems could influence how they are treated in the foot clinics and could also impact treatment outcomes and the quality of life. This study well supports the statements made by the study participants. Most of the participants reported feeling besieged with powerful emotions that started when they first heard about their lame foot. These emotions varied from person to person and were unique to each participant as they described the time line leading up to the amputation, and the catastrophic changes of on-going physical and mental impact. **Kwami** recalled as he shared his frightening experience the day he was told with urgency that he had to get to the hospital. He explained that he was defiant, reluctant, and angry because he had an idea of the days ahead of him. **Kwami** also remembered how his wife refused to take him to the hospital, and as such asked his daughter to accompany him. **Kwami** recounted:

She said, "I have bad news for you." "What's the bad news?" You have to go to the hospital with this foot. I said straight up, Why going there? I don't want to go

there, I know exactly what is going to happen to me there, my life is over. So I went home and I told my wife, "I have to go to the hospital with this foot. So my wife just looked at me, left the kitchen, went to the bedroom and came back in about ten minutes and told me, "I have your bag packed. So here am I thinking, how can she have my bag packed to go to the hospital? I don't want to go there. You want to get rid of me? And she told me, I cannot take you to the hospital, but I am gonna get our daughter to take you to the hospital.

Kwami went on to further communicate that he sensed some anger, depression, grief, sadness, and fear in the voice of his wife and his daughter, and he resorted to calling a friend to take him to the hospital. He continued his routine of ignoring the doctor's request, deciding insolently that he was going on his own time. **Kwami** shared:

So I tell her don't worry, I'm gonna get somebody to take me. So I called my friend. You won't know who my friend is. I told him, I want you to take me to the hospital. He told me, I'm coming now. Would you believe I called back and said, don't come yet. When I'm ready I will call you. I went about my normal Saturday routine and then I called him and I was ready. I told him, I'm ready now. So he came and he took me to the hospital. You don't know how that news about going to the hospital to get my leg off had me feeling? I was really low, yah, does feel helpless, and a lot of negative things does go through yah head when yah start to think about amputation.

The participants in this study could not help but ask why, as they were faced with this *devastating* sequela of diabetes and foot de-vascularization that was going to forever change their lives.

Kofi recalls being in a state of desperation when he heard the *devastating* news:

I did not know where to turn, I told my wife that I needed her to call the pastor, call all the people in the church that does act as counselors because I needed somebody to explain what was really happening to me.

Akosua also revealed feeling devastated by the news, initially joking with the doctor about carrying her to kill her. She later explicated that the news left her “bewildered, not knowing where to turn, and not wanting to think about the amputation.”

Akosua stated:

I was just there numb, like you could just stick a pin in me and nothing would come out, that is how bad I was feeling when they tell me that my leg would be gone. Nobody want to hear that kinda news, amputation is like a death sentence to some people my lady. My son and them call the church and the people at the center to talk to be because they thought that I was going to pine way, [waste away] I did for a while, I did not eat, I was depressed, I was losing weight, and I could not sleep, they had to give me sleeping pills for a while.

Chapman, Shuttleworth, and Huber (2014) conducted a quantitative study addressing the complications of a rare but *devastating* Charcot foot condition and its relation to high levels of anxiety and depression in diabetic patients. The aim of the study was to assess mental health in diabetic patients with Charcot foot and to investigate

the moderating effects of socio-demographic factors. A cross-sectional questionnaire was utilized to obtain data with the Hospital Anxiety and Depression Scale (HADS). Demographic background information was also collected from 50 patients with diabetes and Charcot complications (males 62%; mean age 62.2 ± 8.5 years). Anxiety and depression levels were high, (anxiety and depression scores 6.4 ± 4 and 6.3 ± 3.6 respectively). Females reported more severe anxiety and depression on the HADS.

Data indicated that diabetic patients with Charcot foot experienced more serious levels of anxiety and depression. The high levels of mental health problems found in this study in diabetes patients with Charcot foot require recognition by researchers and clinicians. Furthermore, the findings implied the need to screen for mental health problems in diabetic patients with Charcot foot.

Charcot foot is a rare complication caused by diabetic neuropathy. It is a disabling and devastating condition with unknown etiology, characterized by acute inflammation, which results in the collapse of the foot, and/or the ankle from weakened bones (La Fontaine, Lavery, & Jude, 2015). Many of the participants in this current study described the horrific pain and the lack of sensation to the incapacitated limb. The diagnosis of Charcot foot was not addressed; however, some participant accounts of the symptoms associated with this condition were articulated throughout the transcripts of this study. **Lariba** lamented:

Well, I realized the leg start getting like really painful to walk and things like that. I was telling the doctor; I keep on telling her that my foot was like hurting very bad. She just look at it. She didn't actually give me nothing for it so I just had to

live with all this pain all that time. I didn't really know it was bad circulation and blood didn't actually going down to my leg. And at that time it was just only dealing with like the feet down to the bottom, near down to the ankles but it seems over time to get worse.

Lariba's pain was unmanageable, and she spent 6 months in the hospital hoping that the doctors could restore function to her leg. She mentioned:

It come to a point then after like spending 6 months in a hospital. It get to a point then that it get worse, I actually had pain coming up, and the pain was gangrene. I really didn't take when them den teck [take notice] notice of it although I was complaining about this pain coming up. I was feeling like if my feet, hands, and my whole body was going to fall apart, de agony, 1 minute I was sad, then I was anxious, de nurses keep telling me to calm down, when dat pain hit yah, yah does ball for murder. I hear one nurse telling another that I behaving like I going mad and maybe they need to send me to Jinkins wid de psychys [Psychiatric ward].

Akua's experience was similar to **Lariba**. She was attending the clinic for several weeks hoping for some resolve of her lame foot. At the end of her journey, she, too, became distraught after hearing the *devastating* news of her amputation. **Lariba** admits to some defiance and disbelief, recalling the *devastating* news and the memories that resurfaced when she was diagnosed with thyroid cancer some years back. She pointed to the surgical scar on the base of her neck, indicating the surgical site for the thyroidectomy. **Lariba** tremulously recalled:

I didn't think I could handle that, that took a toll on me, girl I felt that I was going to lose it there and then, I was in shock at the news, I started asking them to try some more wid the leg, depression set in, I stop eating, I would be in de house all day without talking to anyone, and finally my church sister and some other people started cooking for me because the diabetes went hare wire when I was not eating, it was too much. I was on medication for depression and medication for sleep, that kinda news will kill you if you aint strong.

In 2007, de Oliveira Chini and Boemer conducted a phenomenological study aimed at understanding the implications and feelings associated with the experience of amputation. A total of six thematic categories were revealed in this study:

- Living the preoperative period in an attempt to keep up appearances
- Experience permeated by a dualism, the logical and the experience
- Dependence as a possibility of an existence marked by daily suffering
- Difficulty living in the hospital world
- Phantom limb as the extension of one's own body
- Prosthesis as a means of fully continuing in the world

This study made it possible to reveal several aspects of the amputation phenomenon, from the time the prognosis was given through the realization of the surgery. Feelings of sadness, pain, suffering, inferiority, and low self-esteem existed among these amputees, and the female study participants in this current study spoke of feeling ashamed of the amputation.

Lahari admits to wondering if she could face her neighbors with her altered appearance. “Me and some of the people around my house does live good, but how dem gine look [going to] at me now?”

Esi spoke of thoughts of remaining in the hospital so she did not have to face reality, and **Sibri** also spoke in shame as she reported feelings of obesity, limited mobility, and having to depend on family and friends in the community. **Sibri** stated:

I so big, my neighbor next to me and the one down the street say dey [they] will come to help, but I look like I get bigger since de foot off. Dis thing [thing] got me feeling like an invalid.

In another quantitative study conducted by Mansoor et al. (2010), the prevalence of psychiatric co-morbidities in traumatic amputees was explored. The aim of this cross sectional study was to determine and address the various socio-demographic variables of lower-leg amputees in an outpatient setting, and to find out how psychiatric disorders plagued these amputees. The DSM-IV criteria for psychiatric comorbidities were used as the criteria for assessing the 100 amputees in this study. The results of the study revealed that the majority of the amputees were males in the age group of 15-30 years who resided in rural areas. Motor vehicle accident accounted for the majority (53%) of amputations followed by (21%) those from ongoing sociopolitical disturbances (landmines, blast, and firearms). Sixty percent of the subjects were diagnosed with depression, and 40% were diagnosed with anxiety and other anxiety-related disorders such as PTSD, generalized anxiety disorder, and panic disorder.

The results of this study were also illuminated in **Abena's** narrative when she expressed her feelings about the devastation associated with her amputation. **Abena** stated:

I used to mind my aunt. I used to look after my aunt, so I used to be moving backwards and forwards and onetime I lived with her. When they tell me that they was going to cut off my leg I was so upset that I said a few choice words, you know, I could not believe. I call my daughter and she come over to the hospital right away with the pastor and the people from the counseling service. They were acting like I was going to jump in de [the] sea. The news had me questioning God, I was angry, I was blaming whomever I could blame and de [the] doctor give me a medication to calm my nerves because he said I was getting too upset, and I was going to have a stroke.

The dreadful thoughts that **Abena** experienced on that abysmal day are all depicted in the following poem, *Behind the Mask*.

“Behind the Mask”

Hiding the hurt, hiding the pain

Hiding the tears that fall like rain.

Saying I'm fine, when I'm anything but.

This ache in my soul rips at my gut.

My skin is on fire, I burn from within.

The calm on my face is an ongoing sin.

The world must stay out, I've built up a wall.

My fragile lie will collapse should it ever fall.
Loneliness consumes me, it eats away the years
Until my life is swallowed by unending fears.
Waiting for someone to see I wear a mask
And care enough to remove it, is that too much to ask?
..... Bernard, (2015)

Madsen, Hommel, Baath, and Berthelsen (2016) conducted a grounded theory study titled, *Pendulating: A Grounded Theory Study Aimed at Providing Insights While Constructing a Grounded Theory* (GT) about how patients with vascular complications behaved post-amputation. The patients' experiences were collected during the first 4 weeks post-surgery, and the results indicated that the process of transition could be understood in three phases, as the reality of the life-changing event was eminent. Phase One included feelings of losing control, being overwhelmed, and becoming dependent. Phase Two identifies issues with the individual coming to terms mentally with the amputation. Phase Three is proactive, as the individuals sought to regain control, manage consequences of the limited mobility, and begin feeling hopeful and motivated. Pendulating was recognized as being a central theory in this research as it described the observed pattern of amputee behavior. It provided discernments and demonstrated how patients vacillated back and forth emotionally and cognitively during the research as they spoke of their concerns. The theory also offered valuable insights about the role health professionals can play in offering support to amputees during the transition. For many of the participants in this current study, the *devastating* news of the amputation was forever

etched in their psyche, and they continued to report sentiments of devastation pre-amputation, during hospitalization, and post-amputation, and their return home, as well as through their subsequent active physiotherapy rehabilitation.

Afia indicated that she felt “awful” when she was told of her amputation and recalls how *devastating* it was for her as she thought of not being able to do some of the simpler and fundamental things that she once did. “I have to lay down and pray for you. I have to lie down and pray, you can’t kneel down and pray.” She further stated:

That first day when I got the news will remain with me until I die. I just cannot tell you, I don’t know where to start. First, I shut down, I was so quiet, just thinking bout my life, my grandchildren, I was depressed, I did not talk to my children for a long time, I would just sit there and feel sorry for myself, who want to live with one leg, that news is really bad like a calamity, you feel like the world is coming to an end. I went home after they cut off the foot and I was still the same, sad, quiet, snapping at people sometimes. My children call a friend, who works at the mental, and he came by and they threaten to put me down there because I was bad. I get a little better, but I still feel like calamity Jane, when I go to therapy they say here comes sad sap, [sad face], and they does ask me to smile. How can you smile knowing that your foot gone?

Ama and **Lahari** also reported similar outcomes. **Ama** expressed:

Hearing bout the amputation was very disruptive to me, my mind was not in the right place, I was behaving like a chicken with its head cut off. My children say that I was like I was going mad, calling different people trying to get an opinion

before they took off the leg. When I went home I sat down on my bed all day and cry, cry, cry. My son came home and said, “What are you crying for?” I said because I would like to get up and do things and I can’t manage it now. I was just thinking bout how my life change, I was depressed for along time and I was angry, you would be too if you were in my shoes. The therapy was ok but you know that you are up there with other people who look like you and you have to relive that day when they tell you that your foot have to get cut off. Man, you does feel like hurting somebody but who you gine [going to] hurt? I have to cope now.

Themes of low self-esteem, changes in self, and a struggle to accept a new identity as disabled (Senra, Oliveira, Leal, & Vieira, 2012) are described as dominant among amputees in the months following amputation. **Lahari’s** account of such feelings is congruent with these foregoing outcomes. **Lahari** recounted:

I was mad as hell when I first got the news, my toe was broken, they fix that, and then they tell me that my leg had to come off. I could not understand how you go from a toe or toes to a whole foot. I would get depressed, cry, pray all day, fast, not paying attention to the diabetes, I just did not care. I finally pulled myself together, had the surgery, and I hit another low when I got home, people would come to the house to see me and I would make up excuses as to why I can’t see them, I would stay with the blinds closed all day, and I would only get up when my children come home. I was really sad. I went to see the psychiatrist and he put me on medication and I still take it up to now, I still see myself as a one foot

women since the surgery, I have a hard time looking at new people in the face, I guess I will be like this until I die.

Norlyk et al. (2013) noted in their qualitative study that losing a leg can be *devastating* and has dire consequences altering the individual's day-to-day existence.

The literature review has provided consistent findings related to the devastation reported by the study participants of this current study as they explained their thoughts and feelings regarding the prognosis of amputation. The consistencies of these studies clearly demonstrates the psychological impact upon receiving the daunting news eliciting feelings of sadness, depression, shame doubt, anger, hopelessness, helplessness and dependence. These findings were also insightful in another qualitative study by Liu, Williams, Liu, and Chien (2010), in which participants expressed feeling lost in the dark woods and suffering an emotional collapse, after receiving news of an amputation. The study participants in this current study found themselves in an indeterminate perplexed state as they attempt to fully comprehend and digest what was happening to them physiologically and psychologically.

This poem by Rebecca Kohlmeyer is an open letter to a prosthetic leg from an amputated limb, as she says goodbye. The poem reads:

You don't know how it feels.

When you are cut from your lifeline

like an apple being picked

when it isn't fully grown.

When you are replaced

with hard plastic and metal
where bone should be.
You probably want to know why he hates you.
It is because he has to learn how to walk again.
Because you can't run like I could.
Because you can't kick a soccer ball like I could.
Because you can't make him itch like I could.
Because you are a reminder of the infection.
The infection...
that took me away from him.
I was made with him.
You were made for him.
You took 6 weeks to be created
I took 9 months.
I was his first step,
You were a puzzle piece
that didn't quite fit
You had to be forced
by people in white masks and blue gloves
They couldn't touch you and
neither can he.
So instead you lay on his bedroom floor.

And I will not feel bad for you because
I am lying in a medical waste bin.
Waiting for my turn to enter the fire.
This is my hell.
I miss him,
will you tell him
that I miss him?
Let him know the feeling is mutual.
I understand if you tear this up
there is no warmth in you.
No blood will ever pump through you.
Trust me, I get it.
When the heart dies, it is buried where it belongs.
Being hugged by its fellow vital organs.
it's just like taking a nap
they say.
But when I die,
I am surrounded
by other dispensable body parts.
We are the forgotten few.
People do not have funerals for finger tips.
It feels like I am being eaten alive.

You can't tell me I should feel bad for you.

Or that I should feel sorry for you.

Because I was alive,

I was moving

and you

are plastic.

Just,

tell him goodbye for me (Kohlmeyer, 2015)

Accepting

The second theme revealed in this study was *accepting*. To accept is to embrace without judgment and without trying to alter, eliminate, or change (Prevedini et al., 2011). In the rehabilitation process, acceptance might have different meanings for different individuals as they begin to accept the reality of a medical condition/illness, the uncomfortable emotions, and physical discomfort associated with the presence of a medical condition. Elizabeth Kübler-Ross (1969) acknowledged five stages of grief, which include denial, anger, bargaining, depression, and acceptance. Kubler-Ross' theory was initially intended to address terminal illness. However, Kubler-Ross' stages of grief and dying are applicable to the amputees in this study, as noted in the narratives of the participants. Limb loss severely impacts an individual's psychological state; feelings of bereavement, grieving the expression of the loss can be equated to the loss associated to death. Each participant acknowledged receiving the news of a pending amputation differently as they tried to make sense of the prognosis. According to the

stages of death and dying as outlined by Kubler-Ross, an individual moves from a vantage point of denial and disbelief to anger, bargaining, depression, and finally acceptance. Most of the research participants appeared to reach the acceptance phase initially, and worked through the other stages of the Kubler-Ross steps, as they prepared for the surgical intervention. **Kwami** recalled:

There was no talk about taking measures to try to heal the foot, get the infection out, or nothing like that. The decision was to take off the foot. So here I was on the bed sitting down, laying back, crying of course, 'cause I didn't go expecting the foot to be taken off, amputated. So I admit freely I cried. I told them, "You cannot take the foot. What do you expect me to do?" The guy told me then, the doctor told me then, "You are relatively fit, so you can be fitted with a prosthesis and you should be able to walk again. You should be able to drive and all those kind of things that you were accustomed to doing. You should still be able to do those things." So the decision was made there and then to take off my foot.

Sibri also spoke of her acceptance of her limb loss long before the actual removal.

My lady, I had make up in my mind that I was going to have the amputation done long before I started getting really bad. Do you know what it is like to live with pain? I accepted the surgery and the rest is history I am still here.

Yaa also remembered *accepting* her amputation the moment she was given the prognosis, "I was all well I say "I it gotta go. It gotta go" 'cause it used to be very painful. I could not sleep. I couldn't eat, bear pains." **Kwasi's** acceptance of his amputation was

not as immediate as some of the other participants'. He recounted, "I didn't take the decision." **Kwasi** remembered receiving the news and pondering "for a good little time" before he decided to accept his fate:

I was holding on, I don't know what for because I know that it had to go, but I could not just tell him ga long wid [go along with] de [the] foot, I was holding on for about a week or so.

My Uniqueness, the following poem by Liliana Kohann, is a reflection of the sentiments expressed by some of the participants.

"My Uniqueness"
it's not my weakness,
it is my openness.
It's not my doubts,
it is my questioning mind.
It's not that I say too much,
it's my courage to share.
It's not my fear,
it's my prudence.
It's not my stupidity,
it's my choice of what I
want to know.
It's not my credulity,
it is my trust.

It's not my depression,

it is my **acceptance.**

It's not my recklessness,

it is my curiosity,

and love of life.

It's not my chaos,

it's my artistic soul.

It's not my weakness,

it is my

Uniqueness (Kohann, 2001)

Lewko, et al. (2007), conducted a quantitative study assessing the association of the diabetic amputee's quality of life and their experiences and how they accept their illness. Fifty-nine diabetics with neuropathy and without neuropathy took part in the study. The Acceptance of Illness Scale (AIS) was used to measure the degree of acceptance of illness, and quality of life (HRQOL – health-related quality of life) was measured using the SF-36v2. Diabetics who had not accepted their illness had severe impairments in their QoL. Patients with peripheral diabetic neuropathy verbalized feelings of being burdensome to family and friends, as well as feeling that their illness made others in their circle feel anxious.

These patients also defined their health status as being worse off than that of diabetic patients without other comorbidities. There was a strong relation between the quality of life QoL and acceptance of the illness. Those patients with chronic peripheral

diabetic neuropathy expressed lower degrees of acceptance than did diabetic patients without peripheral diabetic neuropathy. These patients' subjective assessments of their health status was significantly worse than those of diabetic patients without neuropathy, and those patients with peripheral diabetic neuropathy expressed lower levels of illness acceptance when asked about their concerns about being a burden to their family and friends, as well as fearing that their illness caused people in their company to experience heightened levels of anxiety.

The research participants in this current study introspectively discussed their journey with diabetes, neuropathy, and de-vascularization, noting and accounting for instances in which they experienced anger, levied at whosoever were in their path. Many of them also spoke of being apologetic and ashamed of their behavior as caregivers' also sometimes negatively internalized anger. Bargaining was not addressed by many of the participants, but a few of them spoke of having quiet reflections with God, asking Him to perform a miracle and save the limb in exchange for something that was less catastrophizing. Acceptance for many of the amputees came almost immediately after being told that something was wrong with the leg, and that amputation was inevitable. Many of the participants spoke about gangrene and its sequela. However, pain was the main catalyst for *accepting*.

Akousa grimaced as she remembered the pain. "Well I did say I wanted it off because I was in so much pain. Yes, and I marked where I wanted it to. Yes, I tell him that there is a certain amount I want you to cut off." **Esi** also remembered her moment of acceptance. "So they tell me it's my choice 'cause I had a young doctor who said no

blood at all ain't going in to that one, and you know, gangrenous come on very quickly and it works through your body.” They say, "It's up to you." I say, "Well, if it's to save my life, I will live without it."

Freysteinson et al. (2016) conducted a hermeneutic phenomenological study of the amputee's experience of self-imaging. The aim of the study was to describe the trajectory of viewing self in a mirror after an amputation and what the participants felt that healthcare professionals should know about mirrors. The findings of the study revealed that the mirror experience for the amputee had three components: decision, seeing, and consent. The course of viewing the self in a mirror had four key elements: mirror shock, mirror anguish, recognizing self, and acceptance: a new normal. The study participants' recommendations included introducing the mirror post-amputation to avoid skin breakdown and infection and using the mirror to assess and correct gait and balance disturbances. This study provided valuable insights into the lifeworld of lower-limb amputees. Nurses and other healthcare professionals employed in rehabilitation centers are encouraged to consider the effect and value of mirrors when caring for those who have had an amputation. Many participants stressed the importance of thinking of the amputation as, “the new normal,” indicating that the mirrors helped the amputees accept their amputation, and that by looking into mirrors they could experience an easier transition into acceptance of the amputation.

As amputees in this study grappled with the prognosis of the amputation and moved towards acceptance, many of them reported how family members coped with the diagnosis, and their acceptance of the amputation. A number of amputees had difficulties

viewing themselves in mirrors, while others conveyed that family members expressed feelings of sadness, anger, and fear, in relation to looking at the surgical stump.

Kofi and Kwami both explained that their families had difficulty seeing them with one leg, and **Adowa** reported that her daughter has not seen her stump since her operation, some 14 months ago. All participants received physiotherapy services at the Queen Elizabeth Hospital and spoke of their renewed acceptance when faced with viewing themselves in the mirror while engaging in therapy. **Kobby** stated, “I don’t have big mirrors at home so I can’t really see all of me ... but when I am here I look in the mirror and I really see the new me, and it is a reminder of my life now.” **Ama** also spoke of seeing herself in the mirror. She said:

You know the mirrors at home in the vanity is small so you can’t see, but when you come to de center you get to see the whole thing, and sometimes I does get sad, even though it has been a long time, I have to accept things.

Collectively, all study participants felt that acceptance of their amputation was needed in order for them to prepare themselves for their future. Spiess et al. (2014) communicated that acceptance can be defined as a feeling of resolve and steadfastness; the period of time during which the patient is ready to become an active participant in their care, and they take ownership of their loss and their actions. The use of mirrors as a therapeutic measure is not one of the main tools used in Barbados with amputees as they rehabilitate. Nonetheless, acceptance of the lost limb is a daily reminder following each physiotherapy session in the rehabilitation centers. The physiotherapy area is outfitted with mirrors, and the amputees are able to see their full body as reflected in the mirrors.

The prognosis of an amputation was met with trepidation, disbelief, anger, and other negative emotions. The acceptance of the prognosis also elicited a vast number of emotions as participants in this study began to cope with the traumatic experience that was about to have life-altering effects on their well-being as well as their futures. In the literature reviewed, acceptance has been linked to positive outcomes, and individuals who were at the acceptance stage of their illness had worked through all of the previous stages as outlined by Elizabeth Kubler Ross (1969). For many of the amputees in this study, the acceptance of the surgical intervention, and a positive favor of amputation was instantaneous and without hesitation as they described the pain, anguish, and suffering they had been enduring for months. The following poem reflects the participants' acceptance of their amputation.

“Tabula Rasa”

I am fighting un-winnable fight
with un-conquerable dragons
I am riding a train to - No End
In invisible wagons
I am hoping for hopeless hopes
dreaming a “never come true” dream
re-building un-rebuildable vision
with foundation of “no self-esteem”
How pathetic, how sad, how cruel
Miserable my life, I’m a fool!

And I went to the top universities
Just to learn that I must – unschool.
Whatever I’ve learned I must forget
Whatever I believed I must erase
Whatever I knew I must ignore
My convictions must go to waste
Tabula Rasa once again
Emptiness, silence, just a gleam of light
Clear, white paper... as pure as a child
letting myself be, and letting God.....(Kochman, 2004)

The American theologian Reinhold Niebuhr (1892–1971) authored the *Serenity Prayer*. This prayer also reflects the sentiments of all of the participants in this study.

“The Serenity Prayer”

God, give us grace to accept with serenity,
the things that cannot be changed,
Courage to change the things
which should be changed,
and the Wisdom to distinguish
the one from the other.
Living one day at a time,
Enjoying one moment at a time,
Accepting hardship as a pathway to peace,

Taking, as Jesus did,
This sinful world as it is,
Not as I would have it,
Trusting that You will make all things right,
If I surrender to Your will,
So that I may be reasonably happy in this life,
And supremely happy with You forever in the next.
Amen (Niebuhr, 1951)

Adjusting

According to Seaton (2009), psychological adjustment is now widely being used in research to measure how an individual's self-esteem. The absence of distress, and the level of anxiety or depression are related to their ability to adjust to their present situation. *Adjusting* to life as an amputee meant something different for each participant in this study, although their physical functioning and independence appeared paramount to them all. Amputation is associated with a sense of loss, which is not only related to the loss of the limb. Significant changes are observed physiologically as well as psychologically, and recognition of these changes, based on individual responses, provide some indication of how the individual will adjust positively or negatively to their amputation.

To elaborate this further, Coffey, Gallagher, Horgan, Desmond, and MacLachlan (2009) conducted a study addressing the psychosocial *adjustment* to diabetes-related lower-limb amputation. Thirty-eight participants with diabetes-related lower-limb

amputations were recruited from two limb-fitting centers. These participants completed three psychological self-report assessments, which included the Trinity Amputation and Prosthesis Experience Scales (TAPES); the Hospital Anxiety and Depression Scale (HADS); and the Amputation Body Image Scale—Revised (ABIS-R). The results of the study revealed that over 18% of the participants scored above the normal range for depression on the HADS and 18.5% scored above the normal range for anxiety. Both depression and anxiety scores were significantly associated with body-image disturbance, as measured using the ABIS-R. There was a significant relationship between body image disturbance and three TAPES subscales that measured psychosocial adjustment, general adjustment, social adjustment, and adjustment to limitations. The study findings concluded that diabetic amputees may bear elevated risk for psychological distress as a result of their co-morbid medical condition. Recommendations included regular screening for anxiety and depression and adequate follow-up care for this population.

Psychological distress is defined as a state of emotional suffering characterized by symptoms of depression, anxiety, and anger (Drapeau, Marchand, & Beaulieu-Prevost, 2011). Research addressing the effects of physical illness and disability on psychological distress has long been a topic of interest, and is noted as a positive predictor of poor clinical outcomes. In this research, 15/16 participants verbalized their concerns about the lack of psychological intervention pre-, during, and post-amputation. Moreover, they indicated how the lack of psychological preparation impacted each of them. The majority of them reported feelings of depression, anger, helplessness, and hopelessness in relation to the lack of psychological intervention. **Lariba** lamented:

Well, they amputate the feet and after they amputate the feet, they send you home without counseling and then you have, say you then to come to physical therapy to get exercise for the feet. They don't give yah [you] no counseling before they cut off yah foot, and they don't even talk to yah while yah in de hospital. I was so mad and upset that I just shut down one time, I stop eating, I stop talking to my family, and for a while I just did not care, I was really down.

Kwami and **Lariba** both shared their experience about the lack of psychological intervention. **Kwami** divulged:

One of my peeves is that I do not think that having made the decision to amputate ... this is from a healthcare professional's point of view... having made the decision to do the amputation, there should be some post amputation counseling given. There is none. I was already feeling broken from the time they tell me that the leg had to come off. It's like they take your limb and how you manage after that, you manage. I was like an emotional wreck. But I'm thinking that there should be some kind of counseling given to the amputees about how you can go forward and cope with it being an amputee.

Lariba felt disrespected and angry as she recalls the lack of preparation psychologically. She stated:

They just don't do nothing so at this hospital, just pick you up and look at your feet and they just tell you one morning you have to get it amputate. You don't get counseling and they just force you to sign a paper for surgery and just carry

you and just take it off without counseling or without explaining too much about the procedure. They just carry you up and do it and bring you back and just place you back there and you just got to live with it. Oh, you cry and get emotional about it, they tell you get over it.

Livingstone et al. (2011) conducted a qualitative study using grounded theory, aimed at providing professionals with a comprehensive understanding of the realities associated with post-amputation. The study sample included five diabetic amputees and their caregivers. Imposed powerlessness, adaptive functionality, and endurance emerged as the three core themes detailing the participants' paths to perpetual resilience. All three themes highlighted the physical, social, and psychological consequences of having a lower limb amputation. This pathway is representative of the life of the participants as they lived optimistically, while trying to cope with the loss of the limb. The participants' initial voyage began with them feeling and reporting a sense of powerlessness and incapacitation. They, however, persevered while remaining resilient on their journey, adapting to their disability. The culmination of the journey was met with a sense of healing and acceptance of the loss of their limb. The authors were able to reaffirm the importance of the ability of the amputee to move from feelings of anger, fear, and uncertainty to a more positive adjustment and acceptance of their disability.

Most of the participants spoke positively about *adjusting* to their new life as an amputee. Participants felt that having a positive attitude was needed, and speaking positively about the future was also a way of coping with the loss, while feeling uncertain about the future. **Kofi** reported, "I was more rational about it... like, okay we have a

problem. You know, cause/effect action. You have a problem, you have to deal with it yourself first and then can cope about where to go from there.” **Adwoa** mentioned:

I had to really come to terms with this amputation, and I had to tell myself in the early that I was going to rise above this and move on, otherwise I would be lost, and having no direction is no good. I cannot tell about tomorrow but I can live for today and hope good for tomorrow.

Kobby exclaimed, “I’m a bachelor.” He reflected back on his childhood, remembering how his mother taught him to cook and clean, in addition to teaching him the importance of being self-sufficient without a wife. He admits to drawing on those basic activities of daily living to get him through the crisis. “It was hard at first, but when I look back at how I was before, I and say that I did a good job at helping myself with this amputation. I used all my mudda [mother] teach me to help me now.”

Kwasi spoke of his mother’s nursing experience as one of the tools that assisted him in *adjusting* to his new lifeworld. “Well lucky for me my mother was a nurse so she understands somewhat, what has to happen.” He reminded this researcher that he was a contractor by profession, and he needed to get back to his business as soon as he could. “I have to make adjustments now, not only as a builder but as a human being.”

A prospective, descriptive study by Coffey et al. (2014) explored the life goal characteristics and goal adjustment capacities of persons with lower-limb amputation on admission to a rehabilitation center. Sixty-four patients with lower-limb amputation from two inpatient rehabilitation centers in Ireland participated in the study. Life goal characteristics (goal importance, goal disturbance) were assessed using the Goal

Facilitation Index, while the goal adjustment capacities (goal disengagement, goal re-engagement) were measured using the Goal Adjustment Scale. All assessments were done on admission. The Beck Depression Inventory-II and the Trinity Amputation and Prosthesis Experience Scales-Revised assessed depressive symptomatology and psychosocial adjustment to amputation six months after discharge.

The study included 31 below-knee amputees, 28 above the knee amputees, and five bilateral amputees. Most of the participants listed the cause of amputation as peripheral vascular disease, diabetes, or cancer. The time since amputation ranged from 6 to 260 weeks, with a median of 20 weeks. The most significant finding of the study was that depressive symptomatology and psychosocial adjustment to limb loss 6 months after discharge among individuals with lower-limb amputation was a predictor of life goal characteristics and goal adjustment capacities. Higher goal importance predicted fewer symptoms of depression, and better general and social adjustment to amputation, while higher goal disturbance predicted poorer general and social adjustment outcomes. A stronger disposition towards goal disengagement predicted lower depressive symptomatology. Stronger goal re-engagement tendencies were predictive of poorer general adjustment. The findings of this study support the assumption of self-regulation theory. This viewpoint also offers valuable insights into the fundamental processes of psychosocial adjustment to lower-limb amputation and merits further application to persons with acquired physical impairment.

Similarly, Hamill, Carson, and Dorahy (2010) conducted a qualitative study exploring the amputee's experiences of psychosocial adjustment within the first 18

months following amputation. Three overarching themes emerged from the analysis: (a) pre-amputation decision-making process and control, (b) renegotiation of self-identity and the struggle to accept a new “disabled” identity, and (c) adjustment as a social process. This research highlights the importance of understanding of pre-acute, acute, and post-acute adjustment processes from the insider’s standpoint of individuals who have experienced amputation. In conclusion, the study emphasized and showed how individuals adjusted to amputation and its sequela through a process of re-negotiation of self-identity mediated through a wide range of decisional, informational, and social factors

Adaptive functionality resonated loudly in the data of this study with each participant speaking of their limitations and how their environment was modified to accommodate their physical limitations. Returning home presented the biggest challenge for the participants, and many of them were not able to modify their homes in a way that could accommodate a wheel chair, the use of a walker, and crutches. **Kwami** remembered telling his wife:

I kept telling my wife that I had to start putting my priorities in order if I want this thing to be successful. I could not continue to feel sorry for myself; I had to think positive, and I had to make it work if I wanted to see progress. When I went home I had no clue how I was gonna navigate through my house because my house I have some steps that go from one section of the house to the bedroom. Not a lot, just a few. I had no clue how I was gonna get from the car on the road

into the house because my house is not a straight house where everything is on one level.

Adwoa admitted, “Well sweetheart, I manage real good at home. You see this? I walk with this. I does swing bout with this, in my front house, my bedroom, my kitchen, with my chair.” **Ekua** acknowledged that she also had many challenges when she returned home, but she had to set some goals in order to cope. She echoed:

My house was not up to par and I had to think about how I could make it work for me. I sit down wid [with] my wheel chair and I had to study how and where to move about, this thing will make you crazy and send you to jinkins [psychiatric hospital]. I started thinking fast, how I could get back outside, and that was what motivated me to adapt to keep pushing forward. I feel optimistic about everything.

Persons with an optimistic disposition tend to show confidence and tenacity in striving towards their goals when faced with diverse life challenges, even when progress is slow or difficult (Carver & Connor-Smith, 2010). Optimists are also more sensitive to the nature of the stressful situation in their coping responses, using problem-focused strategies, such as planning or seeking instrumental social support as long as a stressor appears to be within their control, but switching to emotion-oriented strategies such as positive reframing and acceptance when faced with an uncontrollable stressor such as a traumatic health event (Aspinwall & Richter, 1999; Nes & Segerstrom, 2006). **Esi** referred to herself as an “eternal optimist”, saying, “yah know you have to stay positive, wah yah [when you] can do no better, yah gotta go wid de [with the] flow, yah gotta start

getting back to yah self.” **Sibri** also recollected feeling optimistic and hopeful for her future. She mentioned:

I know that my sister and I trying to do de best we can, I trying to see if I can get back down de road to look for she, so I gotta get this ting under control, I does do everything I suppose to, my children tell me that I real obedient because I does follow what dey tell me because I want to get back to doing for myself around de house and maybe outside.

Valizadeh, Dadkhah, Mohammadi, and Hassankhani (2014) conducted a qualitative study and explained that understanding the trauma of patients and the experience of support resources during the process of *adjusting* to a lower-limb amputation can have a positive impact on the amputee’s mental state, thus influencing their QoL. Participants in their study of support resources included 20 traumatic lower-limb amputees. The main theme extracted from the data was support services. The classes included “supportive family,” “gaining friends’ support,” “gaining morale from peers,” and “assurance and satisfaction with the workplace.” The study concluded that identifying and strengthening support sources could be a way of impacting amputee adaptation to the disease and improvement of QoL. Participants expressed that they received most of their support from the family, which brought hope and encouragement to the patient to make him or her feel respected, loved by others, and connected to a social network of relationships and mutual obligations. Social factors, primarily those of family, play an important and effective role in mental health of individuals.

In a study conducted by Gallagher et al. (2009), results showed that over 18% of the participants scored above the normal range for anxiety and depression, even though 3.5 years had passed since amputation. These results support the findings of this study as the research participants spoke of the mental health sequela associated with amputation and not having adequate psychological interventions as they adapted to their circumstance. According to their study, there is a paucity of literature examining psychosocial adjustment to diabetes-related amputation. This researcher found the same to be true. However, the few studies reviewed were able to provide insights into amputee adaptation in this study. The amputees also spoke of their frustration and the physical limitations associated with *adjusting*. Despite this, all of the study participants were tenacious, determined, and resilient as they adapted to their new life. The following poem written by Gertrude McClain is a reflection of the participants' adaptation to their new lives and new beginnings.

New Beginnings

It's only the beginning now

...a pathway yet unknown

At times the sound of other steps

...sometimes we walk alone

The best beginnings of our lives

May sometimes end in sorrow

But even on our darkest days

The sun will shine tomorrow.

So we must do our very best

Whatever life may bring

And look beyond the winter chill

To smell the breath of spring.

Into each life will always come

A time to start anew

A new beginning for each heart

As fresh as morning dew.

Although the cares of life are great

And hands are bowed so low

The storms of life will leave behind

The wonder of a rainbow.

The years will never take away

Our chance to start anew

It's only the beginning now

So dreams can still come true... (Gertrude McClain, 2013)

Similarly, another poem by Richard Lackman, also courageously speaks to the positive adjustment to an individual's new persona as an amputee. "My Amputation."

The poem reads:

I woke up from the surgery minus my left leg
With searing pain below my hip as if a powder keg
Exploded deep within my thigh leaving nothing there
But tissues sewn together which was more that I could bear

O God why have you chosen me to undergo this pain
What have I done to justify this horrible disdain
What can my life offer me now I am so beset
The sunrise of my life on earth replaced by cruel sunset

Time passes, first the minutes then the hours then the days
As memory of the first few weeks is shrouded in a haze
But slowly I recover and each morning I arise
Committed more to life than to incurring my demise

The pain, so knife-like, so intense has melted with the snow
And now as spring awakens in my chair I slowly go
To the window of my bedroom and the windows of my mind
Wondering if I will be forever so confined

Then spring gives way to summer and my strength and spirits soar

Life's images return to me now clearer than before

No longer does the vision in the mirror cause such dread

No longer must I hide beneath the covers of my bed

Amazingly my life regains familiar normalcy

As I recoil from the depths of my infirmity

And while I know I never will exactly be the same

I still retain my sense of worth and have not changed my name

For I am still the one I was and what is yet to be

Did not die with my left leg but lives inside of me. (Lackman, 2013)

Transitioning

All the participants in this study verbalized *transitioning* to their new life as an amputee. *Transitioning* to life as an amputee meant something different for each participant in this study; however, their physical functioning and independence appeared paramount to all of them. The process by which the participants in this study were able to transition to their new life and find a willingness and desire to move on without any noted psychological issues was astonishing. *Transitioning* for them was positive, and this meant acclimating to life with their new prosthetic limb or ambulatory aid.

Hawkins et al. (2016) conducted a cross-sectional, observational, multicenter study to determine and assess the association between social support and outcomes after

amputation. They hypothesized that patients with greater social support will have better post-amputation outcomes. Subjects were recruited from November 2011 to May 2013. Social integration was measured by the social integration subset of the Short Form Craig Handicap Assessment and Reporting. Systemic social support was assessed by comparing a United States and Tanzanian population. Walking function was measured using the 6-minute walk test, and quality of life (QOL) was measured using the EuroQol-5D.

One hundred and two amputees were recruited. Sixty-three patients were enrolled in the United States, and 39 amputees were from Tanzania. Forty-two participants were males. Patients with low social integration were more likely to be unable to ambulate (no walk 39% vs. slow walk 23% vs. fast walk 10%; $p < .01$) and those with high social integration were more likely to be fast walkers (no walk 10% vs. slow walk 59% vs. fast walk 74%; $p < .01$). This relationship persisted in a multivariable analysis. Increasing social integration scores were also positively associated with increasing QoL scores in a multivariable analysis (.002; standard error, 0.0008; $p (.02)$). In comparing the United States population with the Tanzanian cohort, there were no differences between functional or QoL outcomes in the systemic social support analysis. In the United States population, increased social integration is associated with both improved function and QoL outcomes among MLE amputees. Systemic social support, as measured by comparing the United States population with a Tanzanian population, was not associated with improved function or QoL outcomes. In the United States, steps should be taken to identify and aid amputees with poor social integration.

The concern of returning to normal or near normal functioning resonated in this current study throughout the transcripts and was of utmost importance to all of these participants, as frequently emphasized throughout the interviews. Reconnecting with family, friends, and peers in the community was the driving force for the amputees returning to functionality. For many of them, just being in the presence of those that nurtured them, supported them, and accepted them unconditionally fostered their returning to the community. **Adowa** was all smiles as she spoke of her prosthesis, rehabilitation, and the opportunity of returning to the rum shop so she can lime [hang out] with the fellas. She **recalled:**

Everyday somebody usually stop by and ask when I coming back, we does live good, so they always checking on me. I does go by there to lime and talk foolishness wid de fellas [with the fellows]. I usta [used to] spend a lot of time wid the guys, I never usta [used to] drink, but I just enjoy my time there, when you retire you can lime as much as you want, to me those guys was a part of my life.

Kwami commented substantially on the advantages of his prosthesis, noting that he was able to resume driving independently after several months, and he will be returning to the school where he taught to assist the recreational staff with coaching the children in volleyball. He stated:

I consider myself a fairly active person. I used to do lots of walking and I played games. I played volleyball. I played football as a youngster. I played volleyball in my 20s. So I went from as a youngster, as a teenager I played lots of football.

In my 20s, I took up volleyball and played lots of volleyball, and in my 30s, I coached volleyball to my school team. Having lost a leg then I obviously would miss it because I couldn't play the sports I liked anymore, but with the prosthesis I am going back to school to help coach in the capacity as a volunteer. I still have a lot to offer the children.

Kofi also shared that despite the cost of the prosthesis, having one in these times was a necessity if being functional was the desired outcome. He passionately spoke of his desire to connect with other amputees and being an advocate for them. *Transitioning* meant starting what he calls a “grassroots” organization. **Kofi** passionately explained:

I would like at this point in time to see a real change; I mean like some effort. I would say to myself that I haven't seen any significant effort from that time to this transition where I'm actually in the middle of the pond, or something like that, you know. And people are still where they starting out with the same complaints, and this is years. This is probably for the part of my life. So I would like to see really that some real effort is being made with all the questions being asked, all the statements being made, and I think somebody making some effort. I am not seeing any life-saving device or anybody soaring you a life raft. That is why **Kuami, Kwasi** and I decided to form Barbados Amputee Rehabilitation Enabling Society.

Peer support is a reciprocal system of giving and receiving help. It was established and premised on understanding another's situation empathically through the shared experience of emotional and psychological pain (Mead & MacNeil, 2006).

BARES provides an outlet for the amputees as they meet monthly to discuss, strategize, and make plans to grow the organization in a way that will benefit all involved. This grassroots assembly, or affiliation, according to Mead (2006), has a profound, well-rounded understanding based on common experience where people are able to “be” with each other without the constraints of traditional (expert/patient) relationships. As **Lariba** concluded her interview, she recounted:

Is that I don't know. It's like I think that they have to do better than this. I don't know. They have diabetes all over the world. The same states, it's in England, it is in Canada. This country the only country that always seems to get like so much amputation. Other parts of the world everybody got diabetes and they deal with diabetic foot every day and it seems like they get better, but I don't know what's wrong with this country here. It always got to seem that your foot got to get amputated and this is something that I think they should look at seriously about how to care for diabetic foot 'cause I don't really think they do a good job here. Being a part of BARES groups with other amputees is helpful to me now that I am getting back to myself. But just hearing the other amputees talk about their struggles and all of the things they had to overcome, does make me feel like I need to be doing more to help those amputees coming behind me. Being an advocate for them is what all of us do at BARES.

Kobby admitted that he did not want to be a part of the group when first asked; however, as he attended the meetings, he became more involved and engaged, and he admitted that he started feeling like he was alive again.

Peirano and Randall (2012) conducted a prospective study aimed at describing the role of spirituality in individuals with limb amputation and to determine whether spirituality has any bearing on the amputee's quality of life (QoL). A total of 108 lower-limb amputees were recruited through prosthetics, physicians, amputee support groups, the Amputee Coalition of America, and amputee listserv discussion groups of amputees in the United States and Canada. A quantitative descriptive research design examined the relationships between existential spirituality (belief that an individual's life is meaningful or has purpose) religious spirituality, and QoL among individuals with limb amputation. The research findings revealed that amputees used spirituality to assist them with coping with their amputation, and existential spirituality was a strong predictor of satisfaction with their life, their general health, and their social integration.

Many of the participants in this current study appeared very religious and very spiritual as they spoke of coping with the amputation and *transitioning* back into a life that has religion as a core. **Sibri** and **Esi** spoke about being in God's good graces and feeling optimistic that they were going to return to their roles as "mothers" in the church. **Sibri's** affect changed, as she recalled her role in the church, and how she hopes to return. She stated:

I used to go to church every Sunday, but as de foot start to get real bad, I had to stop going. I was a mother in the church, and as a mother, I was responsible for what you would call the small children that come to Sunday school. We have a nursery, and de parents would drop them off to me, and I had to make sure that they were "ok" I had help but I was de one responsible. I was telling my daughter

that I have to make haste and get back there because God bring me through this far, and I have to do my part now for him. De ramp out dey [there] is for my chair, and that is how I am able to get back out of this house and go back to church, God is good, and all the time God is good.

Esi also attended the same church, and she too had a role before her amputation. She communicated that she had been a member of the church for over 50 years, and she was also known as a senior mother, responsible for the selection of hymns for the morning and evening services. **Esi** passionately reminisced:

I was a member of the church from de time I was a little girl, I grow up in de church, and all of my children grow up dey [there] too. When I get sick with de foot, I had to stop, and the pastor and some of the people would come to the house and pray for me. I was on the sick and shut in list. Dey [they] miss me at church because I used to have to help select the songs for service based on what was going on, for funerals too. That was my job, and I had that job for more than twenty years now. My heart hurt me when I see my name on that list, that I tell my son that he has to work wid [with] me to get me back out to church so I can do my job. I don't want to be on the shut in list.

The two previous studies highlighted the importance of social support and re-integration, the impact of being involved in a support group, and the impact of religion and spirituality on the lives of amputees. All participants in this current study discussed their personal challenges with the prosthesis and ambulatory aids, as it related to their improved functionality and returning to some sense of normalcy. All of the Barbadian

amputees were very articulate and had some understanding of the rehabilitation process; however, the opinions were filled with discontent and displeasure with the lack of information regarding the rehabilitation process. **Abena** recalled:

I was really happy with the training I get because I can use my chair and thing to get around, but I feel like it would have been better if they would tell yah more about what to expect, I is a big woman and It was hard for me, but I come away good, I getting round real good.”

Yaa also verbalized having mixed feelings about the *transitioning* process. She admitted to working tenaciously with family and others to secure the funds for the prosthesis, and was pleased with the outpour of support. However, she also spoke of the lack of information during the rehabilitation process, saying:

I was able to get the prosthesis finally, and I was so happy because I was now ready to move, and get back to living, but they did not tell me bout all the tings dat [things that] you should know, it is a lot you know, too much.

Kwasi spoke of the importance of having the conversation about a prosthesis as soon as the decision to amputate is made. He spoke adamantly of his prosthesis being necessary for survival in Barbados and what he needed to be mobile again and help him transition back to some type of normalcy supervising the men who worked for him in his construction company. He explained:

Well, I decided at the time when I decided to take off the leg that I would have to get a prosthesis, because I wanted to be mobile still. The prosthesis is still artificial but I am still getting to learn it, that is the only way I could see an

amputee surviving, is a prosthesis. I am glad that I was able to get one; I am getting back to normal with [with] this thing. I can go back on the job site and supervise de [the] men myself instead of having to pay someone to do that for me. At first I used to go in the wheel chair, but that was not good because de [the] job site is full of rocks, but with the leg, I have to be careful, but I am back on the job.

One of the concerns with *transitioning* back at home was the issue related to stairs and ramps with the new prosthesis. Many of the participants reported fear and ambivalence climbing the stairs, despite having the prosthesis, while others said that the length of time in physiotherapy was extended due to the number of stairs in their home, or the ramps that were needed for entry into the home. A cross-sectional study conducted by de Laat, Rommers, Dijkstra, Geertzen, and Roorda (2013) assessed the ability of persons with a lower-limb amputation (LLA) to climb stairs, and the relation of this ability with personal and clinical variables. One hundred and fifty-five participants were recruited between 1998 and 2008 in the outpatient department of a rehabilitation center in the Netherlands. The Dutch version of the Prosthetic Profile of the Amputee (PPA) was used to measure the necessity to climb stairs. The PPA is a patient-reported outcome measure assessing factors related to prosthetic use in persons with an LLA. Three questions of the PPA specifically addressing the necessity to climb stairs in the house and in entering or leaving the house, and their interference with daily activities were used.

Results of the study demonstrated that the ability to climb the stairs is important for a considerable number of persons with an LLA who have to climb stairs in their house, or to enter or leave their house, while their ability to do so is limited. Being a

woman and being of advanced age were independently related to (most of the indicators of) the ability to climb stairs. There were no independent relations between the ability to climb stairs and amputation cause, amputation level, comorbidity, or the type of prosthetic knee. **Kwami** recollected the initial difficulty he had navigating and transition back through his home with his prosthesis. He admitted to the fear of navigating the stairs with the prosthesis and reverting back to the wheelchair as a means of assistance.

Kwami stated:

The living room has a recess, you go down, and then you come up, and then you go up steps to, so I had to get out of the chair, sit on the steps, go up the steps on my behind [buttocks], and then have the chair collapse, put it up the steps, and then have it reassembled or have it open up, get up into the chair, then to go up to the bedroom. This went on for a while until I finally learned how to grab, hold, on and go, you should see me now, a little up and down, but I am good at it [chuckles].

Afia also reported some initial difficulty with her return home, the physiotherapy, and trying to use the stairs. She stated:

At one point I give up, I felt like licking down the stairs and another time I was ready to move. It was hard. They were trying with me at therapy, but all I keep seeing was my body rolling down de stairs, no body home, and that is the end of me. I can get up a few stairs but not a lot.

Sauter, Pezzin, and Dillingham (2013) conducted a quantitative study examining the effectiveness of rehabilitation received in an alternative post-acute care setting used to

improve functional outcomes among 297 patients undergoing major lower extremity amputation. This prospective study took place between 2001 and 2006 and analyzed the physical functioning and impairment in ADLs six months' post amputation. Outcomes were measured using two instruments: the MOS Short Form (SF-36) tool captured physical and mental health and the basic ADL tool was used to gather information on physical functioning. Both tools were used at the beginning of the study and again at six months follow up. The level of amputation was classified into four categories: foot (transmetatarsal or above), unilateral transtibial (below knee), unilateral transfemoral (through or above knee), or bilateral amputations (excluding toe amputations).

One hundred and twenty-nine patients received the majority of their post-acute care in an acute inpatient rehabilitation facility (IRF), 95 patients were discharged to a skilled nursing facility (SNF), and 73 patients were sent home. Transtibial amputations accounted for the highest percentage of amputees in this population, and the least number of patients received transfemoral amputations and foot amputations. Patients who received transtibial amputations were more likely to receive post-acute care in an inpatient rehabilitation facility or skilled nursing facility compared to home care, and patients with bilateral amputations were more likely to receive post-acute care in a home setting compared to a skilled nursing facility. Sample characteristics were ascertained by using descriptive statistics according to their socio-demographic profile, amputation level, and health status.

The researchers concluded that patients who received post-acute care in an inpatient rehabilitation setting experienced better outcomes six-month post-amputation

than those treated at a skilled nursing facility or discharged directly home. These results confirmed a positive association between inpatient rehabilitation and several health-related outcomes for dysvascular amputees. Patients who received care at IRFs, experienced better physical functioning and physical composite scores compared to those who were discharged directly home. In addition, IRF patients were more likely to show better general health in IRF, compared to SNF or home, and less likely to score in the lowest quartile for physical functioning, role physical, and physical component summary score in IRF compared to SNF. Lower ADL impairment was observed in IRF settings as compared to SNF. This study stressed the importance of increasing access to inpatient rehabilitation facilities for persons undergoing major lower-limb dysvascular amputation.

The participants were gradually able to return to near-normal physical functioning with the prosthesis or ambulatory aid, but they had various limitations at the beginning. Nonetheless, these challenges dissipated gradually, as they continued with physiotherapy and were able to transition back to some sense of normal functioning. **Afia** spoke of some difficulty with the fitting of the prosthesis and stump issues; however, she finally realized that she had to be patient and continue on in therapy in order to be successful.

She stated:

I was really weak, and I could hardly stand up because the prosthesis felt funny, and my stump kept hurting, but I pay too much money for the foot so I had to continue on. Now is much better, the more I go down to de place for exercise, de more I feel like I gine [going] get better at getting around, and de more I can do for myself.

Akousa has had her prosthesis for over 10 years, and she recalled some initial difficulty back then. However, she stated:

My family push and push me until I started feeling like I could get the courage to go on my own, sometimes I does still go back to the center and do therapy now and then because I getting old, but I glad for mercy and blessings, if my children did not push me, I would be an invalid today.

Ama also remembered attending physiotherapy twice a week. “I started going Tuesdays and Thursdays, and it was hard at first but as Mr. Coder tell me to keep going, and now I can get around pretty good and I can finally put on ma clothes, bathe ma self, God Is good.” The process of *transitioning* in the context of this research study is related to the Barbadian’s amputee’s ability to return to function with prosthesis or an ambulatory aid. Limited physical mobility is a common denominator in relation to a patient’s ability to continue to complete daily habitual tasks. According to Dunne, Coffey, Gallagher, Desmond, and Ryall (2015), in order to decrease the overwhelming feelings associated with these challenges and reestablish mobility, the use of assistive technologies such as a prosthesis, are needed to enhance functional capabilities.

According to Asano et al. (2008), mobility was a good predictor of quality of life among lower-limb amputees, and the participants emphasized the changes in their everyday life because of the amputation. Liu et al. (2010) reported similar findings in their study when three of the participants described feelings of frustration due to loss of independence and increased dependence on caregivers. The participants in this research study were all motivated to participate in rehabilitation with their prosthesis or

ambulatory aid, and saw the device as a way for them to cope as they worked towards re-integration back into the home and communities. Some of the amputees who were not financially able to afford the prosthesis shared how having the prosthesis would help with the feelings of frustration they experience, as they had limited mobility with the use of their walkers and wheelchairs. However, they also had positive comments about the use of walkers, and wheelchairs to transition with dignity. The concern of returning to normal or near-normal functioning resonated throughout the transcripts and was of utmost importance to all of the participants, as frequently mentioned throughout the interviews. Although participants verbalized an interest in walking, some of them spoke of boundaries beyond walking. Stair-climbing and ramp negotiation skills were also on the minds of the amputees.

This literature reviewed supports the view that the experience of participation in a structured rehabilitation program, engaging in support group activities, having a good support network, engaging in some physical activity after discharge from formal rehabilitation, and being spiritually grounded can significantly add to the reintegration of the amputees back in society, as they transition back to some normalcy in their lives.

The following poem echoes the sentiments expressed by these participants:

“The Goodness of God”

God Gives...

Peace - in the midst of turmoil

Underlying joy - in time of sorrow

Strength - for today's hardships

New vision - for tomorrow
Calmness - in the storms of life
Grace - in time of need
Love - in the midst of hatred
Charity - in place of greed
Cheerfulness - where there's gloom
Faith - when there is doubt
Light - in the midst of darkness
Hope - to those without
Healing - where there's sickness
Comfort - in times of grief
Wisdom - to those who ask
Knowledge - to souls who seek
Guidance - to all who'll follow
Instruction - to ears that hear
Rest - to the heavy laden
Security - in place of fear
Salvation - to the lost and perishing
Forgiveness - where there's sin
Life - to the spiritually dead
Purity - within
How could we cease to be amazed?

at The Goodness of God?.....(Campbell Bratcher, 2000)

Theory of Transition

The theory of transition proposed by Meleis (Im, 2011; Meleis, 2010; Meleis, Sawyer, Im, Messias, & Schumacher, 2000) provided a lens to comprehend further the Lived Experience of Barbadians with Lower-Extremity Amputations as a Complication of Long-term *Diabetes Mellitus*. Transitions, according to these authors, are a central concept of nursing. This theory is being used as a guide to methodically examine the process of how Barbadian diabetic amputees transition from receiving the *devastating* news of their amputation to *transitioning* to their new life as an amputee. Afaf Ibrahim Meleis and Karen L. Schumacher first articulated the theory of transition in their seminal work, *Transitions: A Central Concept in Nursing*. Meleis further developed this theory back in the 1960s while she was a doctoral student, and later refined the theory during her post-doctoral studies working as a researcher and educator (Sitzman & Eichelberger, 2015). The theory of transition has undergone several metamorphoses over the years, (Im, 2011; Meleis, 2010). According to Im (2011) and Meleis (2010), transition theory has been well accepted and received in nursing research, education, and practice because of its applicability to this discipline. Consequently, it provides an excellent lens through which a nursing phenomenon can be systematically and comprehensively viewed (Im, 2011).

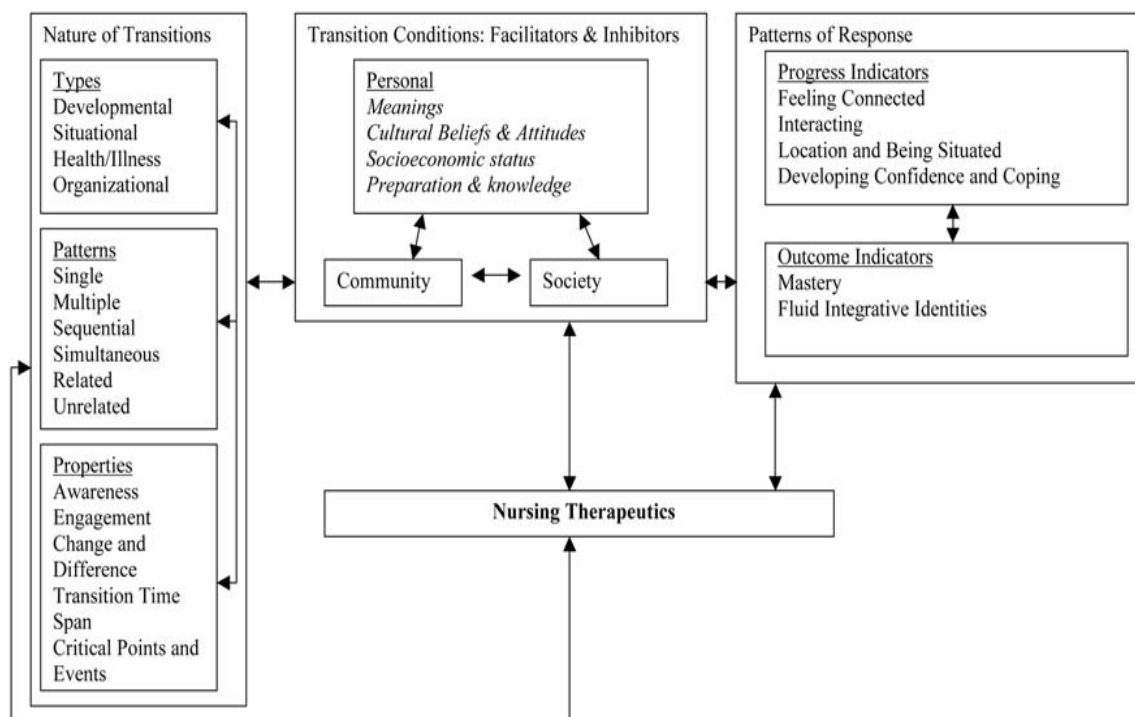


Figure 4. Theory of transition (Brathwaite, 2016, adopted by, Meleis 2000).

The central tenet of the theory of transition is to identify situations inherent to nursing. It was first conceptualized to demonstrate how people transition through life, and how nursing issues can be explained on a health/illness continuum across the life span of an individual. This middle-range theory elucidates the understanding of moving from one situation or circumstance to another, while highlighting the complexities, and multidimensional progressions, which include health/illness experiences as well as lifespan transitions such as aging (Meleis, 2010). Transition theory provides an appropriate window for exploring the phenomenon of the Barbadian diabetic amputee, because several of the constructs inherent to this theory are applicable to this study. The first element in Meleis's theory is *Nature of the Transition*, and it encompasses the types,

patterns, and properties of the transition. The second element is *Transition Conditions*, the third element is *Patterns of Responses*, and the last element is *Nursing Therapeutics*. All elements of this theory will be discussed; however, the properties will be explained in detail, since a connection was made with the themes that emerged in this study.

Types of Transitions

Meleis et al. (2000) identified four subcategories of transitions' experiences: *developmental*, *situational*, *health-illness*, and *organizational*. *Developmental transition* encompasses the stages that transpire during the lifecycle (e.g., the transition to parenthood). *Situational transition* refers to the transition from one role to another role (e.g., transition from hospital to home). *Health-illness transition* is concerned with the impact of illness on patients and families (e.g., the transition of the patient and family after an amputation), and *organizational transition* characterizes transitions that impact the environment and the lives of the persons who work within the setting and their patients (Meleis et al., 2000).

Patterns of Transitions

According to Meleis et al. (2000) transitions can be complex, related, or unrelated, and can occur singly, multiply, sequentially, and/or simultaneously. These authors also noted that multiple transitions often occur concurrently. For example, developmental transitions and health-illness transitions often overlap throughout childhood if a chronic illness is diagnosed in childhood. Consequently, a diabetic living with a chronic illness can experience all six of the subcategories (single, multiple,

sequential, simultaneous, and related/unrelated) at the same time when preparing for the transition from a world with two legs to living in the world as an amputee.

Properties of Transition

Meleis et al. (2000) identified five attributes of transition: *awareness*, *engagement*, *change and difference*, *transition time span*, and *critical points/events*. The first property of the theory of transition is *awareness*. According to Meleis et al. (2000), *awareness* is present when an individual has insight, is knowledgeable and has the ability to recognize that the transition is occurring. The second property of the theory of transition is *engagement*. To be engaged is to be involved, and according to the Theory of Transition, a patient's engagement in their care is a key strategy that can assist them in the decision-making process and behaviors that will provide better health outcomes. According to Meleis et al. (2000), engagement is influenced by *awareness*, and these two concepts have to co-exist in order to facilitate a smooth transition.

The third property of the theory of transition is *change and difference*. According to Meleis et al. (2000), changes and differences are vital to the process of transition, and even though transitions will take place with change, change is not necessary for transition to occur. These authors further communicated that in order to fully understand the critical elements of transition, the meaning, influence, and scope of change must be understood as it relates to nature, temporality, perceived importance or severity, personal, familial and societal norms and expectations. Differences as articulated by Meleis et al. (2000) are characteristic of feeling different; being recognized as different; having opposing interpretations; and having a different perception of the world and self with

others in the world. These perceived differences have the ability to alter behavior and provide a unique perspective for each individual transitioning.

The fourth property of the theory of transition is time span. This property of transition is indicative of the steady flow and movement over time (Meleis et al., 2000). This steady flow over time is thought to have a starting point marking the first sign of change. The process continues on a tumultuous trajectory and a somewhat unpredictable state, mixed with uncertainties, trepidation, confusion, and anguish, finally culminating with a period of stability. Meleis et al. (2000) warned that transitions that have time constraints can prove to be challenging or futile.

The fifth and last property of the theory of transition is critical points and events. Meleis et al. (2000) asserted that critical points can be understood as events such as births, deaths, menopause, or diagnosis of chronic illness, and these critical points are connected to the awareness one has of the transition experience. Meleis et al. (2000) concluded that critical points produce positive changes and provide a sense of relief and changes in schedules, lifestyles, competencies, and self-care behaviors.

Transition Conditions

Transition conditions refer to the incidences having a direct influence on how an individual progresses through a transition (Meleis et al., 2000). These situations can be either personal or representative of an individual's community or society in nature. They can either provide conditions that encourage or hinder the progress of the patient throughout the transitional process (Meleis et al., 2000). Personal conditions are divided

into four different designations: *meanings*, *cultural beliefs and attitudes*, *socioeconomic status*, and *preparation and knowledge*.

Meanings ascribe to events triggering the transition or the transitional process and therefore obstruct a healthy transition progression. Cultural beliefs and attitudes and the humiliation attached to a transition can have a direct impact on the transition. Socioeconomic status can also have a direct impact on the process of transition. The preparation and knowledge-level of the person(s) participating in the transition also directly impact the overall transition progression.

Community conditions refer to the resources readily available to assist in the facilitation or inhibition of the transition. An example of community conditions could be the lack of knowledgeable and educated healthcare providers, or a lack of resources to support a chronic illness diagnosis. Societal conditions refer to the negative connotations associated with the transitional experience. Various cultural elucidations of this process can also foster or hinder the experience of the individual/s participating in the transitional event (Meleis et al., 2000).

Patterns of Response

Patterns of response are categorized as process indicators and outcomes (Meleis et al., 2000). Process indicators are associated with the positive aspects of transition, and include feelings of connectedness, interacting, being situated, confidence building, and positive coping. During this phase of transition, the nurse is seen as the catalyst to a healthy transition. Healthy transitions result in the patient's positive interaction with peers, family, and healthcare providers throughout the process. These encouraging

interactions help expose, clarify, and acknowledge the implications of the transition and the behaviors developed in response to the transition.

Being situated refers to the path along which an individual is moving, and developing confidence and coping is an enlightened experience that occurs on the transitional continuum as the patient gains insights and understanding of the diagnosis/prognosis and the impact the disease and its trajectory will have on his or her life (Meleis et al., 2000).

Nursing Therapeutics

Nursing therapeutics are thought to be measured using three distinct criteria: *assessment of readiness, preparation for transition, and role supplementation*. The *assessment* of the patient's readiness for transition is multi-focused and involves all disciplines. Providers are encouraged to engage thoroughly with the patients, while attempting to gather a comprehensive and thoughtful understanding of the patient. *Preparation for transition* involves the edification needed to produce a smooth transition, and *role supplementation* involves the supports necessary and available for the patient or families involved in a new transition. The focus of nursing therapeutics is tertiary, focusing on the prevention of unhealthy transitions, while promoting perceived well-being, and dealing with the transition experience. The nurse's role in nursing therapeutics is critical, since nurses are intimately involved in the discharge planning process and coordination with families and caregivers.

Properties of the Theory of Transition and Connection to Study Themes

Awareness-Devastating. Feelings of devastation surfaced as each participant was made aware of the pending amputation, and each participant's account and immediate reaction to the amputation varied. However, the devastating news brought about a consciousness pressing awareness of their new reality. This meant coming to terms with the magnitude of the loss, what was needed presently, and how they were going to handle changes in the future. The first property in the theory of transition is *awareness*, and according to Meleis et al. (2000), this represents an individual's perception, knowledge, and transition experience. The concept of awareness supports the theme of *devastating*. In this study, *awareness* is not only applicable to the amputees, but to their families. Having an awareness of the diagnosis of diabetes was the inkling that change was inevitable for the participants in this study. Shock is the feeling experienced when first diagnosed with diabetes, and learning about their diabetes was the first step toward finally realizing what was wrong. This led them to start feeling better and consciously making an effort to live a healthier life.

Abena remembered admitting that she was not testing her blood sugar as required. She recalled: "The first thing I did was to go and get strips for my monitor, I guess it was too late, but I had to do something." Most of the participants had been living with diabetes for many years, and all of them spoke of being knowledgeable about the disease process, the nutritional restrictions, and the medications prescribed for the disease. Many of them had a heightened awareness of the consequences of the disease and the dire complications that could result with them becoming amputees. **Kwasi** narrated,

“I blame myself, my mother is a nurse, and she used to warn me.” **Kofi’s** wife is also a nurse, and he also experienced anger turned inward on himself when he realized that he had to have the leg amputated. He described his feelings:

Actually I attended the doctor, I decided to go to the doctor when I was around 55, because by that time I could probably look at, I guess like most males, on one hand how many times I had went to a doctor my whole life. I did not like going to the doctor, and believe me, I was really mad at myself when he tell me the news.

Akua remembers just sitting and reflecting on the news and reassuring herself that she was going to be “OK,” while **Afia** spoke of how her children and family members reacted.

I say make the best of it. It's something that you have to live with now, you have no choice, so you make... at first I had find a little difficult accepting it, but I never really after that had any problems. I try to cope with everything.

Afia recalled:

It is very awful to have a leg amputated, especially above the knee because it is uncomfortable, it is not comfortable, my family was more afraid than me, at first it was hard watching the nurses dress the wound, but now they understand and they are more willing to talk about it more than before, they can see that I am good with it so they good too.”

This theory understands that individuals and families are unique beings, with different socioeconomic backgrounds and therefore will experience awareness at

different points and times on the continuum, and will have a different perspective as it relates to their illness. Despite the devastation, they had to become aware of the dos and don'ts in order to live a healthy life, despite having diabetes and knowing the dreaded consequences.

This poem, *Being Aware* by LaNita, clearly speaks to the amputee's mental awareness.

“Being Aware”

I remember,

younger days, being depressed.

feeling the weight,

pressure

on my chest.

heaving,

breathing slowly, aware of a change.

that pressure, that

melancholic low hum,

just buzzes and hums,

consciously capturing

my mind.my thought.

breaking free takes work.

awareness is first. just
being
aware of your thoughts
and how you react.
it a healing power
we all have. we can heal.
we can.....(LaNita, 2016)

Engagement – Accepting and Adjusting. The *devastating* news of the amputation brought about an awareness that was enlightening. It prompted a shift in the participant’s ability to recognize that being fully engaged in their care would begin to bring about positive change and outcomes. Engaging meant enlisting help from others to restructure priorities and accepting that changes were needed and inevitable. It also meant becoming being more assertive, pulling on inner strengths, and advocating for themselves to make a positive adjustment to a new life.

The second property in the theory of transition is *engagement*, and according to Meleis et al. (2000), this represents the degree to which a patient demonstrates involvement in their transition process. Barello, Libreri, and Bosio (2014) also articulated similar findings, indicating that patient engagement is highly regarded as a key factor in the improvement of health behaviors and outcomes in the management of chronic disease, such as Type 2 diabetes. According to their perspective, patient *engagement* is crucial and is seen as the catalyst needed to turn individuals into co-producers of their health and enhancing their care experience. This collaborative

engagement is intended to improve health outcomes and lower healthcare costs. The property of *engagement* supports the themes of *accepting* and *adjusting* that emerged in the study.

For the participants in this study, their health care provider is the first professional to address the issue of compliance with their diabetic care, encouraging them to check their blood sugars regularly, as well as to follow up with the recommended testing necessary to identify new issues. **Kofi** detailed how he took an active part in his treatment based on his education as an engineer. He recollected:

And then I said to myself, “You know what, I need to know what affect it has if I use a cherry how that affects me. I think that is why I may be tested and all that, and so I started to embark on the project. I went to a spreadsheet. The spreadsheet suggestion, and I started to use a bowl with cornflakes and milk. Take a note of that. At this time, as a matter of fact I was taking note of my readings before I started eating breakfast and use that, take the medication, and then after about 2 hours I would note the difference, the variance, and the changes and all that. And that process took me before I began to see because of several things that I could possibly use, I began to see, and it began to get more interesting so I just started to buy into it, so I was enthusiastic about seeing this thing, you know. I could actually see a graph of oh, when you use this here and what time you use it in the day, you use it and you had this.... whatever. And after about a year or so I had a sort of profile of what my system, according to my metabolism, you know. It looked like a snapshot.

Ama explained the meeting she had with the rehabilitation team as they informed her of the prostheses. She appeared so enthusiastically engaged and motivated to learn about the prosthesis, that she was given two referrals, one of which led to a Canadian family's donation of her prosthesis.

Well, the first one I came in to Dr. Mosley and he gave me the paper. He tell me there are 2 persons who do prosthetic leg here in Barbados, Mr. Codeer and gentlemen in Christ Church. So I said by coming here to exercise on Tuesdays and Thursdays. So I let him know Mr. Codeer. So Mr. Codeer told me what to expect and not to expect. He wanted to put me back on my feet and what's not... So I came the next morning at 6 o'clock and (I can't remember the man name, but I think he came from Canada or something, and his wife come here. So they donate this one and finish off this one for me.

Akousa joked of her acceptance by engaging the doctor as he informed her of the amputation. She reminded him that he was only allowed to take off so much of her leg and instructed him where to cut the leg.

Engagement is said to be influenced by *awareness*, and these two concepts have to co-exist in order to facilitate a smooth transition. As the participants in this study moved from *accepting to adjusting*, it was evident that they made inquiries, and some of them verbalized seeking second opinions about the pending surgery. Being aware prompted the action of seeking out other health professionals who could offer another perspective as they painted their clinical picture. The theme of *adjusting* permeates here as well. As the study participants struggled to become acclimated to their new life as an

amputee, they verbalized requesting information about ambulatory aids. Those who were financially disenfranchised and could not afford the prosthetic limb spoke candidly about using a wheelchair, cane, and crutches to adapt and engage themselves in their daily routine as much as possible.

Lariba spoke of her frustration:

Well, it is very hard because where I live I got my bedrooms are upstairs and I cannot get up 14 steps to get to my bedroom. I had to get my son to bring down a bed and I had to transform my living room half of my living room into a bedroom. When I am down here I use my wheelchair and my walker, and I get around “ok.”

The participants were able to reach their physical abilities gradually, but they stated that their initial limitations gradually became extinct as they accepted and adjusted.

Akosua reported *adjusting* very well to her new surroundings: “Well sweetheart, I manage real good at home. You see this? I walk with this. I does swing bout with this in my front house, my bedroom, my kitchen, with my chair. While **Ama** admitted to some feelings of sadness initially as she tried to adapt. “I sat down on my bed all day and cry, cry, cry.... I would like to get up and do things and I can’t manage it now.”

Those participants who had the means to afford the prosthetic limb also spoke of spending long hours with the prosthetic practitioner inquiring about the limb. These self-motivating activities speak to a positive transition, as they engage themselves in not only accepting their prognosis of a dreadful amputation but also adapting to their new life as much as possible.

Change and Difference – *Transitioning*. Change was unavoidable to these participants, and the changes they were facing evoked certain emotions that effected their perception of their being, notably in their mind, body, and spirit. Differences, as conceptualized by Meleis (2010), also impacted the participant's mental and physical state. Transitioning as an amputee meant starting to live life to the fullest, trusting others, trusting themselves, becoming more confident, and being a role model and change agent for others who had similar circumstances.

The third property in the theory of transition is *change and difference*. This supports the theme of *transitioning*. In this research study, change is understood as the moment in time when the research participants were told that an amputation was inevitable, urgent, and required immediate attention and thought. The severity of the prognosis required that the research participants summon family and friends and relay the news of the amputation, and how they were going to move forward. **Yaa** recollected:

It affect my family a little bit when I tell them bout [about] the amputation. I remember calling my children and them saying mommy, if it hurt you, do what you have to do. I'm not bearing the pains for you, you bearing the pains for me to me, yourself, so all what you say goes.... now, I still get around Mrs. Lasscels will tell you [Laughs] I went to a fair up to May day, I go all about I go out pun dat [on that] pasture pun [on] a Friday evening with some friends and sit down and enjoying myself.

Kwasi shared his thoughts about his decision-making process, his thoughts about the prosthesis and how it would allow him to return to his position as the owner of his construction company.

Well, I decided at the time when I decided to take off the leg that I would have to get a prosthesis, because I wanted to be mobile still. The prosthesis is still artificial but I am still getting to learn it, that is the only way I could see an amputee surviving, is a prosthesis.

As previously discussed, the receipt of the news was met with a myriad of feelings and issues relating to the perceptions of others in the community, knowing the marginalization of persons with physical disabilities. However, as the amputees moved towards *transitioning*, the negative self-talk and an awareness of self in a positive light was evident. Difference is conceptualized as feeling, being, and acting different. For these study participants, the feeling brought about by the change left them dazed, feeling different, as if they had been catapulted from one lifeworld to another instantaneously without warning, with no time to adjust. However, as they internalized the situation, a positive change took place that could be synonymous with a paradigm shift. **Ekua** articulated:

It does not make sense to keep feeling bad for yourself and make the people around you feel the same. At some point you have to tell yourself that life goes on, and so you must go on with it or be without life, which is death, so I chose the latter. I am a young woman and I have a lot to live for, I need to get back to my job at the hotel.

Prominent self-esteem issues were not apparent as these research findings unfolded; however, indirect, subtle references to weight and appearances did speak to how some of the amputee's feelings of difference came to the surface. **Ekua**'s self-esteem and her perception of how she looked, was of major contention for her as she transitioned. She spoke of being overweight and not being able to ambulate properly with the prosthesis: "Had I known it was so much trouble I would not because I don't know, I can't walk. I see my son walk but because it aint getting on, I really put on weight but you know doesn't matter."

Abena speaks of her weight issues and how certain ambulatory aids were not recommended, because she was "too big," comparing herself to others in the room.

Yeah, I can't use it because of the...it heavy, I is a big woman. So it's gonna be heavy. Hers would be light because she's small. But like me, or you or Ms.

Lascells, as the research participant's thinking changed, and they moved towards transitioning, it is evident that they started putting mental processes in place to facilitate a transition that would result in thinking and actions that were futuristic instead of immediate.

Time span – *Devastating*. The fourth property of the theory of transition is *time span*, and this supports the theme of *devastating*. This steady flow over time is thought to have a starting point the first sign of change is noticed, and it proceeds through an unpredictable volatile state, mixed with uncertainties, trepidation, confusion, and anguish, to culminate with a period of instability. The instability and volatility noted at this stage of transition was evident as the study participants moved from *devastating to*

transitioning. **Ekua** also recalled days when she uttered some expletives at the clinic staff. She explained:

I was in pain and they had me there sitting for a long time past my appointment, the pain was so bad that I had to tell them about their parts [laugh] I don't get on so but when that pain hit me, I usta [used to] say that I am not responsible for the other me and what come out of her mouth.

Many of the participants described situations that resulted in minor assaults on practitioners, as the pain from foot ulcers was too much to bear, and in the end uttering sentiments indicative of the calm after the storm. **Kwami** smiled as he remembered the incident when he felt like kicking the doctor and an incident that occurred when he returned to see the surgeon for a follow up visit post-amputation. He stated:

He came back with a second surgeon and this second guy came, looked at the foot, and he was on the foot just pressing, squeezing and forcing, doing all kinds of crazy things to the foot. So I was thinking, I wonder if this man knew that this foot is hurting? And I will tell you that – this wouldn't go in the report, but I will tell you what I thought. I looked at him and I felt like kicking him off the foot because he was really hurting the foot. It was hurting already and here he was on the foot just – so I really felt like kicking it, honestly.

Kwami returned to the hospital some time later for a follow-up visit and as he met with the surgeon, he shared his thoughts on that day and reminisced:

I went back to see the same doctor that was poking my foot as if it was a pin cushion, and I reminded him of what he did, he smiled, and I smiled as we both

reflected. He admitted that he was used to it but he was very glad that I did not carry out the act on my feelings because I may have ended up without two hands and two legs [laughs].

Kwasi mentioned his mother's reaction and disbelief as he informed her of the surgeon's recommendations. He spoke of her as a nurse and the care she provided him; however, as she received the news of his amputation, she became angry, filled with self-doubt, and she began to question God, asking him how he could have allowed her son to suffer another devastating disability. **Kwasi** remembers that day:

I remember going home and telling my mother what the doctors were recommending, all I remember is her being quiet at first and then yelling like somebody was killing her. She was questioning God, questioning her skills and knowledge as a nurse, and saying that my situation was too much for her to bear. That day she cried for about an hour until I had to tell her that she was not to blame, and that I was determined to take back to my life.

Critical Points/Events – *Devastating, Accepting, Adjusting, and Transitioning*. The fifth property in the theory of transition is *critical points and events*, and according to Meleis et al. (2000), this is representative of the point in the patient's journey when they start to integrate themselves to their new lifeworld. This construct supports all the themes illuminated in this study. The *critical points* for the amputees in this study were their initial diagnosis of diabetes, which later led to the amputation of the limb. As this researcher worked to connect the properties to the themes in the study, the event of amputation

brought about awareness of the consequences of diabetes and its *devastating* consequences. **Ama** recalled crying when she heard the news: “It was very, very embarrassing. I cried actually to this because I didn’t want to lose my feet. **Akosua’s** moment of acceptance came when she was about to go to surgery. She remembers asking: “Are you carrying me to kill me?” He said, “No mom I am not going to kill you, I am going to save your life.” **Akosua’s** final recollection before the surgery was the physician stating:

Come mom I am ready for you, alright son I am coming, he carry me and put me and I lay down in my bed very comfortable and I look up, I say father me and you and all who will look at me.

Adwoa recollected going home and being adamant about adapting to her surroundings with little help from others.

I like helping myself. I think I am very independent so that's why at home, anybody can tell you, oh, she don't want any help. She does everything herself. I cook myself. I do everything. I try not to use the oven too often because then the heat come back on my feet. So I try not to do that very often, but I cook. I can handle myself.

Lahari spoke about her prosthesis and how she was able to reintegrate back into society. “I take the bus now, I go to church, go to the supermarket, and I can go to the doctor by myself.”

Despite their grim prognosis, all of the study participants, at some point in their journey began to verbalize feelings of resilience and began to speak of *acceptance* of

their limb loss. This acceptance then mentally propelled them towards *adjusting* to a life without limbs. All of the study participants became engaged in their care either with a family member or with a healthcare provider, and the collaborative involvement brought about positive change, which was evident as the participants *transitioned*.

Significance of the Study

A review of the literature revealed that there is a paucity of literature related to amputees and their lived experience of Barbadians with lower-extremity amputations as a complication of long-term *diabetes mellitus*. It is important for nurses to explore the numerous approaches and treatment options available to help deal with the dire global health problem of diabetes and its complications. Community and public health nurses, as well as diabetic educators, are all positioned to educate patients and their families regarding the dangers and complications of this non-communicable disease. Without a thorough understanding from those who have experienced the phenomena and the descriptions of their meanings regarding this dilemma, nursing would not have the tools and knowledge to provide a basis for culturally appropriate interventions to perform evidence-based practice. Nurses must be emphatically and convincingly involved in identifying those individuals who are at risk for amputation. Furthermore, healthcare professionals must understand the common denominators that have placed individuals at risk of becoming amputees. As such, the findings of this study have implications for nursing education, practice, research, health, and public policy.

Significance of the Study to Nursing

Diabetes-related lower-extremity amputations have a detrimental impact on a person's quality of life. The individual's understanding of amputation is of importance to nursing science because there has been limited documentation in the literature to address the issue of lived experiences of the diabetic amputee in the Barbadian population. It is important for nurses to explore the numerous approaches and treatment options available to help deal with the dire global health problem of diabetes and one of its most devastating complications. A phenomenological study of this capacity provides unique insights into the lives and experiences of those Barbadians who have experienced a lower-limb amputation. There is limited information in the literature about the lived experience of Barbadians as it relates to amputations. Understanding the essence or meaning of the phenomenon from rich descriptions of experience of persons who have lived with the phenomenon has implications for the nursing profession. Hence, the findings from this study should add to the body of nursing knowledge and hypothetically advance nursing education, practice, research, and public/health policy.

Implications for Nursing Education

This study explored the lived experience of the Barbadian diabetic amputee and provided an understanding of the meaning of their lived experience. The implications of this study for nursing education are significant for a number of reasons. Barbados is referred to as one of the countries with one of the highest rates of amputees in the world, otherwise called "the amputee capitol of the world." The loss of a limb is a traumatic event, and the post-operative care of the amputee is most challenging for the patient and

the families involved. As patients recuperate, they consider the constant presence of nurses to be particularly important to the process of rehabilitation (Royal College of Nursing, 2007). To effectively care for the lower-leg amputee, nurses working in rehabilitation should possess the knowledge needed to address issues related to the physical loss of the limb; the psychosocial stressors associated with the loss; the functional limitations and the individual's quality of life post-amputation. As the population of diabetic amputees continues to grow in Barbados, nurses there are faced with the daunting task of teaching and educating patients and families about caring for themselves post-amputation, and assisting the patient in reaching his or her maximum level of functioning.

The results of this study will hopefully influence nursing educators in Barbados to re-evaluate their curriculums to reflect on the advances in treatment options as they relate to the amputee. Persons with disabilities are often seen as marginalized and are faced with many challenges. A physical disability is not only perceived negatively by the individual but also by those who are charged with providing care. Furthermore, the stigma associated with the disability can have negative consequences on the care delivered and received, leaving some individuals feeling shameful, dehumanized, useless, and dependent on others. Moreover, caregivers should also be mindful and sensitive of these issues, focusing on respecting and reducing the humiliation of these individuals; to foster an atmosphere of caring and protecting the self-esteem and dignity of the individuals in their care. The influence of hearing the participants' voices as they tell their stories motivates changes in curriculum development and clinical arenas. With an

adequate understanding of the phenomenon, nurse educators should focus their efforts on helping students understand the psychological aspects of amputation so that they will be better prepared to handle issues related to amputation.

Implications for Nursing Practice

Psychological support is essential in every specialty of nursing, particularly when patients are experiencing chronic illness and its complications. Individuals with lower-limb loss experience significant disruptions in many realms of their life, including mobility, occupational status, social relations, participation, and mood (Coffey et al., 2014). Nurses caring for patients with lower-leg amputations because of *diabetes* experience many issues with functionality and overall quality of life. The research findings of this study provided insight into the challenges of the participant's experience. As a result, strategies may be developed to assist the nurses in planning and providing care to this population of patients. Understanding the experience of the Barbadian diabetic amputee provides the nurse with the tools needed to assist the patients in better understanding their life post amputation. The themes generated from this study—*devastating, accepting, adjusting, and transitioning*—could provide guidance and the evidenced-based practice models offer the nursing staff with the knowledge needed to improve patient outcomes.

Implications for Nursing Research

According to Polit and Beck (2010), being a nurse in the 21st century can be challenging as well as exciting, given the practice arena in which nurses are expected to be knowledgeable, extraordinarily skillful and talented, while delivering high-quality,

superior care. To accomplish this task, nurses must be able to engage in a systematic nursing scholarship designed to develop trustworthy proof and confirmation of pertinent issues related to the nursing profession (Polit & Beck, 2010). This engagement is known as nursing research. Nursing research evidence is believed to guide professional practice, and this evidence to action continuum is referred to as Evidenced Based Practice (EBP) (Polit & Beck, 2010). EBP is a lifelong integrative problem-solving approach addressing the delivery of health care with the best evidence from well-designed studies (i.e., external evidence). Furthermore, it integrates a patient's preferences and values and a clinician's expertise, including internal evidence gathered from patient data (Spencer et al., 2013).

The best clinical decisions made are those that yield positive patient outcomes. They are inevitable when EBP is delivered in a context of caring and a culture, as well as an ecosystem or environment that supports it (Melnik et al., 2014). This merger of nursing research and evidence-based care, as practice norms must be utilized as powerful tools in the fight of chronic diseases and their complications. This phenomenological inquiry provides additional EBP facts that could be used to design further studies that address the issues related to caring for the diabetic amputee. There is little research available on the lived experience of the Barbadian diabetic amputee, and the findings of this study contributed to the body of qualitative nursing knowledge.

Implications for Health/Public Policy

Health policy is intended to address problems or changes that need to be made within a health care system. However, it is crucial that the identification, exploration,

and understanding of the problem are the first steps before intervention at the policymaking level (Harrington & Estes, 2008). Brownson et al. (2009) further articulated three key domains that are necessary in health policy process: (a) understanding approaches that will enhance policy adoption, (b) content to identify specific elements that will prove to be effective, and (c) outcomes to document the effectiveness and impact of the policy. The process by which public policies are created in the United States can be complex, confusing, dynamic, and even mysterious. Public policies are initiated and introduced at all levels of governments, and include all policies that originate at all levels. The three major policy categories of public policies are defense, domestic, and foreign. Social policy, which falls under the umbrella of domestic policy, includes legislation pertaining to health and welfare (Carroll & Estes, 2008).

In Barbados, the Ministry of Health (MOH) is the sole agency responsible for the delivery of health care and is headed by a minister responsible for defining policies, strategic direction, regulations, norms and standards, as well as political direction. The decision-making is centralized, and there are no local health authorities. The Minister of Health represents the government of Barbados in many regional and international health-related organizations and works collaboratively with the Caribbean Community Secretariat (CARICOM), the Pan American Health Organization (PAHO), and the World Health Organization (WHO) to ensure that programs and policies are implemented to eliminate disease, while trying to improve the quality of life of those served (Pan American Health Organization Health Systems Profile Barbados, 2008). Despite the differences in governments, they all try to improve the health of their people, while

working on controlling the cost of health care. Identification and prioritizing resource allocation, assuring that all health care services are equally distributed, and pursuing measures to insure that quality of care is enhanced, are of primary importance to governments (Bodenheimer, 2005).

The International Council of Nurses (ICN, 2012) believes that nurses hold key positions and are charged with improving access to quality cost-effective care, while improving the health of populations. It is therefore essential that nurses are able to efficiently and effectively influence change at local, organizational, system, national, regional, and international levels. Being knowledgeable about the legislative processes is a valuable tool for nurses wishing to improve access to care and the quality of health care provided (Harrington, Carroll & Estes, 2008). The results of this inquiry offer a point of influence on policymakers in the Caribbean region to focus their efforts on allocating more financial resources at the primary care level, while emphasizing and highlighting services that stress the importance of health promotion and disease prevention.

Government task forces headed by health professionals, educators, and administrators could focus their efforts on implementing strategies to help control diabetes and other chronic conditions. Brownson et al. (2009) concluded that the incorporation of qualitative data could be used as a powerful tool when trying to implement new policies by setting priorities and proposing policy solutions by telling stories that have an emotional impact and intuitive appeal. Public policy is needed to addresses best practice guidelines, standards, and protocols that will guide healthcare practices. Additional policies should focus on programs and initiatives geared toward the

postoperative care of the amputee, as well as measures to provide financial support for amputees, as they try to assimilate back into society.

Strengths and Limitations of the Study

This study embraced its strengths and its limitations. The purpose of this study was to explore the lived experiences of Barbadians with lower-extremity amputations as a complication of long-term *diabetes mellitus* and provide insights into the participants' lived experiences as diabetic amputees. The major strength of this study is the adherence to van Manen's (1990) phenomenological human science approach to research. The methodological and qualitative approach selected for this study allowed the researcher to explore the meanings used to describe and interpret human realities, while elucidating the essence of the phenomenon in the form of themes.

A limitation was the parameters used with the inclusion criteria. The inclusion criteria for this study was a purposive sample of Barbadians, ages 18 years and older, identified as amputees. All participants were expected to be proficient at speaking, reading, and writing English and had to have experienced lower-limb loss secondary to the complications of diabetes. Missing from this research were the voices of those non-English speaking Barbadians who may have experienced amputation due to trauma or other medical causes. Another limitation to this research study was location. The decision to conduct the study in Barbados was met with a number of unexpected circumstances and time limitations. Travel to the hospital and the coordination of the in-home interviews proved to be challenging, noting that this researcher depended on family members for assistance with transportation. In addition, the transcription of the data

proved to be challenging for this researcher, given the thick heavy accents of some of the participants. Nevertheless, this researcher was still able to comprehend and transcribe accurately following each interview.

Recommendations for Future Research

There is a gap in the literature as it speaks to the diabetic Barbadian amputee, and this study provides a basis for concept development to validate current nursing knowledge and trends. It is recommended that further studies be undertaken to fully understand the scope and impact of amputation on the Barbadian diabetic population. In addition, this study adds to the already sparse body of studies addressing this phenomenon. Future research studies could address the lack of psychological and psychiatric services available throughout the amputation process. Information gathered from these studies could help improve the care of amputees as they transition from having two legs to living with one leg. Further inquiry of this nature is warranted on different economic backgrounds, as well as the nature of the amputation. Additionally, the phenomenological approach can also be used for additional or follow-up studies utilizing a larger and more diverse population. Increasing the number of participants would add transferability and confirm saturation to a larger population. It is also important to gather the experiences of more diverse populations.

Conclusions

This study sought to explore the lived experiences of Barbadians with lower-extremity amputations as a complication of long-term *diabetes mellitus*. Sixteen enthusiastic participants shared their stories, allowing the researcher to understand their

experiences, thus accomplishing the goal. The phenomenological principles of Max van Manen were applied, and four themes became evident while the researcher immersed herself in the data scrutinizing the transcripts; *devastating*, *accepting*, *adjusting*, and *transitioning*. Each theme was supported by the properties identified in Meleis' transition theory. Both themes and constructs were central to this study, as they provided a deeper understanding of the phenomenon. The property of **awareness** supported *devastating*; **engagement** supported *acceptance and adjusting*; **change and difference** were supported by *transitioning*; **time span** was supported by *devastating*; and **critical points and events** were well-supported collectively by all the themes in this current study.

Coffey et al. (2014) asserted that individuals who experience limb loss are confronted with a wide range of extensive and evolving threats that are challenging physically, psychologically and socially. In the Barbadian population, these evolving threats were noted as participants in the study provided insights. They openly and transparently shared their experiences, articulating gracefully, remembering the day they were informed of the devastating prognosis. *Diabetes* and its consequences do not discriminate, and the Barbadian amputees in this research study have been able to bring awareness and understanding of this phenomenon forefront to this researcher. This autobiographical sketch by Raghav R clearly speaks to the amputee's journey, while the song, *Ain't No Stopping Us Now* by McFadden and White Head speaks to a positive transition into a new lifeworld:

“How Snakes Lost Their Legs”

When we were born long long ago,
Whether in India or Tobago,
We had numerous legs to move on,
But now they are all gone;

It's a story I was told
By my elders who were old
How we our legs lost
In the ages long past;

One of our tribe on an occasion,
When he was enjoying a vacation,
Had hurt a couple of legs
After he had had a few pegs;

When he could not walk yet,
He was forced to go to a Vet,
Amputation was his advice
Which came as a shock and surprise;

With several legs wrenched off

And to walk with the aid of staff
Was nothing short of death:
He lost all his zest and mirth;

He crawled wherever he went,
With all his legs totally bent,
Soon all of them were hurt,
Bleeding and covered in dirt;

In a short spell of time
When there was a change of clime,
He lost his legs, one by one,
Until a day when he had none;

He knew not how to move,
He prayed to the Mighty Jove,
Days passed without any clue,
So he decided to slither in lieu;

He found it a better way
Than to idle the entire day,
Slithering became easy for him,

As easy as an effortless swim;

He never grew legs again,

His body became round and plain,

Offspring he had many,

But none of them had legs any;

It's how snakes are now born

With no legs their body to adorn,

Born to slither all along,

Whether it be a mile or a furlong.....(Raghav R, 2015)

Ain't No Stoppin Us Now

McFadden & Whitehead

Ain't no stoppin' us now/ We're on the move

Ain't no stoppin' us now/We've got the groove

There's been so many things

That's held us down

But now it looks like

Things are finally comin' around

I know we've got

A long, long way to go

And where we'll end up
I don't know
But we won't let nothin' hold us back
We're putting ourselves together
We're polishing up our act
If you've ever been held down before
I know you refuse to be held down anymore
Don't you let nothing, nothing
Stand in your way
I want y'all to listen, listen
To every word I say, every word I say
Ain't no stoppin' us now/We're on the move
Ain't no stoppin' us now/We've got the groove
Ain't no stoppin' us now/We're on the move
(I know, I know)
Ain't no stoppin' us now/We've got the groove
(We've got it).....McFaden and Whitehead, 1979

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Appendix A
Barry University
IRB Approval Documents

This section contains the Intuitional Review Board Approvals

Appendix A

BARRY UNIVERSITY

IRB APPROVAL DOCUMENT

Barry University

Division of Academic Affairs

Institutional Review Board
11300 NE 2nd Avenue, Miami, FL 33161
P: 305.899.3020 or 1.800.756.6000, ext. 3020
F: 305.899.3026
www.barry.edu

Research with Human Subjects
Protocol Review

Date: February 15, 2016

Protocol Number: 160115

Title: The Lived Experience of Barbadians with a lower Extremity Amputation as a Complication of Diabetes Mellitus.

Meeting Date: January 20, 2016

Researcher Name: Ms. Heather Brathwaite
Address: 2242 SW 130th Terrace
Miramar, FL 33161

Faculty Sponsor: Dr. Claudette Chin

Dear Ms. Brathwaite:

On behalf of the Barry University Institutional Review Board (IRB), I have verified that the specific changes requested by the convened IRB on January 20, 2016, have been made.

It is the IRB's judgment that the rights and welfare of the individuals who may be asked to participate in this study will be respected; that the proposed research, including the process of obtaining informed consent, will be conducted in a manner consistent with requirements and that the potential benefits to participants and to others warrant the risks participants may choose to incur. You may therefore proceed with data collection.

As principal investigator of this protocol, it is your responsibility to make sure that this study is conducted as approved by the IRB. Any modifications to the protocol or consent form, initiated by you or by the sponsor, will require prior approval, which you may request by completing a protocol modification form.

It is a condition of this approval that you report promptly to the IRB any serious, unanticipated adverse events experienced by participants in the course of this research, whether or not they are directly related to the study protocol. These adverse events include, but may not be limited to, any experience that is fatal or immediately life-

threatening, is permanently disabling, requires (or prolongs) inpatient hospitalization, or is a congenital anomaly cancer or overdose.

The approval granted expires on February 31, 2017. Should you wish to maintain this protocol in an active status beyond that date, you will need to provide the IRB with an IRB Application for Continuing Review (Progress Report) summarizing study results to date. The IRB will request a progress report from you approximately three months before the anniversary date of your current approval.

If you have questions about these procedures, or need any additional assistance from the IRB, please call the IRB point of contact, Mrs. Barbara Cook at (305)899-3020 or send an e-mail to dfeldman@barry.edu. Finally, please review your professional liability insurance to make sure your coverage includes the activities in this study.

Sincerely,



David M. Feldman, PhD
Chair, Institutional Review Board
Barry University
Department of Psychology
11300 NE 2nd Avenue
Miami Shores, FL 33161

Cc: Dr. Claudette Chin

Note: The investigator will be solely responsible and strictly accountable for any deviation from or failure to follow the research protocol as approved and will hold Barry University harmless from all claims against it arising from said deviation or failure.

APPENDIX A
UNIVERSITY OF THE WEST INDIES, CAVE HILL
IRB APPROVAL DOCUMENT



In reply please quote
our reference

THE UNIVERSITY OF THE WEST INDIES
FACULTY OF MEDICAL SCIENCES
Formerly The School of Clinical Medicine and Research
Cave Hill Campus and Queen Elizabeth Hospital
Bridgetown, Barbados

Pre-Clinical, Cave Hill Campus:
Tel: (246) 417-4000/4694/4703 Fax: (246) 438-9170
Clinical, Queen Elizabeth Hospital:
Tel: (246) 429-5112 or 437-8335 Fax: (246) 429-6738
PBX: (246) 436-6450 Ext: 6229/6239

March 11, 2016

Ms. Heather Brathwaite
2242 SW 130 The Terrace
Miramar, Fl. 33027

Re: *The Lived Experiences of Barbadians with Lower Extremity Amputation as a Complication of Long Term Diabetes Mellitus.*

I write on behalf of the University of the West Indies-Cave Hill/Barbados Ministry of Health Research Ethics Committee/Institutional Review Board in response the above proposal.

However, approval is contingent on the below revisions:

- (1) Obtain permission from the Ministry.**
- (2) Include the IRB contact information on Appendix D.**
- (3) Identify alternative counseling sites other than the Psychiatric Hospital (polyclinics can provide that service).**
- (4) Clarify the referral process and where persons are being referred.**
- (5) Committee members suggested that convenience sampling can be used in your study.**

Please note that ethical approval does not imply endorsement of your research design.

This approval is for **one year** from the date of this correspondence.

Please remember that you must also secure approval from any individual site or organization, *i.e.*, the relevant ministry, agency, or company, if this is required. Please furnish a copy of this approval.

If you have not already done so, please forward your certificate of completion for ethics training at www.citiprogram.org to kristina.bryant@cavehill.uwi.edu.

All research data and forms must be kept for no less than **five years** after completion of the approved project. Conditions of storage are subject to data security procedures outlined in your proposal. When your research is complete (even if earlier than the approval period ends), please notify the Board in writing to officially close your protocol.

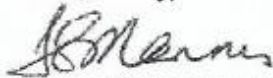
If you anticipate the duration of data collection to exceed one year, please send a letter to the Board at least one month prior to the expiration date. You should indicate why you want the research to remain open (*e.g.*, additional accrual necessary for more robust results, funding from an outside source to continue). Continuation is contingent on Board approval.

Please remember that any change to the protocol will require the submission of a revised protocol via a complete application to the IRB before implementation of the revision.

You must report any unanticipated adverse event experienced by a research subject within five days to the Chair of the IRB through this letterhead address or via e-mail kristina.bryant@cavehill.uwi.edu.

The Committee wishes you the best of luck in your research endeavors. Please feel free to contact us at any time should you have questions or concerns. I remain,

Yours sincerely,



Dr. Thea Scantlebury-Manning
Committee Member

CC:

Dr. Mike Campbell, Chair
Ms. Gale Hall, Deputy Chair
Graduate Studies
Ms. Kristina Bryant, Office of Research
IRB File

Appendix A
**BARBADOS MINISTRY OF HEALTH
APPROVAL DOCUMENT**



GOVERNMENT OF BARBADOS

MINISTRY OF HEALTH
FRANK WALCOTT BUILDING, CULLODEN ROAD,
ST. MICHAEL BARBADOS, W.I.



In Replying the Number and
Date of this letter should be
quoted

Tel. No.: (246) 426-5080
Fax No.: (246) 426-5570

Our Ref:

April 11, 2016

Ms. Heather Brathwaite
2242 SW 130 The Terrace
Miramar, FL. 33027

Dear Madam

The Ministry of Health approves your request to access the health system to gather data on the "The Lived Experiences of Barbadians with Lower Extremity Amputation as a Complication of Long Term Diabetes Mellitus."

You may wish to contact the Chief Medical Officer and confirm the date of commencement of the research after the IRB requirements have been met.

However, it is recommended that you contact Mr. Anthony Harris, Director of Medical Services, at the Queen Elizabeth Hospital to arrange access to the rehabilitation services and the Amputee clinic.

The Ministry of Health wishes you success with your project.

Yours faithfully


TENNYSON SPRINGER
Permanent Secretary

TS:dcb

Appendix B
BARRY UNIVERSITY
INFORMED CONSENT FORM

Approved by Barry University IRB

Date: 2/12/16

Signature: 

Institutional Review Board
Protocol Form
January, 2016 10

Appendix: B
BARRY UNIVERSITY
INFORMED CONSENT FORM

Your participation in a research study is requested. The title of the study is, "The Lived Experience of the Barbadian with Lower Extremity Amputation as a Complication of Long Term Diabetes Mellitus. The research is being conducted by Heather M. Brathwaite, MSN, ARNP, a doctoral student in the College of Nursing and Health Sciences at Barry University, Miami Shores, Florida. The researcher is seeking information that will be useful in the field of nursing and research. The purpose of the study is to describe and understand the lived experience of Barbadians with lower extremity amputations as a complication of long-term diabetes mellitus. Face-to-face personal interviews will be scheduled. The anticipated number of participants will be a maximum of 25. If you decide to participate in this research study, you will be asked to complete the following: a demographic survey form, which will take about 20 minutes, and a one hour face-to-face audio taped interview to discuss your experience in living with limb loss. We will agree on the place, date, and time. When all the data has been compiled, you will be asked to participate in a review of the recorded data for completeness and accuracy. The second meeting will be approximately 30 minutes. The total time requirement is approximately 2 hours. Your consent to be a research participant is strictly voluntary and should you decline to participate or drop out of the study, there will be no consequences to you. You have the right to refuse to answer a question (s) or request that the researcher stop the recording at any time during the audio-taped interview.

There are no known risks associated with this study. This includes the possibility that something mentioned during the discussion could trigger an emotional response. The crisis hotline telephone number to Samaritans of Barbados, and a referral letter for free psychological services at the Black Rock Psychiatric Hospital, will be given to each participant at the beginning of each interview to be used in the event of emotional distress during or after the interview process.

There are no direct benefits to you for participating in this study. However your participation in this study may help illuminate the lived experience of the Barbadian who have undergone a lower leg amputation. A \$25.00 gift basket will be given as a token of appreciation for your participation in this study. You may keep this even if you withdraw from the study.

As a research participant, the information you provide will be held in confidence. Any publishable results of the research will refer to your pseudo name and no real names will be used in the study. Data will be kept in a locked file in the researcher's home office. Your signed consent form will be kept separate from the data. The researcher will destroy the audiotapes 90 days after transcription and verification of accuracy by the participants. The signed consent forms and all data will be destroyed 5 years after the completion of the study.

If you have any questions or concerns regarding the study or your participation in the study, you may contact me, Heather Brathwaite at [REDACTED] or

_____. My faculty sponsor, Dr. Claudette Chin, at _____ or _____, and the Institutional Review Board point of contact, Ms. Barbara Cook, at (305) 899-3020 or bcook@barry.edu. If you are satisfied with the information provided, and are willing to participate in this research, please signify your consent by signing this consent form.

Voluntary Consent

I acknowledge that I have been informed of the nature and purpose of this research project by **Heather M. Brathwaite** and that I have read and understand the information presented above, and that I have received a copy of this form for my records. I give my voluntary consent to participate in this research project.

Signature of Participant

*Date*_____

Researcher

*Date*_____

Appendix C

BARRY UNIVERSITY
LETTER OF REQUEST FOR ACCESS
University of the West Indies, Cave Hill
Barbados Ministry of Health

December 6, 2015

Dear Sir/Madam

My name is Heather Brathwaite and I am a doctoral student in the College of Nursing and Health Sciences at Barry University, Miami, Shores Florida. I will be conducting a research study entitled, “The lived experiences of Barbadians with lower extremity amputation as a complication of long-term diabetes mellitus”. The purpose of this phenomenological study is to explore how amputees living in Barbados experience the phenomenon of amputation.

I am writing you to ask for permission and assistance in gaining access to your facilities to recruit potential participants. Data collection with participants will consist of a face-to-face individual interview conducted at a private mutually designated area lasting one hour and will be digitally audio-recorded. Participants will be contacted for a second interview that will last 60 minutes to verify transcripts of interviews and to add to comments if they desire. A maximum of 25 participants is needed for this study.

I am requesting permission to visit the facility and inform your staff, and post a flyer informing the potential participants about my research to augment the possibilities of obtaining the sample size I need. No information or data from your facility will be utilized. If the Institutional Review Board (IRB) of Barry University approves me, I am hoping to start my research in February 2016. Upon approval of Barry University’s IRB, I will inform you of the exact dates of my research.

Thank you in advance for taking into consideration my request of access and assistance to recruit volunteers for this study. Please free to contact me, Heather Brathwaite at [REDACTED] [REDACTED] with any questions or concerns or email [REDACTED]. You may also contact my faculty sponsor, Dr. Claudette Chin [REDACTED] or email [REDACTED]. The Institutional Review Board contact person is, Barbara Cook, and she can be reached at 305-899-3020 or email to bcook@barry.edu. I look forward to your response at your earliest convenience.

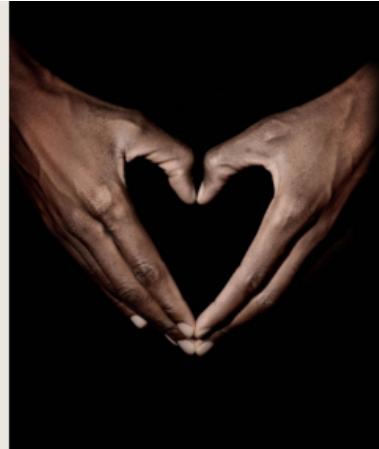
Best Regards,

Heather Brathwaite, MSN, ARNP

Appendix D

**BARRY UNIVERSITY
RECRUITMENT FLYER**

Volunteers needed for a research study



Purpose: To explore and describe the lived experience of the Barbadian with a lower extremity amputation as a complication of long-term diabetes mellitus.

**The Lived experience of Barbadians with
Amputation as a Complication of Long-term
Diabetes Mellitus**

**Heather Brathwaite, MSN, ARNP
Doctoral Student
Barry University**

*In order to participate in this research study,
you must meet the following criteria:*

- ✓ Barbadian age 18 years and older identified as diabetic amputee
- ✓ English speaking and have undergone a lower leg amputation
- ✓ Reside in Barbados for at least one year prior to the time of interview
- ✓ Willing to openly discuss your experience as a diabetic amputee.
- ✓ Willing to participate in a 1-hour face-face taped interview to talk about your experience, and a second follow up 30 minute interview (Total estimated participation time 2 hours)

Participants will receive a Gift Basket as a token of appreciation.

25 volunteers are needed!

BARRY UNIVERSITY
Miami, Florida

Faculty Supervisor



Institutional Review Board
Barbara Cook
bcook@barry.edu
(305) 899 3020

INTERESTED????
Please Contact Heather
Brathwaite

@



Appendix E

BARRY UNIVERSITY

DEMOGRAPHIC QUESTIONNAIRE

Pseudo name: _____

Date/Time: _____

Section 1: Demographic Details

Age: _____ Date of Birth: _____ Married/Single _____

Ethnicity: _____ Level of Education: _____ Children: _____

Gender: *Male* _____ *Female* _____

Occupation: _____ Date of amputation: _____

How far is the nearest Poly clinic/hospital from your home? _____

How do you travel? *Own car* _____ *Relative's car* _____ *Public Transport* _____
Hire private transport _____ *Other, please specify:* _____

Income: *Private pension* _____ *Old age pension* _____ *Disability* _____
Still employed _____ *Other, please specify* _____

Smoking history: Did you smoke?

Before the operation: Yes _____ *No* _____

After the operation: Yes _____ *No* _____

If yes, how often per day?

1-5 _____ 6-10 _____ 11-20 _____ 21-30 _____ Over 30 _____

Do you drink alcoholic drinks?

Before the operation: Yes _____ *No* _____

After the operation: Yes _____ *No* _____

If yes, how often do you drink?

A few times a month _____ *Once a week* _____ *3-4 times a week* _____ *Everyday* _____

Section 2: Medical Information

What is the reason for your amputation? _____

What amputation do you have? *BKA* _____ *AKA* _____ *Left Leg* _____ *Right Leg* _____ *Bilateral* _____

Do you have any of these conditions? *Hypertension* _____ *Arthritis* _____ *Chronic heart disease* _____
Diabetes _____ *Peripheral vascular disease* _____
Others, please specify _____

If yes, are you being treated at this time by a physician? *Yes* _____ *No* _____

Appendix F

BARRY UNIVERSITY

INTERVIEW QUESTIONS

Primary Question: “Tell me what it is like to have a leg amputated”.

Probe questions may be used to facilitate the conversation.

- *Could you please tell me about the day that you were diagnosed with diabetes?*
- *When did you notice that something was wrong with your leg?*
- *What was it like when the doctor informed you that you needed to have your leg amputated?*
- *Please share your experiences and feelings about the impact of your amputation in your life.*
- *How did your decision to have your limb amputated affect your family, and those in your community?*
- *Did you seek any type of psychological help before the surgery?*
 - *If yes: Were those services scheduled as a part of the pre-surgical recommendations, was the assessment mandatory?*
- *What are your experiences about your general function since you returned home after the operation?*
- *What are your thoughts on the use of prosthesis?*
- *Are there any other issues you would like to discuss or add to our discussion today as it relates to your experience as an amputee?*

Appendix G

**BARRY UNIVERSITY
LIST OF FREE SERVICES**

Crisis Hotline: Samaritans of Barbados (246) 429-9999

The main switchboard: (246) 425-8680 or (246) 425-8688.

The Out Patient Clinic can be reached at (246) 425-6362.

The Social Work department can be reached at (246) 425-7192.

The Psychology Department can be reached on (246) 425-7188

Appendix H

BARRY UNIVERSITY

CURRICULUM VITAE

April 1991	BSN, Florida International University, Miami, Florida
June 1991- 1996	Staff Nurse, Inpatient Geriatric Psychiatry Mt. Sinai Hospital, Miami, FL.
September 1991-1996	Nursing Supervisor, Locktowns CMHC Miami, FL.
April 1996	MSN, ARNP, Florida International University, Miami, FL.
April 2016 – Present	Adjunct Professor, Florida International University, Miami, FL.
June 1996 - 1997	ARNP, Dr. Salvato Miami, FL.
February 1997 – 2010	ARNP, Memorial Regional Hospital Hollywood, FL.
April 1998 – Present	Owner, BRAYNE Concepts, Miramar, FL.
August 2009 – 2011	Professor Miami Dade College, Adjunct Professor, Nova Southeastern University
August 2011 – 2015	ARNP, Archways CMHC ARNP, Chrysalis CMHC ARNP, Pathway to Hope, Ft. Lauderdale, FL

June 2015 – Present

ARNP, Florida House Experience
Deerfield, FL

December 2016

Doctor in Philosophy in Nursing
Barry University, Miami, FL