THE JOURNEY TOWARD ENGAGEMENT IN SELF-CARE
MANAGEMENT OF DIABETIC FOOT ULCER: A CONSTRUCTIVIST
GROUNDED THEORY STUDY

by

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Abstract

Background: Worldwide, diabetic foot ulcer (DFU) is the leading cause of emergency room admissions, long hospital stays, and long-term disability for individuals living with diabetes. Of all individuals with diabetes, 15–25 percent develop a DFU at some time in their lives; and 25 percent of these foot ulcers end in lower extremity amputation (LEA). While many investigators of DFU have been focused on pharmacological and technical approaches, little attention has been given to non-pharmacological approaches such as self-care management (SCM). The purpose of this qualitative study was to develop a theory that explains the process of engagement in SCM for individuals with DFUs and to identify the contextual factors influencing their engagement.

Methods: A constructivist grounded theory, informed by Charmaz, was used to guide the study design. Theoretical sampling and intensive semi-structured interviews were conducted with 30 individuals with active DFU attending a wound care clinic in southeastern Ontario, Canada, in August of 2017. Data analysis was conducted alongside data collection in a cyclic research process, which began with initial coding, and proceeded to focused coding or selective coding that resulted in a model representative of the theory.

Results: The study results draw attention to the complexity that exists for individuals seeking to balance life and manage diabetes and DFU. The categories and their set of concepts comprise the theory called “The Journey Toward Engagement in SCM”. The process involved five phases: 1) perception of illness, 2) noticing foot changes, 3) realizing seriousness, 4) beginning to learn about SCM, and 5) engaging in SCM. The process is influenced by multiple contextual factors, including aging and/or living with multiple chronic conditions, motivations, self-efficacy, SCM knowledge, SCM support, and access to services and resources.

Conclusion: The results of my doctoral study showed the pathway participants used to learn about SCM practices and how engagement in day-to-day management of DFU occurred. It has also helped to uncover inequities in accessing formal SCM education and specialized services and resources, which in
turn contribute to inform nursing practice, education, and health policy.
Co-Authorship

This thesis is the work of Idevania Geraldina Costa in collaboration with:

- Deborah Tregunno, PhD, Associate Professor, School of Nursing, Queen’s University (co-supervisor)
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- Dana Edge, PhD, Associate Professor, School of Nursing, Queen’s University (thesis committee)
DEDICATION

I would like to dedicate this thesis to several important people in my life.

To my husband, Gustavo, who has stood beside me for over fifteen years and never wavered in his love, encouraging words, and support of all that I strived to do. Many times you have believed in my potential more than I do. You are my pillar. Without you, this would not have been possible, thank you, my love.

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List of Terms and Abbreviations

The following are definitions of key terms and abbreviations used in this study.

- **Diabetes Mellitus (DM):** Diabetes is a serious, chronic disease that occurs either when the pancreas does not produce enough insulin (a hormone that regulates blood sugar, or glucose), or when the body cannot effectively use the insulin it produces. It also leads over time to serious damage to the heart, blood vessels, eyes, kidneys, and nerves (World Health Organization- WHO, 2016).

- **Diabetic Foot Ulcer (DFU):** is one of the most significant and devastating complications of diabetes, and is defined as a foot affected by ulceration associated with nerve damage leading to neuropathy and/or peripheral arterial disease of the lower limb in a patient with diabetes (Alexiadou & Doupis, 2012).

- **Self-care Management (SCM):** The general definition of SCM is the ability of individuals to promote and maintain health, prevent disease, and “to cope with illness and disability with or without the support of a health-care provider” (World Health Organization- WHO, 2013, p. 16). In chronic disease SCM refers to performing the daily activities that serve to maintain or restore health and well-being, prevent illness, and manage chronic illness (Jaarsma, Stromberg, Martensson, & Dracup, 2003; Moser & Watkins, 2008).

- **Patient Engagement:** normally refers to patient involvement in everyday management and decision-making about their condition (Small, Bower, Chew-Graham, Whalley, & Protheroe, 2013).
Chapter 1
Introduction

1.1 Overview of the Study

Chronic conditions such as diabetic foot ulcer (DFU) profoundly affect the lives of people suffering from them and result in significant high costs to individuals, families, the healthcare systems and society through decreased productivity. The poor outcomes of diabetes affect individuals holistically, including physical, psychological, and social areas of their life and can result in serious and dramatic consequences such as amputation of the lower extremities. Diabetic foot ulcer is the main cause of emergency room admission, long hospital stays and high mortality rates for patients with diabetes (Boulton, Vileikyte, Ragnarson-Tennvall, & Alpelqvist, 2005; Skrepnek, Mills, & Armstrong, 2015). Diabetic foot ulcer can be managed through both pharmacological and non-pharmacological (self-care) approaches. Until recently, efforts have focused primarily on biomedical aspects of healthcare, including pharmacological and technical approaches to the management of DFU (Odegard, Setter, & Iltz, 2006; Scimeca et al., 2010) rather than on self care management. In the biomedical approach, the doctors make the best treatment decision on behalf of the patient without typically involving them in the decision making process. This kind of model prevents patients from being actively involved in healthcare decisions about their own condition and does not usually give them the opportunity to ask questions or participate as a partner. As stated by Charles and colleagues, “there is no sharing of any of the decision making steps in this model so, by definition, a doctor patient partnership does not exist” (Charles, Whelan, & Gafni, 1999, p.781). In contrast to the more passive role of patients in the biomedical model, there is growing evidence that people living with chronic conditions who are actively engaged in their own care have significantly improved clinical outcomes (Health Council of Canada, 2012), including decreased hospitalization, healthcare costs, mortality, and increased quality of life (Malmstrom et al., 2008). Individuals that engage in the management of their own care are likely to identify earlier signs and symptoms of infection, make decisions about their care, and take
action to prevent irreversible consequences (Bourbeau, 2008; Oosterom Calo et al., 2012; Riegel, Jaarsma, & Stromberg, 2012). Empirical evidence has suggested that patients’ voices need to be heard to help understand their roles and abilities in managing their chronic conditions (Barello et al., 2015). Researchers and clinicians agree that diabetes is a disease strongly influenced by SCM, and that patients should be reliable, capable, and sufficiently responsible to take care of themselves to prevent severe consequences of this condition (Sousa, Zauszniewski, Musil, McDonald, & Milligan, 2004). However, the Canadian Institute for Health Information has reported that in Canada 40 percent of adults with chronic diseases reported they rarely or never talking with their primary provider about specific SCM skills or SCM practices to improve their health conditions and achieve better outcomes (Canadian Institute for Health Information, 2009).

Ontario’s Chronic Disease Prevention and Management Framework highlights that patients need a variety of support services to help them to become effective self-care managers of their chronic conditions, including specific information about the disease, its causes and effects, and strategies to mitigate its progress and prevent complications (Ministry of Health and Long-Term Care [MOHLTC], 2007).

Diabetic foot ulcer is a complex chronic wound that has physical, psychological, and social impacts upon individuals’ lives (Ashford, McGee, & Kinmond, 2000; Brod, 1998; Gale, Vedhara, Searle, Kemple, & Campbell, 2008; Watson-Miller, 2006) and therefore requires that individuals become expert self-care managers (Etoria-King, Sinha, & Scammell, 2009). Through my experience as a wound care nurse working in a public health system in Brazil for more than a decade and delivering wound care for marginalized people (e.g., low-income and minority groups) in society, I have witnessed a variety of ways that individuals with DFU are involved in care of their wound. For example, I have cared for patients who were actively involved in their own health care and who questioned healthcare providers and who advocated for the resources and support they needed to achieve better foot outcomes (e.g. healing their wounds quickly and free from infection). In contrast, other patients who struggled to find resources and support seemed to be passively involved in their own health care, and seemed to be prevented from achieving the desired health outcomes. Frequently, I found some of my patients hospitalized in emergency with severe foot infections.
and subsequent foot amputation, which led those patients to face significant clinical, social and economic effects.

To date, little attention has been focused on understanding individuals’ experience in the everyday SCM of their condition, and no theoretical model exists that focuses on the individuals’ experience of living and dealing with daily management of DFU. Further, little is known about the factors that influence SCM of DFU. Researchers usually adapt SCM models from other chronic conditions developed strictly by a deductive approach that uses hypothesized factors influencing self-care management (Moser & Watkins, 2008; Novak, Costantini, Schneider, & Beanlands, 2013). In response to this theoretical and practical lack, and to contribute knowledge about how to improve SCM and outcomes of DFU, this research uses a social constructivist grounded theory approach to understand the process of engagement in SCM by individuals with active DFU, and examines the factors that influence their ability to engage in SCM of DFU.

In the following sections of this chapter, I provide an overview of the problem statement, including the pathway for DFU formation, epidemiology of diabetes and DFU, the burden to the individual, healthcare system and society, and the need to engage individuals in SCM as a strategy to improve health outcomes. I also provide my reflexivity statement and conclude the chapter with the purpose of the study and the research questions explored.

1.2 Problem Statement

1.2.1. Pathway for DFU formation. Foot ulcer formation starts with a combination of uncontrolled diabetes (high glucose level), abnormal foot biomechanics, and impairment of perfusion that leads to peripheral nerve damage resulting in a loss of protective sensation in the feet called peripheral neuropathy (Driver, LeBretton, Landowski, & Madsen, 2012; Pecoraro, Reiber, & Burgess, 1990; Registered Nurses’ Association of Ontario [RNAO], 2013). Neuropathy is associated with loss of sensation that places individuals at high risk for foot injury or re-injury (Botros et al., 2018). The progression to DFU is the result of neuropathy, musculoskeletal deformities, infection and impaired arterial supply or a combination of these factors (Sumpio, 2012). The foot ulceration usually begins with a blister or small ulcer caused by trauma as
illustrated in Figure 1.1.

**Figure 1.1. Pathway for diabetic foot ulcer formation. Adapted from literature review (Driver, LeBretton, Landowski, & Madsen, 2012; RNAO, 2013).**

Although the pathway to DFU is composed of multiple causes, neuropathy is considered paramount and precedes DFU in almost all cases (Richard & Schuldiner, 2008). However, the presence or co-existence of peripheral vascular disease and infection can also lead to skin breakdown. Furthermore, other important signs of underlying diabetes-related pathophysiology are peripheral arterial disease, foot deformity, and limited joint mobility (Pecoraro et al., 1990; Wounds International, 2003). Critical ischemia from acute arterial occlusions has also been responsible for amputations as a singular cause (Pecoraro et al., 1990). Due to its association with loss of sensation, neuropathy makes DFU to have a silent onset and devastating outcomes if not detected early and/or preventive measures are not implemented. The loss of sensation places
individuals at high risk for foot trauma, that in most cases is not immediately noticed and hence leads to diabetes foot complications (DFC) (i.e., ulceration, infections, and amputation). The most common agent responsible for causing traumatic foot ulceration is footwear (Birke, Patout, & Foto, 2000; Tyrrell, 2002). The use of ill-fitting footwear is pivotal in the development of blisters, calluses, and corns that lead to the onset of foot ulceration in patients with diabetes. Neuropathy also leads to a cascade of events resulting in foot changes (e.g., deformity and Charcot foot) (RNAO, 2005). These changes, along with previously mentioned factors, place individuals with diabetes at high risk to develop foot ulceration. It is broadly known that diabetic foot ulceration is a significant end-stage complication of diabetes that takes time to heal and may lead to lower limb amputation (called amputation in this study) (Boulton, Meneses, & Ennis, 1999). For example, while 60 to 80 percent of DFUs will heal, 10 to 15 percent of them will remain active and up to 24 percent will lead to foot ulcer complications such as infection, gangrene, and subsequent amputation if effective ways to address the complications are not implemented (Canavan, Unwin, Kelly, & Connolly, 2008; Pemayun, Ridho, Diana, Nurmilawati, & Minuljo, 2015).

1.2.2. The epidemiology of diabetes and DFU. Diabetes mellitus (DM) has become a disease that ranks as one of the world’s fastest growing, costliest, and most seriously life-threatening chronic illnesses. The number of individuals with DM is increasing globally and becoming a major public health problem. And the likelihood of type 2 diabetes occurring goes up with the growing elderly population. Given Canada’s current demographics, where the number of elderly 65 years or over is estimated to increase from 4.7 million in 2009 to 10.9 million by 2036 and could potentially vary between 11.9 and 15.0 million by 2061 (Statistics Canada, 2010), it is reasonable to expect that the overall number of individuals with chronic diseases, including diabetes, will increase greatly. The growth of an aging population, coupled with existing risk factors (e.g., tobacco use, unhealthy diet, physical inactivity) (Public Health Agency of Canada, 2015) and biomedical innovations that increase longevity (Lichtenberg, 2017), will contribute to a continued increase in the number of individuals with diabetes. In fact, current statistics have confirmed an upward worldwide trend in type 2 diabetes. For example, the latest diabetes report from the World Health
Organization (WHO) estimated that 422 million people were living with diabetes worldwide in 2014 compared to 108 million in 1980 (WHO, 2016). Chronic diseases are the major cause of death and disability worldwide; as a chronic disease, diabetes mellitus is the sixth leading cause of death in the world (WHO, 2011). The global prevalence of DM has been projected to double from 2.8 percent in 2000 to 4.4 percent in 2030, and is estimated to affect over 500 million individuals worldwide (Boulton, 2006; Wild, Roglic, Green, Sicree, & King, 2004) and Canada is no exception (Statistics Canada, 2010). In 2015, 3.4 million Canadians (9.3 percent) were diagnosed with diabetes and this number is estimated to increase to 5 million Canadians (12.1 percent) by 2025 (Canadian Diabetes Association – CDA, n.d). The increase in diabetes also increases healthcare costs. In 2010, the healthcare costs of patients with diabetes were estimated to be $4.9 billion in Ontario, and this number is projected to reach $6.9 billion by 2020, a 42 percent increase in just 10 years (CDA, 2009; MOHLTC, 2012). To make matters worse, patients with DM are susceptible to several complications, including DFU (Yazdanpanah, Nasiri, & Adarvishi, 2015). Diabetic foot ulcer is considered one of the most devastating complications of DM that ends in preventable limb amputations (RNAO, 2005; Wounds International, 2003).

In fact, evidence has helped to uncover social injustice and health inequities for people living with diabetes. For example, previous and recent studies reported that DM and DFU usually affect elderly and socially disadvantaged groups worldwide (Hopkins, Burke, Harlock, Jegathisawaran, & Goeree, 2015; Reiber, Boyko, & Smith, 1995). In Canada, the most common age group with DFU was found to be those between 55 to 64 years old, with the highest prevalence in the 75- to 84-year age group. The study highlighted that DFU was more prevalent in men than in women, 63 and 37 percent, respectively (Hopkins et al., 2015). While few Canadian studies have been focused on ethnicity and socioeconomic factors related to DFU, which represents a literature gap, in the United States diabetes has been shown to be more prevalent in Hispanic (39.8 percent), African American (38.2 percent), and American Indian/Alaska Native (37.9 percent) populations (Margolis et al., 2011). Proportionally, the prevalence of foot ulceration by race has been found to be highest in the same groups of Hispanic (8.6 percent), African American (8.7 percent), and American Indian/Alaska Native (9.6 percent) residents (Margolis et al., 2011). Mexican Americans with
DFU are more than two times (4.6 percent) as likely to have a history of limb amputation as non-Hispanic whites (2.2 percent) (Margolis et al., 2011).

Researchers from Canada and abroad who evaluated diabetes-related amputation due to foot ulcer have shown that the lower the socioeconomic status, the higher (> 30 percent) the incidence of amputation in people with DFU (Amin et al., 2014; Glazier, Bajcar, Kennie, & Willson, 2006; Pham et al., 2000). The Canadian Diabetes Association (CDA) reports that the prevalence of diabetes and its complications are excessively high among lower-income earners and Indigenous groups, being three to five times higher among First Nations than in the general population (CDA, 2015, 2016). The prevalence of foot ulcers among people with diabetes ranges from 4 to 10 percent and the lifetime incidence has been estimated to affect 25 percent of patients, mainly because of underlying comorbidities, such as peripheral neuropathy and peripheral vascular disease (CDA, 2009; Ohinmaa, Jacobs, Simpson, & Johnson, 2004). Canadian national incidence and prevalence rates (per 100,000 population) varied from province to province. The incidence of DFU ranged from 36.9 percent in Ontario to 57.2 percent in Manitoba. And correspondingly, the prevalence rates varied from 64.7 (per 1000,000) in Ontario to 106.2 (per 100,000) in Manitoba (Hopkins et al., 2015).

1.2.3. The burden of DFU on individuals and society. Diabetic foot complications affect the health and quality of life of many Canadians, especially for the growing elderly population and those with low socioeconomic status (Wound Care Canada, 2016a). In addition, diabetic foot ulcer and amputation can lead to an increase in hospital expenditures, loss of productivity and unemployment, social isolation and depression, lack of independence, and disability, as well as an increase in mortality rates (Ismail, Winkley, Stahl, Chalder & Edmonds, 2007; RNAO, 2006; Watson-Miller, 2006;). Foot ulcer complications lead to hospitalization among 50 percent of cases and amputation in 25 percent (Lawrence et al., 2006). Evidence states that every 30 seconds a lower limb is lost due to foot ulcer complications someplace in the world (International Diabetes Federation, 2005). Investigators have also shown that diabetes is responsible for more than 84 percent of non-traumatic limb amputations, and half of those with an amputated limb survive for only two years after surgery (Lawrence et al., 2006; Margolis, Allen-Taylor, Hoffstad, & Berlin, 2005). The five-year mortality rate associated with DFUs ranges from 43 to 55 percent and up to 74 percent for
In summary, the consequences of this devastating diabetes outcome deliver a dreadful impact to the lives of Canadians and the healthcare system. For instance, the high incidence and prevalence of DFU increases the costs to the healthcare system due to ongoing treatment and long hospitalization stays while additionally influencing workforce patterns due to absenteeism and unemployment (Margolis et al., 2005; Singh, Armstrong, & Lipsky, 2005). When DFU ends in amputation it has a direct cost of $70,000 per patient, which results in an annual budget of over $100 million in unnecessary costs for the Canadian healthcare system (Wound Care Canada, 2016a). In 2011, diabetic foot complications such as ulceration, infection, and amputation were associated with 16,883 hospital admissions, 31,095 emergency room or clinic visits, 26,493 interventions, including 6,036 amputations, and 5,796 surgical debridements in Canada (Hopkins et al., 2015). These appalling numbers reflect little or no emphasis on prevention and the issue faced by individuals with primary signs of diabetic foot complication (e.g., infection, gangrene) “who usually do not have another place to go, beyond the emergency room” (Botros & Grinspun, 2014, p. 1). To make things worse there is a lack of universal funding across Canada (Wound Care Canada, 2016b) to cover foot care specialists such as a wound care nurse and chiropodist and offloading devices (e.g., total contact cast, custom shoes, diabetic boots, etc.) aimed to redistribute the pressure under the plantar of the feet, prevent tissue damage, and hence accelerate healing (RNAO, 2005 Wounds International, 2013).

1.3 Possible Ways to Address the Problem

1.3.1. Investing in prevention. The unnecessary costs spent on DFU and amputation could be avoided with investments in prevention by providing access to services such as foot care specialists and resources such as therapeutic footwear and offloading devices. For example, evidence suggests that 85 percent of this devastating diabetes outcome could be prevented with early intervention, which in turn would result in saving money and lives (Apelqvist & Larsson, 2000; Goettl, 2008). Therefore, the Canadian Association of Wound Care (CAWC) has recently declared that it is time to increase awareness of the costs of DFU and amputation and has launched a nationwide campaign titled Save Limbs, Save Lives – Today
I participated in this campaign in 2016 by writing the article titled: “Investing in prevention: Funding foot care specialists and offloading devices” that was published by the diabetic foot Canada e-Journal (Costa, 2016). As a result of this campaign, on November 22, 2017, the Ministry of Health and Long Term Care of Ontario committed to providing $8 million over three years as financial support for three types of offloading devices, which include removable, non-removable, and total contact foot casts (MOHLTC, 2017). Based on the literature of prevention and management of DFU, it is clear that financial support for offloading devices is just one step of many that should be put in place to improve outcomes of DFU. It is expected that this type of funding will be included in the Assistive Devices Program of Ontario as permanent funding and be adopted by the other provinces and territories across the country to reduce the risk of DFU and limb amputations.

1.3.2 Engaging individuals in SCM practices. Although engagement and SCM seem to overlap, engagement normally refers to patient participation in decision-making about management of their condition with their healthcare providers (Small et al., 2013). In primary care, patient engagement implies that healthcare professionals should build a relationship based on social milieu, culture, and knowledge and demonstrate a shift in the way they choose to think and interact with their patients. Self-care management is concerned with empowering individuals as partners in the management decisions about everyday healthcare practices that patients need to perform to achieve better health outcomes (Lorig & Holman, 2003; Small et al., 2013). Skills essential to efficacious SCM include decision-making, problem solving, effective utilization of resources, development of patient-provider partnerships, and adopting actions to manage the health condition (Lorig & Holman, 2003). Nursing theorist Dorothea Orem (2001) defined self-care as the practices and activities that individuals initiate and perform on their behalf to maintain a good lifestyle, health, functioning, and well-being. Self-care management enables individuals to observe themselves, recognize and determine the severity of signs and symptoms, and choose the appropriate strategies for managing them (Sidani, 2003). Self-care management has been also classified as a sensitive nursing outcome and a philosophical orientation that underlies nursing and differentiates it from others disciplines (Sidani, 2003).
Although SCM has been recognized as an important strategy that improves health outcomes of individuals with chronic conditions, primary healthcare providers have not been provided enough SCM support for Canadians with chronic diseases to help them to improve their engagement in SCM and achieve better outcomes (Canadian Institute for Health Information – CIHI 2009). In fact, the investigators of diabetes SCM have recognized the need for a paradigm shift from the focus on compliance and adherence to approaches that focus on empowerment and collaboration, shared decision-making, and patient-centered care (Anderson & Funnel, 2000; Cyrino, Schraiber, & Teixeira, 2009; Funnel & Anderson, 2000). The terms “compliance” and “noncompliance” are common under the biomedical model of care and have been criticized as a set of judgmental terms in diabetes care (Dickinson, 1999; Hutchison, Levesque, Strumpf, & Coyle, 2011). In this model, healthcare professionals frequently label patients with “good” (normal) management of DFU as “compliant”. Conversely, those who are struggling to manage their DFU usually are labeled as “noncompliant” individuals with “bad” self-care behavior. Actually, the traditional model that focuses, especially on disease and/or illness, has not helped to improve outcomes for DM and DFU as noted in the epidemiological data described previously. Thwarted outcomes can be linked to the predominant biomedical model of care that has not always considered patients as partners in their own health care, and has emphasized that patients follow a predetermined plan of care that includes neither their needs nor their preferences (Anderson, Funnell, Fitzgerald, & Marrero, 2000; Cyrino et al., 2009; Glasgow & Anderson, 1999). Therefore, the engagement in SCM requires an empowerment and patient-centered care approaches with a focus on patients’ needs, preferences, and freedom to make informed decisions. Thus, it is important to be aware that even though patients are vulnerable and struggling in managing their daily activities with a chronic condition, they are human beings capable of making decisions based on their needs, experiences, and knowledge shared by their healthcare providers in a way that fits their social and cultural context. In short, they always need to be heard (Bodenheimer, Lorig, Holman, & Grumbach, 2002).

Given the complexity of DFU and the physical, psychological, and social impact it causes on people’s lives, individuals are required to become experts in SCM. However, research that focuses on understanding how individuals with active DFU engage in their own health care and become good self-care managers is
sparse. While researchers usually explore the lived experience of individuals with DFU, minimal attention has been directed toward developing a theory that explains the process of engagement in SCM practices from the individual’s unique experience of living with and self-managing an active DFU. Furthermore, the factors that influence engagement in SCM practices for populations with active DFU are unknown. As such, the need for specialized knowledge of subjective data is significant, as it will assist us to improve our understanding and to develop stronger wound care practices for individuals living with and providing care for their DFU on a daily basis. Following a constructivist grounded theory approach, my doctoral work addresses this knowledge gap by uncovering the process of SCM and the factors that enhance or limit their engagement.

1.4 Study Purpose and Research Questions

The overall purpose of this grounded theory study was to develop a substantive theory that explains the process of engagement in SCM of DFU and to explore factors influencing the ability to engage in SCM from the unique experience of people living with active DFUs. In grounded theory, the central (broader) research question is determined first in order to guide the formulation of sub-questions to explore the central question (Charmaz, 2006; Strauss & Corbin, 1998). Thus the central question for this study was: What theory explains the process of engagement in self-care management for individuals with active diabetic foot ulcers?

My research questions were developed around my general interest in developing a substantive theory that explains the process of engagement in SCM from the unique experience of people living with active DFUs and explored factors influencing their capacity and ability to engage in their everyday SCM. The following sub-questions emerged to explore my general question:

1. How do individuals engage with the processes of taking care of themselves?
2. How do individuals with DFU make meaning of and interpret their day-to-day experience of living with and managing their foot ulcer?
4. What are actions and motivations associated with the everyday management of DFU?
5- How do individuals with DFU perceive their role/function in the management of their DFU?

6- How do DFUs affect individuals’ lives and influence the way that they navigate their social world?

1.5 Reflexivity Statement

After self-interrogation and reflection on my experience as a wound care nurse, educator, and social actor, I wrote this reflexivity statement to purposely expose my professional identity, values, and experience in taking care of individuals living with DFU. As a wound care nurse and an educator with over fifteen years of experience, I believe in the uniqueness of each human being who has their own needs, preferences, and choices in the process of caring for themselves. Thus, I felt that when I decided to embark on a grounded theory study to explore factors influencing individuals’ engagement in SCM of DFU, I should approach the research with these values in mind. I wanted to consider questions, such as how healthcare providers might better meet the needs of individuals with chronic wounds if they looked beyond just the illness itself. I believe that the inseparable nature of physical, psychological, and social factors should be considered when providing care for an individual with such a multifaceted chronic condition. Furthermore, I honestly believe that there is much to be learned from patients’ experience of living with DFU. My study might teach us something about the impact of this condition on patients’ psychological and social lives and help us to discover factors influencing their ability to take care of themselves. Are there any factors about the current healthcare model and patients’ beliefs and social structures that prevent them from using their full human potential to improve their own care and achieve better outcomes of DFU?

I believe that my extensive experience with this population and with their struggles spoke directly to my theoretical sensitivity when I analyzed and interpreted the data. I also understand that my assumptions, values, beliefs, and experience (further explained in section 3.4) may have influenced my writing during interpretation of data. Furthermore, Charmaz states that researchers working in the area of study for a long time possess a greater ability/sensitivity to construct a theory (Charmaz, 2014). Additionally, only through rigorous scholarly research will others come to know, and possibly understand, the processes underpinning individuals’ ability to engage in SCM of DFU. Hence, the understanding described in this study, through the development of a substantive theory, may help wound care professionals to advance practices and improve
health outcomes for individuals with DFU, and possibly other kinds of chronic wounds. It also may influence policymakers and healthcare professionals to shift the healthcare system from a focus on pharmacological treatment and compliance to patients’ engagement and patients as partners in their own healthcare.

1.6 Thesis Structure

The thesis has been organized into five chapters. This chapter provided an introduction to the research topic and presented the overview of the problem, which includes the pathway to DFU, epidemiology of diabetes and DFU, the burden to the individual and healthcare system, and key ways to address the problem, including investments in prevention and individuals’ engagement SCM. It also includes the study aim and the research questions, as well as my reflexivity statement and own positioning in the research, consistent with a constructivist grounded theory approach.

In Chapter 2, I describe the literature of DFU management and engagement in SCM of chronic conditions, including DFU. In Chapter 3, the research methodology is outlined, including the evolution of grounded theory, its different philosophical assumptions, with a focus on the chosen approach for this study, and constructivist grounded theory as described by Charmaz (1990, 2006, 2010, 2014). Then I draw attention to symbolic interactionism, which is recognized as the theoretical underpinning of grounded theory and to my own philosophical assumptions, including the ways in which I identify myself with Charmaz’s approach to grounded theory. I finish with a description of the methods I used to collect and analyze data and an explanation of how rigor and trustworthiness were ensured.

Chapter 4 presents a description of the research findings. It begins with an overview and summative introduction to the theory, “The journey toward engagement in SCM”, as well as the contextual factors that facilitated or postponed participants’ engagement in SCM of diabetes and DFU. This chapter also provides an in-depth presentation of the findings of the properties of the theory that comprise my analysis, interpretation, and supporting literature for each category and its set of concepts. Chapter 5 presents four key findings that highlight the needs voiced by the study’s participants, examines the contributions of this theory to practice, education, and policy; and describes the future directions, challenges, and the conclusion.
Chapter 2

Literature Review

2.1 Overview of the Chapter

In this chapter, I present an overview of the current approach used to manage DFU and the importance of engagement in SCM. This approach consists of pharmacological and technical management, as well as the knowledge and skills of an interdisciplinary DFU team. Another approach is the non-pharmacological management that involves patients’ ability to engage in SCM of their condition. Together, these approaches support the urgency of developing a theory that explains processes of self-care management engagement for individuals with diabetic foot ulcer.

2.2 Evidence-Based Management of Diabetic Foot Ulcer

Given that DFU is a complex chronic condition with a significant long-term impact on people’s health, the successful management of patients with DFU requires a systematic approach to address the complexity of this management (CDA, 2013). The systematic approach has three major components that involve: 1) an interdisciplinary team including foot care specialists such as wound care nurses and chiropodists to address local wound care and relief of pressure to the wound (RNAO, 2013); 2) the role of individuals in SCM; and 3) an educational intervention to improve patients’ knowledge, engagement, and SCM skills, that should also be strengthened in this systematic approach (Adams, Orchard, Houghton, & Ogrin, 2014; Chen et al., 2013; RNAO, 2013). These three major components are summarized below.

2.2.1 Component 1: The role of an interprofessional team in managing DFU. The best practice guidelines recommend that a planned intervention aimed at healing of DFUs is most effective in the context of an interprofessional team consisting of wound care nurses and the primary caregiver, working with other healthcare specialists (chiropodist, physiotherapist, endocrinologist, vascular surgeon, psychologist, social worker, etc.) by referring patients to address specific situations that may arise (e.g., infection, vascular
The management of DFU involves obtaining a comprehensive health history to assess underlying causes, comorbidities, and health status, as well as physical examination of ulceration including (a) wound measurement (e.g., length, width, and depth); (b) classification of exudate, odor, condition of peri-ulcer skin and pain; and, (c) identification of infection using clinical assessment based on signs and symptoms and subsequent diagnostic testing, if indicated (CDA, 2013; RNAO, 2013; Wounds International, 2003). Wound care nurses should also determine if the DFU has the potential for healing. For example, while wound healing progress at four and eight weeks is a strong predictor for wound closure at twelve weeks, poor healing progress at four weeks is a strong predictor for non-healing (Flanagan, 2003; Warriner, Snyder, & Cardinal, 2011). Additionally, it is important to include appropriate interventions to improve healing including local wound management (e.g., dressing, moisture balance, debridement), and relief of pressure to the wound (e.g., offloading devices) (National Health and Medical Research Council, 2011; Orsted et al., 2006; RNAO, 2013; Wounds International, 2003).

Although the systematic approach is crucial to improve healing of DFU, successful resolution of the wound requires formal support by healthcare providers to guide the multiple demands of treatment (e.g., advanced dressing, antibiotic, debridement, etc.) and daily SCM by the individuals with DFU (e.g., wearing offloading devices, keeping the dressing dry, changing the dressing at home if it gets wet, identifying early signs of complication, etc.). Thus, a systematic approach to wound care should include not only the expertise of an inter-professional team, but also integrating patients as part of the wound care team and, therefore, as active participants in daily management decisions to achieve the best SCM and optimal outcomes.

2.2.1.1 Local wound management and factors contributing to delayed wound healing.

Considering that DFU wounds do not occur as an isolated event, the principle of wound management to achieve healing involves addressing the multiple factors that contribute to delayed wound healing (Orsted et al., 2006; RNAO, 2013; Wounds International, 2003). These factors include local wound conditions (e.g.,
infection, pressure, necrosis, foreign body, trauma, etc.), internal factors (e.g., age, co-morbidities, smoking, self-care ability, etc.), and environmental factors (e.g., family and clinician support, access to services and resources, etc.) (Guo & DiPietro, 2010; Hess, 2011; RNAO, 2013). Regarding local wound management, evidence does not support the use of one dressing versus another (CDA, 2013; RNAO, 2013). However, to maximize wound healing, the wound care nurse needs to focus first on wound bed preparation to restore a physiologic wound environment (Orsted et al., 2006). Thus, the decision for choosing a dressing will be guided by the characteristics of the wound bed and the principles of a physiologic wound environment such as adequate moisture balance, temperature control, pH regulation, and control of bacterial burden through local (e.g., debridement and antimicrobial solutions) or systemic treatment (e.g., antibiotic therapy) (Orsted et al., 2006; Rolstad, Bryant, & Nix, 2012; Sussman & Weller, 2006).

2.2.1.2 Relief of pressure. The loss of sensation (in the plantar of the feet) resulting from neuropathy prevents individuals from feeling pain (the most important defense mechanism) caused by trauma or injury. It also affects individuals’ ability to perceive the pressure or shearing force under the plantar of their feet (RNAO, 2005). Furthermore, the development of motor neuropathy causes changes in the musculature and shape of the foot. These changes lead to an increase in peak plantar pressure and modify the way a person walks, which leads to the formation of calluses and micro-trauma (Thompson, O’Sullivan-Drombolis, Kuhnke, & Botros, 2014). Thus, offloading and redistributing pressure is a basic principle to both the prevention and healing of an active DFU (Driver et al., 2012), whereas inadequate pressure offloading leads to tissue and/or bone damage and contributes to delay in wound healing of DFU (America Diabetes Association, 2013; CDA, 2013; RNAO, 2013; Wounds International, 2003). Recommended methods for offloading include total contact cast, custom shoes, depth shoes, modifications to shoes, diabetic boots, and forefoot and heel relief shoes (Lavery et al., 2016). Optional methods for offloading are bed rest, wheelchairs, and crutches (Driver et al., 2012; Lavery et al., 2016). However, to be effective, offloading devices should be prescribed and worn by patients particularly when they ambulate (Bus, 2012; Bus, Armstrong, Deurse, Caravaggi, & Cavanagh, 2016a; Bus et al., 2016b; Bus et al., 2013; Waaijman et al., 2013). I argue that to maximize the use of offloading devices, foot care specialists should
inform patients about the variety of offloading options to help them in making informed decisions and address their needs and preferences.

2.2.2 Component 2: The role of the patient in the SCM of DFU. When planning wound care management, wound care nurses should include the patient at the center of all decisions to ensure understanding and agreement with the recommended treatment plan. Thus, wound care nurses need to be aware that patients are responsible for the implementation of the plan of care in their day-to-day wound management. In fact, patients perform the majority of daily foot care tasks including inspection of the feet, use of appropriate footwear to reduce shearing and pressure, foot exercises to promote circulation, application of any medication or skin products as necessary, and daily changes of primary and/or secondary dressings (Rolstad et al., 2012). Patients should be engaged in healthcare decisions to become aware of the consequences of DFU and the need for avoiding self-damaging behaviors such as walking barefoot or using ill-fitting footwear, as well as seeking regular professional foot inspection and nail care (RNAO, 2013; Wounds International, 2003). In fact, for most individuals with chronic disease, SCM is a lifetime task, and patients play an important role in the management of the day-to-day care over the length of the illness (Lorig & Holman, 2003). To improve clinical outcomes, patients’ needs, concerns, and preferences must be heard, and the plan of care should incorporate goals and decisions mutually agreed upon by the client and wound care nurses (Corbett & Ennis, 2013; Holmström & Röing, 2010; Vermeulen, Ubbink, Zwart, Goossens, & deVos, 2007).

Given the complexity of DFU and the impact it causes on people’s lives, individuals living with DFU are required to become experts in applying the variety of self-care activities needed to manage their condition-state changes (Etoria-King et al., 2009). Relatively little research has focused on self-care activities for preventing DFU (Dorresteijn, Kriegsman, Assendelft, & Valk, 2014; Dorresteijn, Kriegsman, & Valk, 2011; Ren et al., 2014; Sae, 2013; Sun et al., 2009; Wilson & Lawrence, 2013; Woodbury, Botros, Kuhnke, & Greene, 2013), and on SCM carried out by patients with active DFUs (Lincoln, Radford, Game, & Jeffcoate, 2008; Viswanathan, Madhavan, Rajasekar, Chamukuttan, & Ambady, 2005). Most patient activities were identified through quantitative studies (Harkness, Spaling, Currie, Strachan, & Clark, 2015;
Riegel et al., 2012; Sund et al., 2014) based on positivism and critical realism with its assumptions of objective external reality. Therefore, I noticed the need to conduct a study that uses an inductive approach to explore patients’ engagement in SCM of DFU and describe the factors influencing their ability to play their central role as self-managers of their condition. Thus the development of a theory informed by patients’ experience in their day-to-day self-care management practices was the focus of this study. Grounded theory was the ideal methodology to guide me toward the development of such a theory. It allowed me to learn from the experience of the participants while I developed this theory (Charmaz, 2014) that explains self-management practices and processes undertaken by individuals living with DFU.

2.2.3 Component 3: Educational interventions. Educational interventions have been used as a means of improving self-care of the feet and reducing the risk of DFU. Research findings have shown that effective educational interventions for people living with diabetes are those that shift from traditional approaches such as didactic methods of delivering information that place patients as passive learners to interventions that focus on patient centeredness and collaborative decision-making (Kuo, Lin, & Tsai, 2014; Norris, Engelgau, & Narayan, 2001). Advocates for shifting the traditional education model of intervention in diabetes have recognized that a gap currently exists between the promise and the reality of diabetes care (Funnell & Anderson, 2004). However, educational interventions to facilitate a collaborative provider-patient relationship and foster patient-centered practices are the key to closing this gap (Funnell & Anderson, 2004). Ultimately, wound care nurses willing to help patients in achieving engagement in their SCM to improve wound healing are expected to work in partnership with patients, to engage in shared decision-making, to assist the development of self-efficacy, skills, and knowledge, and to provide theory-based structured education (Adams et al., 2014; Lindenmeyer, Whitlock, Sturt, & Griffiths, 2010). Yet, educational interventions that focus on improving SCM of chronic wounds, and in particular for individuals with DFU, are still relatively scarce.

2.3 Engagement and Empowerment in the Context of Self-care Management

Patient engagement is linked with individuals’ involvement in all decision-making regarding their health care and daily management of their chronic condition, which is aligned with the concept of
Empowerment (Protheroe, Rogers, Kennedy, Macdonald, & Lee, 2008). Empowerment in the context of SCM is used in a general sense to focus on individual actions and freedom to engage with one’s own health care (Funnell & Anderson, 2004; Funnell et al., 1991; Protheroe et al., 2008). The empowerment concept is closely aligned to the patient-centered care approach that enables individuals to express concerns, needs, and preferences (Holmström & Röing, 2010). It also offers patients autonomy to make decisions as well as to develop control over their own lives (Holmström & Röing, 2010; Kuo et al., 2014). It has been reported that patient-centeredness and patient empowerment are complementary concepts that do not contradict one another. Therefore, patient empowerment can be perfectly achieved through a patient-centeredness perspective (Holmström & Röing, 2010). The literature on SCM also supports the need for empowering individuals to become partners in choosing a pathway to move toward desirable health outcomes and in making decisions about daily healthcare activities (Lorig & Holman, 2003).

General outcomes of patient engagement in SCM have been described as improvement in quality of life, coping skills, symptom management, self-care efficacy, and a reduction in healthcare expenditures and service utilization (Novak et al., 2013). Education and behavioral strategies are part of the process of improving SCM skills to achieve better outcomes (Lorig & Holman, 2003). However, for designing an educational intervention to enhance patients’ engagement in SCM of DFU, a theoretical model needs to be developed that reflects the unique experience of patients that will help to understand the process of engaging individuals in their everyday management of DFU. To date, there are only SCM models designed specifically for individuals living with chronic illness in general (Riegel et al., 2012) or specific types of chronic conditions, such as heart failure (Moser & Watkins, 2008), diabetes (Berhe, Demissie, Kahasay, & Gebru, 2012; Sousa et al., 2004), asthma, (Altay & Çavuşoğlu, 2013), and chronic obstructive pulmonary disease (Kaptein, Fischer, & Scharloo, 2014). However, most of the models have been adapted from previous studies or theories such as Orem’s theory of self-care. Therefore, qualitative approaches, including grounded theory methodology, have not been applied to develop a theory from individuals’ experiences in their daily SCM to explain their journey toward healing of DFU and the contextual factors influencing their ability to implement SCM. There is a need for models informed by patients’ experience in their day-to-day
self-care management practices.

### 2.4 Chapter Summary and Conclusion

This chapter provided a summary of the literature on the systematic approach required to address the complexity of the management of DFU and the link between engagement, empowerment, and SCM. From the literature, a systematic approach to DFU management that involves not only the role of an interdisciplinary team, but also the role of patients in daily activities of SCM, is supported. Evidence exists that suggests an educational intervention is necessary to improve individuals’ abilities and skills to engage in SCM of their conditions. Furthermore, the literature on SCM also reinforces the need for empowering individuals to become partners in choosing a pathway to move toward desirable health outcomes and to make decisions about daily healthcare activities (Lorig & Holman, 2003).

It is important to note that although the literature on management of DFU highlights that individuals play an important role in day-to-day wound care management, authors neither elaborate on how it could be best achieved nor provide a theoretical model that explains patients’ role in SCM from their own perception that would help to enhance patient engagement in SCM of DFU. Therefore, there is a lack of qualitative research exploring the process of SCM, the role of patients in SCM from their unique experience of living with active DFU, and to date a theoretical model depicting the factors that influence SCM of active DFU has not yet been developed. The current study was unique in that it uses grounded theory methodology to help close the knowledge gap by developing a theory that reflects the unique process of engagement in SCM among individuals with DFU.
Chapter 3

Research Methodology

3.1 Overview of the Chapter

This research study is guided by symbolic interactionism and the methodology of grounded theory. I begin this chapter by presenting the reasons for choosing a qualitative approach and grounded theory methodology for this study. Next, I position myself philosophically and provide the reason for choosing social constructivism as the interpretive framework for this research. Subsequently, I provide an overview of grounded theory with its different versions and philosophical approaches and highlight the constructivist grounded theory version developed by Charmaz (2014). I also describe the overall design of this study, and the methodological decisions I made regarding theoretical sampling, setting of the study, recruitment of study participants, and data collection and management.

3.2 Selection of Appropriate Methodology

My central research question concerns the development of a theory that explains the engagement of individuals with active diabetic foot ulcers in the self-care management process. My focus on SCM from the unique experience of individuals living with DFU led me to realize that a positivistic approach following quantitative methods does not apply to my research question. To date no research studies have explored the process of how people with active DFU engage in self-care practices to improve their health outcomes. Most previous studies used quantitative methodologies to evaluate programs and interventions that had been delivered to this patient population (Harkness et al., 2015; Riegel et al., 2012; Sunde et al., 2014), and did not address the process patients use to engage in SCM or the factors influencing their engagement in SCM of DFU.

Three reasons explain my decision to choose grounded theory for this study. First, when seeking to understand human behavior, engagement in, and experience of SCM of DFU management for each unique person and context, the quantitative approach is inadequate to capture and interpret the experiences and
feelings associated with the diagnosis of diabetes and its consequence of DFU. Nor could quantitative methodologies capture the meanings, motivations, and actions associated with the everyday management of DFU. Thus, considering that grounded theory aims to explore, describe, and interpret human problems within a natural context, and with interaction between the researcher and participants (Charmaz, 2014), such methodology aligns perfectly with the aims of this research that describes, explains, and interprets human behavior in daily management of DFU.

The second reason is the compatibility of grounded theory with the role of the nurse. The goal of nursing in delivering healthcare is to assist people with chronic conditions to adopt lifestyle changes, implement SCM practices, and live well with their disease. Nurses are at the forefront providing integrated healthcare services for people with diabetes and their complications.

The third reason is rooted in my need as a researcher for in-depth information about the processes involved in managing DFU from the perspective of individuals in their natural, social, and cultural context. The use of grounded theory is relevant to this study, where individuals with DFU are viewed as social actors in constant interaction with their world and living a unique reality of having a chronic condition about which only they can describe its meaning.

3.3 My Philosophical Assumptions and Interpretive Framework

I understand that the assumption that a researcher brings to his/her study can be related to his/her values, beliefs, experiences, and scholarly community in which he/she works (Creswell 2013). My experience of living in a middle-income country for an extensive period of my life, working as a nurse, and providing wound care for marginalized people with chronic wounds has undoubtedly contributed greatly to shape my view of the world with different realities and possibilities of changes. However, I am aware that assumptions are subject to change over time and over a career. Creswell (2013) states that these changes are usually perceived by the scholar that moves from his/her own field of a discipline and begins to work in a broader field that involves a trans- or multidisciplinary way of working with different contexts and realities.

After exploring the literature and deciding to embark on a grounded theory study, I perceived that positioning myself philosophically was an important part of the journey to conduct this research. I
discovered that determining my philosophical assumptions would help to make a choice between the different versions of grounded theory. This choice would not only need to fit with my worldview and with the purpose of this study, but also reflect directly on the selection of the interpretive framework for this study. Consequently, it would help me to explore and uncover any possible biases or preconceptions that I may carry with me and thus would move me forward as a researcher.

As a researcher and wound care nurse, my philosophical assumptions are more aligned with the social constructivism paradigm used by Charmaz’s version of grounded theory (Charmaz, 2014), and my beliefs resonate with symbolic interactionism, a theoretical framework of grounded theory. Aligned with symbolic interactionism, constructivists view individuals in society as active subjects working collectively and sharing experience to re-construct their world and realities (Lincoln, Lynham, & Guba, 2011).

When using social constructivism as a framework, researchers need to be aware of the subjective meanings of participants’ experience toward certain objects or things. Usually, participants bring a variety of multiple meanings that lead the researcher to look into several categories or ideas. Thus, the researcher’s goals are to rely as much as possible on participants’ views and experience of the situation being investigated (Creswell, 2013). The inquirers using social constructivism must recognize that their own experience and background contribute to shape their interpretation, and therefore, they position themselves in the research process and admit that their own personal, cultural, and historical experience is used to interpret and analyze data (Creswell, 2013). Social constructivism also denies the existence of objective reality and acknowledges subjectivity as inseparable from social existence (Charmaz, 2004, 2006). Rather than beginning with a hypothesis (as in positivism), investigators inductively develop a theory or pattern of meaning (Creswell, 2013). The use of induction is a crucial factor that distinguishes grounded theory from other methods of inquiry. Induction involves starting with data and then moving from the data into more abstract categories through a process of constant comparison.

In constructivist grounded theory, researchers are in constant involvement in the construction and interpretation of data by stressing social contexts, interaction, sharing points of view, and interpreting understanding (Charmaz, 2004, 2006, 2011, 2014). Constructivist grounded theory is known as a
contemporary version of the grounded theory that adopts methodological strategies such as coding, memo-
writing, and theoretical sampling of the classical version (Charmaz, 2014). However, it shifts its
epistemological foundations and takes into account flexible guidelines rather than methodological rules and
requirements (Charmaz, 2014). Thus, constructivist grounded theorists attend to the production, quality, and
use of data to understand and explain the process of interest. Constructivist grounded theorists aim for
abstract understanding of studied life and view their analysis as located in time, place, and the situation of
inquiry (Charmaz, 2014).

3.4 Selection of an Appropriate Version of Grounded Theory

Since its origin, grounded theory has been defined as a systematic yet flexible guideline for
collection and analysis to develop a theory grounded in data (Charmaz, 2014). Glaser and Strauss, two
sociologists who worked in collaboration to develop a grounded theory study in the 1960s, eventually
disagreed with each other on the theoretical foundation of the original grounded theory methodology they
created (Charmaz, 2014). By 1987, the disagreement led to the creation of two first versions of grounded
theory – Glaserian and Straussian (Howard-Payne, 2016). The Glaserian version is based on the original
work and subsequent publications of Glaser. Its ontological roots are based on positivism and critical
realism, with its assumptions on an objective external reality. In the Glaserian version, the researcher is a
neutral observer who discovers data, manages research problems, and objectively interprets data (Charmaz,
2000). The Straussian version of grounded theory happened in the 1990s, based on refinements Strauss
made to the original version in collaboration with Juliet Corbin who had a background in nursing. In their
version of grounded theory, Strauss and Corbin defend an objective external reality aimed toward unbiased
data collection, and proposed a set of technical procedures, including one more step of coding (i.e., axial
coding) and verification. Thus, their position moved grounded theory as a method of verification with
ontological roots in post-positivism. They also proposed to give voice to their participants and represent
them as precisely as possible to discover the conflict between participants’ reality and their own view of the
world (Charmaz, 2000).

In the 2000s, Charmaz, also with a background in sociology, developed another version of grounded
theory – constructivist grounded theory. Although Charmaz adopted the guidelines of classical grounded theory, she did not advocate the positivist assumptions formulated earlier in this methodology. Rather she found a middle ground between positivism and postmodernism. Her goal was to offer accessible and suitable methods for taking qualitative research into the 21st century (Charmaz, 2000; Charmaz & Mitchell, 2001). Therefore the constructivist approach to grounded theory assumes a flexible and exploratory strategy to multiple social realities rather than a prescribed procedure (Charmaz, 2000). It is in part a reaction to Glaser and Strauss’s invitation in the original statement of a grounded theory method for researchers to use flexible approaches in their own way (Sengstock, 2008). Thus, my qualitative study followed the particular grounded theory approach put forward by Charmaz (2014). Her detailed and flexible guideline, in combination with the use of an intensive interview guide, were helpful and useful for me, as a novice researcher in grounded theory, to make insights into concepts, meaning-making, motivations, and actions around SCM of DFU. Since my research is concerned with developing a theory around SCM within a specific context, Charmaz’s middle ground approach was undoubtedly suitable for this study.

3.5 Symbolic Interactionism

Symbolic interactionism is a theoretical perspective first described by George Herbert Mead and eventually named and popularized by his student, Herbert Blumer (Charmaz, 2014; Oliver, 2012). Later Strauss adopted this theoretical perspective as the philosophical underpinning of grounded theory (Charmaz, 2014). Therefore, symbolic interactionism offers to grounded theorists an open-ended theoretical perspective that can inform grounded theory studies. The main reason for that relies on the fact that symbolic interactionism combines theory and method into a coherent, integrated whole without imposing the researcher’s data and ideas onto a pre-determined set of concepts (Charmaz, 2014). Thus, Charmaz states that “symbolic interactionism and grounded theory methods fit, complement and can advance each other” (Charmaz, 2014, p. 277). Symbolic interactionism assumes that interaction is inherently dynamic and interpretive and therefore addresses how people create, interpret, endorse, and alter meanings and actions in their life (Charmaz, 2014; Oliver, 2012). This type of theoretical perspective allows the researcher to understand and interpret “how people act and interact in their daily lives” (Oliver, 2012, p. 411), what
individuals know about their world, and what they believe is an important issue or concern from their own experience and point of view (MacDonald, 2001). In symbolic interactionism, “human beings are viewed as active participants and constructors of the world in which they live and interact” (MacDonald, 2001, p. 117). These concepts were particularly relevant to this study in which I aimed to understand the meanings and the interpretation individuals with DFU give to their experience of living with and managing their foot ulcer on a daily basis.

The premises of symbolic interactionism described by Herbert Blumer include that: a) human beings act toward things based on the meanings they have for them, b) the meanings of things grow from human social interaction, and c) meanings are controlled and modified through interpretive processes used by people as they deal with things they face (Chamberlain-Salaun, Mills, & Usher, 2013; Charmaz, 2014). Charmaz added three more premises to clarify and extend Blumer’s position: a) meanings are interpreted through mutual language and communication, b) the mediation of meaning in social interaction is differentiated by a continually emerging processual nature, and c) the interpretive process becomes explicit when people’s meanings and/or actions become problematic to deal with or their situations change (Charmaz, 2014). Therefore, the premises of symbolic interactionism were a good fit for this constructivist grounded theory study that attempted to understand the experience of individuals with active DFU, and their interpretation of concepts, meaning-making, motivations, and actions taken in daily SCM.

Symbolic interactionism sees human beings as active participants and social actors engaged in practical activities in their world/situation and emphasizes how people undertake these activities (Charmaz, 2014). Although individuals with DFU did not seem aware that their interaction and relationship with a situation/process led them to continual modification of attitudes and actions toward their own care, the combination of symbolic interactionism, social constructivism, and grounded theory methodology were crucial in helping me to uncover, understand, and explain such modifications. In conclusion, this theoretical framework was relevant to my research interest whereby individuals with DFU are also constantly modifying their behavior and actions within their social milieu and in the process reconstructing their reality through daily management of their condition. Therefore, their voices needed to be listened to explore the
factors that have influenced their ability to engage in the SCM activities of their foot ulceration. Finally, the concepts and premises of symbolic interactionism helped to uncover what I saw and how I saw the process, which was facilitated by the intensive interview designed to capture participants’ experience of living with DFU to uncover how they manage their condition daily.

3.6 Ethical Considerations

Regarding ethical considerations for this research, I gained access to a wound care clinic that is a referral center for treating individuals with DFU in the South East Local Health Integration Network (LHIN) in Ontario, Canada, after contacting the physician who is the owner of the clinic and explaining the purpose of this study. The data collection began after approval from the Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (HSREB) (Appendix A). The participants were provided with a letter of information with a detailed explanation of the study and were interviewed after agreeing to take part in the study and signing the informed consent (Appendix B). Confidentiality was assured by using pseudonyms instead of the participants’ real names. The participants were asked to choose a pseudonym before engaging in the interview. They were informed that all information collected would be kept confidential and that the data they provided would be reported only in a way that does not identify them. The participants were informed that they could withdraw from the study at any time during the period of data collection and that the tape recording would be kept in encrypted form in a locked cabinet up to five years and after that would be destroyed. To date, no participants have requested to withdraw from the study.

3.7 The Pathway to the Research Inquiry

3.7.1 Research setting. Once I had ethics clearance (Appendix A) and administrative approvals, the time had come to begin my study. I contacted the wound care clinic, located in Ontario, Canada. This setting was chosen because this clinic provides wound care consultation and treatment service for patients with lower limb wounds including those with DFU. It also receives referrals from clinicians across Eastern Ontario as well as works closely with the Community Care Access Centre team (CCAC) and community wound care nurses, nursing agencies, chiropodists, orthotists, enterostomal therapist nurses, and diabetic
educators to provide multidisciplinary wound care. The wound care clinic has a team composed of five physicians and seven nurses who have developed expertise in lower limb wound care and who have striven to provide wound care according to national and international best practice guidelines. I gained access to recruit participants in this clinic after presenting a summary of my research proposal to the owners of the clinic.

3.7.2 Recruitment Strategy. My first step was to present my research proposal to the wound care nurses and physicians working in the clinic. Wound care nurses provided the invitation letter to potential participants (Appendix C). The response from healthcare professionals truly went beyond the expected. Therefore, on Wednesday April 5, 2017, I received an email from the manager of the clinic stating that they had recruited three participants who agreed to be interviewed on Friday April 7, 2017. On that day, I was at the clinic and interviewed two participants. The third had cancelled the appointment and the interview due to rainy weather. After this first day of the interview a three-week gap followed. I contacted the manager and found out that the wound care nurses were having problems recruiting subjects due to the time it took to provide services while explaining the research to potential participants. Therefore, this recruitment strategy was viewed as a barrier and after discussion with my supervisor we decided to choose a different strategy.

I contacted the owner of the clinic and requested permission to recruit participants in person during their wound care appointment on Tuesdays and/or Fridays when the wound care clinic was open. The owner of the clinic gave me permission and allowed me to use one of the medical offices that was empty (only on Fridays), which served as a private room for the interview to take place in case participants chose to be interviewed in the clinic. This second recruitment strategy worked better with my presence in the setting.

During my first meeting with patients I provided general information about this study and the invitation letter to be read at their convenience. For those interested in scheduling an interview after their next appointment at the clinic, I requested their names and contact information and booked the interview for one hour before or after their appointment as they requested. Those potential participants unsure about the day or time of availability also received the invitation letter with my contact information.
3.7.3 Study participants. This study was comprised of 30 participants with active diabetic foot ulcer, most of whom (n=17) were 65 years of age and older. The majority of the sample consisted of males (n= 20), married (n= 21), and living with family (n= 23). Most participants (n= 26) had completed “some college,” “some university” or “some high school.” Eight participants had completed university and four had completed college. Fifteen participants were retired and seven were employed. Those who were unemployed were dependent on financial assistance from either family or government income support (Ontario Disability Support Program- ODSP).

The decision to recruit individuals with active DFU rather than individuals at risk for developing foot ulceration was made because little research has been done on individuals with active ulceration as well as those at closest risk for limb amputation. Thus, the participants were individuals with active DFU attending the foot care clinic during the period of data collection that started on April 7 and finished on August 8, 2017. Participants in this study were eligible to participate if they met the following inclusion criteria:

1) A confirmed medical diagnosis of a DFU for at least two months, which ensured enough experience to reflect on the process of taking care of DFU.

2) 18 years or older.

3) Able to speak and read in English comfortably and articulate their experience of having DFU.

4) Willing to engage in active self-reflection and self-disclosure about their experience of living with and managing DFU.

3.8 Data Collection and Management

In this section I provide details of the steps involved in the data collection and management of this grounded theory study. Constructivist grounded theory offers guidelines rather than step-by-step rules for the research process (Charmaz, 2014). In grounded theory studies it is strongly recommended that the researcher approach data collection and analysis simultaneously and in a non-linear way, which allows the data collection to inform analysis and focus on constructing the theory (Charmaz, 2014; Hallberg, 2006). Data collection involves initial and theoretical sampling and may be collected from several sources such as
interviews, memo writing, observations, documents, or from a combination of these sources (Charmaz, 2014). The aim is to obtain rich, detailed, and focused data to provide a broad view of the process and solid materials to consolidate my analysis and facilitate my understanding of the process of engagement in SCM of DFU to develop a substantive theory. Rich data uncovers the participants’ views, interpretations, feelings, intentions, and actions as well as the structures and contexts influencing their experiences (Charmaz, 2006).

3.8.1 Initial and theoretical samplings. Initial and theoretical samplings were used to collect data for this study. Initial sampling is considered the first stage of data collection in grounded theory studies. It helps the research to get started by establishing criteria and planning how to access data (Charmaz, 2014). For instance, before I entered the field I determined inclusion and exclusion criteria, the population, the setting of the study, and the interview guide. Therefore, I started first with initial sampling by seeking variations in and heterogeneity of participants’ experiences. Later in the simultaneous process of collecting and analyzing data, the initial sampling was followed by theoretical sampling. While the initial sampling helped me to get started, the theoretical sampling guided me to the next step toward saturating each emerging category/concept (Charmaz, 2014; Hallberg, 2006). It is important to note that the goal of theoretical sampling was not to increase the number of informants, but to collect pertinent data to elaborate and refine categories of the emerging theory (Charmaz, 2014; Hallberg, 2006). The logic of theoretical sampling distinguishes grounded theory study from other types of qualitative inquiry. Theoretical sampling was essential to this grounded theory study because it guided me to take better direction and prevented me from becoming stuck in out-of-focus analyses as stated by Charmaz. By following this process I progressively recruited participants according to emergent categories (Charmaz, 2014).

3.8.2 Sources of data. Data was collected using several methods including intensive interviews, field notes, and researcher’s journal. The detailed narratives from each method of data collection provided a sizable description. The aim was to obtain rich and detailed date that would provide solid material for profound analysis. Rich data revealed the participants’ experiences, views, feelings, intentions, and actions as well as the contexts and structures of their experiences (Charmaz, 2014). The various sources of data
collection contributed to my understanding of the process of self-care management for participants living with DFU.

**3.8.2.1 Intensive semi-structured interviews.** Intensive semi-structured interviews are one of the most common data collection methods in grounded theory studies and are an effective method for interpretive theory building (Charmaz, 2014). In grounded theory studies it allows an in-depth exploration of a particular topic and goes beyond a superficial conversation (Charmaz, 2006). In this type of interview the participants are at the center of the interview and thereby active respondents to give meaning and understanding of their experience (Hiller & DiLuzio, 2004). A constructivist approach views interviews as an interactive process between the interviewer and interviewee, whereby through active collaboration in a meaning-making experience, a place for understanding rather than explaining is allowed, and hence gives rise to the production of knowledge (Charmaz, 2014; Hiller & DiLuzio, 2004). Thus, instead of being used merely to retrieve information and describe experience, the interview becomes a tool for exploration of “emergent understanding, legitimation of identity, and validation of experience” (Charmaz, 2014, p. 91).

Grounded theory studies rely on collecting data to develop abstract conceptual categories and advance the theoretical analysis. Therefore, the content of the interviews demands careful assessment throughout the study process, which helps to construct theoretical plausibility, directions, centrality, and adequacy (Charmaz, 2014). Thus interviewing gives the interviewer more control over generating data than in most other forms of qualitative data gathering (Charmaz, 2014).

Constructivist interviewers focus on the language and conversation to encourage participants to reflect on their experiences in a productive way to advance theory construction (Charmaz, 2014). To explore participants’ perspective and their personal experience with the phenomena of interest, I practiced the following recommendations described by Charmaz (2014): 1) selected participants who had first-hand experience with SCM of their DFU; 2) ensured in-depth exploration of participants’ experience; 3) adopted an intensive semi-structured interview guide with open-ended questions; 4) focused on obtaining detailed responses to understand participants’ perspective, meaning, and experiences; 5) asked the same questions in the same way to all participants to ensure consistency and logic; and 6) during the interview encouraged
participants to talk while I listened and learned about their experience of living with and managing DFU.

One-to-one interviews were conducted with participants using an intensive semi-structured interview guide developed from and based on the existing literature on self-care and management of DFU, on my experience as a wound care nurse caring for this population, and also informed by Charmaz’s constructivist grounded theory approach (Charmaz, 2014). I developed a first interview guideline that was used with the first five participants. After this experience, I gained insights into different approaches to understanding the process of self-care management for this population. After discussing with my supervisor my impressions and reviewing the transcripts of those interviews, we set a time to modify the research questions and interview guide. The second version of the intensive interview guideline also organized the questions by topic to avoid repetitions and facilitate data entry in NVivo software. This new interview guide also helped me to re-enter the research setting with different perspectives about the process. It provided better direction, confidence, focus, and clarity for exploring the process of engagement in SCM of DFU, which also guided the development of the substantive theory. Below I provide some examples of the interview questions used in my second interview guideline with some probe questions:

1. Tell me about the time you were diagnosed with diabetes.

2. How have you taken care of yourself since you found out about your diabetes?

   **Probe:** Has anything changed? Do you go to the Internet to learn?

3. What kind of support have you gotten to help you to take care of yourself since you were diagnosed with diabetes?

   **Probe:** Who helps you? In what ways? What does it mean to have help?

4. Tell me about the first time you found a wound on your foot.

   **Probe:** How did you react?

5. Where did you first go to get help with your wound?

   **Probe:** What were you told about how to take care of your wound?

Having an interview guide with broad (open-ended) and non-judgmental questions enabled me not only to explore the process of engagement, but also to move to another topic when the participant had
already mentioned the answer to a relevant question. The open-ended questions also encouraged unimagined statements and stories to arise. For instance, a significant number of participants stated they were surprised with how many things they could recall from their experience of living with and taking care of DFU. While others did not provide enough detail of their experience in taking care of their wounds, they focused mostly on the personal struggles in navigating in their social world with diabetes and DFU or on the impact of DFU on their lives. Charmaz (2014) states that the combination of how questions are constructed and conducted help to achieve a balance between making the interview open-ended and focused on significant statements.

The constructivist grounded theory’s author recommends inserting sympathetic *uh huhs* and some clarifying questions or comments to keep the stories coming when interviewees can and want to disclose them (Charmaz, 2014). To this end I included probing questions such as: *Could you tell me more about that? What was that like? Can you tell me more about this experience? Is there anything you wish to add? Could you give me an example?* Questions such as these were very helpful and essential to the interview process because they helped me to gather more information, especially when the participant did not provide details about specific information. Additionally, probing questions helped to certify that the key issues were addressed and the flow of the interview was maintained naturally (Whiting, 2008).

To explore individuals’ ability to engage in SCM of DFU and understand their process of engagement this interview was conducted in an interactive way that allowed participants to reflect upon their experiences. The number of encounters with participants did not exceed two in person and two to three followups over the phone. The length of the interviews varied from 45 to 95 minutes. Only one participant chose to be interviewed at his office during lunch time. At the conclusion of every interview, each participant was given a thank you card and $15 to cover expenses for travel and food.

3.8.2.2 *Field notes.* I wrote field notes following each interview to record my reflections and what I learned during the interview (Strauss & Corbin, 1990, 1998). Field notes enable me to have a place to document my impressions about the participants’ experiences and my reactions, or systematic questioning of pre-existing ideas related to my previous experience and what I said in the interview (Strauss & Corbin, 1990, 1998). The field notes helped me to document important description of data such as the date, time,
actions, behaviors, type of shoes or offloading devices worn by participants as well as side conversations.

The following is a good example of my field note:

**Field note**

Shelby was waiting for me in the foot care clinic’s waiting room. She was watching TV when I approached her and invited her to go to a private room for the interview. She was wearing an offloading device on the affected foot (left) and a sandal on her unaffected foot (right).

She slightly smiled when I approached her and at first impression did not seem keen to talk about her experience of having and managing diabetes and diabetic foot ulcer. Shelby, a 52-year-old female participant, had been diagnosed with type 2 diabetes for fifteen years after having had signs of complications. She stated, “I lost my eyesight. I couldn’t see. I went to the hospital, I was diagnosed with diabetes. My blood sugar was twenty-nine something at the time.” Shelby was frustrated because at that time she did not have a family doctor to fill her prescription and it took about two- and-a-half years to get one. Shelby disclosed that she had fallen off the track many times and does not consider herself a very good diabetic because she does not take her diet seriously, doesn’t exercise, and is not able to quit smoking. The first time she found an ulcer on her foot she tried to treat it herself by applying over the counter medication. However, it got worse and she went to an after-hours clinic where the doctor prescribed an antibiotic that did not work well. She continued having an infection for over two months, which made her feel frustrated. Then one day she decided to go to her family doctor and she got a referral to the wound care clinic. She said the infection gets better and she is discharged from the wound care clinic, but after two or three weeks it comes back again in the same location of her left foot. During her interview Shelby also disclosed that her ulcer keeps her family close to her in a certain way because they give her more attention and show concerns about her health, which makes her feel important. Another frustration she is facing is to buy another kind of offloading device because her health insurance is not going to pay and she can’t afford it. Shelby’s motivations to keep taking care of her foot and coming to the wound care clinic are due to both fear of losing her foot or leg and because her family needs her, especially one daughter that has been divorced and has children to raise by herself and Shelby wants to be able to support her going through this experience in life. In regard to her engagement in the process of taking care of her foot ulcer she tries her best to follow instructions given by the wound care team. In summary, she was very aware that she needs to quit smoking, but feels impossible to do that without support. At the end of the interview Shelby was smiling and happy, saying she was not sure of what to say during the interview or if she really wanted to talk about her experience, but she really liked it as it helped her to gain insights into her life (May 26, 2017).

**3.8.2.3 Researcher’s journal.** I also used a researcher’s journal as an additional methods to collect my personal reflections after each interaction with research participants. Throughout the study process, the researcher’s journal helps to detail thinking about the research area and how it might influence analysis of the data (Strauss & Corbin, 1990,1998). This journal served as a place where I stopped to write my ideas and interpretation of participants’ reactions to the invitation to participate in the research or their reactions to some questions (e.g., support and resources needed to take care of diabetes and DFU). It also helped me to
understand that individuals with DFU sometimes face many personal and health issues that may affect their engagement in self-care management. An example of my reflective journal is described below:

**Reflective journal**
This is my personal reflection after I have interviewed Ms. Shelby. After a week of trying to book an interview with Shelby I finally had a chance to meet her in the wound care room while she was having her ulcer debrided by her usual assigned nurse. My first impression after talking to her was that she was afraid of talking and therefore avoided eye contact with me in the wound care room. At the beginning of the interview she again avoided eye contact. I learned from her that she was afraid of being judged for not being always on top of her wound care. She shared that she had been questioned a lot about being a smoker and having an ulceration, but that it was a challenge for her to quit. I definitely learned that she was facing many personal and health issues that may have prevented her from engaging in self-care management. Shelby was seen as a strong person by her family, but I had an impression that she was tired of being strong and carrying everything on her back. It also seemed to me that her health was not as much a priority as was her family. My impression was that she has gone through many difficult situations in her life such as depression that prevented her from keeping up with the management of her ulcer and general health such as diabetes control. Shelby’s experience of having many recurrences of DFU taught me that it is easy to lose hope. Being hopeless led her sometimes to not take care of her ulcer, miss some wound care appointments, and resign being seen as noncompliant. I also learned that a person who has had DFU for long time needs more support to keep up with self-care practices than those that have had it for short time. Although Shelby was aware that she needed to be more engaged in self-care of her ulcer, my feeling was that she had been trying her best and needed more support both clinically and socially. This interview was one of the best I had, not only because she was a unique person but also because although patients play an important role in their SCM and healing of their wounds, their success all depends on how they have been affected by their social context while living with a health issue and how a health issue has affected their social context. (May 26, 2017)
3.8.3 Data management. Recorded interviews were audiotaped by me and transcribed verbatim by a professional transcriptionist. While the literature contains recommendations for only transcribing parts of the data considered important, in my study, entire interviews with research participants were transcribed so that I did not risk losing something that might later be recognized as significant. I organized the raw data chronologically into files on an encrypted computer; data files were labeled according to the date of the interview and the participants’ pseudonyms. Each interview was password protected. Data from transcripts of the participant interviews, examination of personal field notes, and memos were included in the data analysis process to facilitate development of the substantive theory. The information can be accessed only by my supervisor and myself and will be kept in a locked cabinet in my supervisor’s office at Queen’s School of Nursing for up to five years per Queen’s HSREB guidelines (n.d).

The information obtained from the intensive interviews was entered into the N-Vivo© (Version 11.4.1) computer-aided qualitative data management software, which was essential to assist in the management and analysis of such robust data. A total of 732 transcribed pages from 30 intensive interviews were entered into NVivo 11.4.1 and another 87 transcribed pages were entered after the follow-up interviews over the phone to validate and clarify data. The number of pages in each transcribed interview ranged from 15 to 56 and the length of the interview ranged from 36 minutes and 41 seconds to 1 hour and 42 minutes. NVivo was used to assist with the two types of coding in constructivist grounded theory, open and focused coding. Codes were organized into nodes within NVivo 11.4.1. Open coding occurred with identifying, naming, and categorizing the data. The idea-by-idea coding yielded 529 codes. The conversations in the interviews covered a broad variety of topics such as the experience of having and managing diabetes and the length of time of finding the first DFU. As stated previously the open codes were identified by action or in vivo words as recommended by Charmaz (2014). To organize them into a more manageable format, I grouped them into nodes within NVivo 11.4. and assigned titles to the nodes according to the topic of the intensive interview guideline that later became categories.

Following open coding, I re-examined all codes and quotations and combined codes into those categories and collapsed or deleted redundant codes. Through this process of focused coding, I employed
the constant comparative method (Charmaz, 2014), comparing code to code, code to category, and category to category to find similarities and differences that could inform the analytical process. I also stopped any time to write memos within NVivo related to what I was seeing and my impressions, insights, and ideas. After this process of focused coding was completed, and some redundant codes were collapsed into categories, advanced memos helped to define and refine conceptual categories and to adopt certain categories as theoretical concepts. Therefore, about 250 codes were grouped mostly into the five phases and categories of the core category “The Journey Toward Engagement in SCM,” whereas others were grouped into the six contextual factors influencing SCM of this research’s participants. It is important to highlight that when more than one idea was implied by a code, it was grouped in more than one category.

Beside assisting in the coding process and providing the format for coding the data, the NVivo 11.4.1 also helped in storing the categorized data, memo-writing, and analyzing the frequencies found within the data. This was when focused codes and categories began to emerge from the collected data. As the categories developed the analytic process became more elaborate and similarities and differences between participants’ experiences were identified. This coding process and the software assisted in the development of concepts, categories, and boundaries within the research data. These analytic codes and categories also became the foundation of the follow-up interview questions. A conceptual relationship between these categories was discovered and the theory started to emerge inductively from this process (Charmaz, 2014). The theory with its components are represented through conceptual models and confirmed with a literature review to compare the research findings to current research.

3.9 Data Analysis

This section presents a description of the methods I used throughout data analysis, drawing on the guidance of Charmaz (2014) to code and integrate theory. Data analysis in grounded theory study begins with coding. Initial coding was the first level of coding and was used to label and form early minor conceptual categories, followed by focused coding and driving analysis toward theoretical category development. Throughout the analysis a flexible approach was utilized, as is normal practice within
constructivist grounded theory (Charmaz, 2014). The following section provides a transparent overview of how findings were developed to account for the final theoretical representation described in Chapter 4.

Analysis of the transcripts of participant interviews followed Charmaz’s approach of grounded theory coding, which consists of at least two phases: initial and focused coding (Charmaz, 2014) that are subsequently detailed. Charmaz stated that through coding “you define what is happening in the data and begin to grapple with what it means” (Charmaz, 2006, p. 46). In this study, a substantive grounded theory that is a product of emergent processes occurred through data collection, analysis, comparative methods and interaction (Charmaz, 2014). The full processes were difficult to document in a form that fully captures its complexity and the abstract nature of parts of the work. The following sections on analysis of the data provide a written account of this part of my research journey. Several phases occurred in the development of concepts and theoretical frameworks (Charmaz, 2014):

1) Creating and refining the research and data collection questions
2) Data collection and initial coding
3) Initial memos raising codes to tentative categories
4) Further data collection and focused coding
5) Advanced memos refining conceptual categories—adopting certain categories as theoretical concepts
6) Sorting memos
7) Integrating memos and diagramming concepts
8) Conceptualizing
9) Writing the first draft

Figure 3.1 outlines the steps involved in this grounded theory study. This figure is my own elaboration inspired by many online diagrams of qualitative methodology and in particular constructivist grounded theory by Charmaz (2014).
Data analysis in this grounded theory study began with the first interview and was conducted alongside data collection through a “fluid, interactive and open-ended” process according to the procedure of constructivist grounded theory analysis described by Charmaz (2014, p. 320). This type of analysis allowed a progressive focusing of interviews to uncover the process of individuals’ engagement in self-care management of DFU and factors affecting their ability to take care of themselves. The sequence of theory development began with substantive coding, which includes open (line-by-line, word-by-word or idea-by-idea) and focused coding (Charmaz, 2000, 2006, 2014; Glaser, 1992, 1998). The open coding helped me to interpret the phases of the process through the views of participants’ realities. The result of this open coding coupled with successive level of abstraction through comparative analysis led to the inductive generation of the substantive categories (Charmaz, 2014; Glaser, 1978). Another distinctive characteristic of grounded theory is the constant comparative method, which is seen as the core of grounded theory analysis (Charmaz, 2014; Hallberg, 2006). This means that each part of the data such as emerging codes, categories, properties, and dimensions as well as dissimilar parts of the data were continuously compared to explore variations,
similarities, and differences in data (Charmaz, 2014; Hallberg, 2006). Thus, this process of coding and comparing was used throughout to guide my analysis.

3.9.1 Data coding procedures. Coding is the crucial link between data collection and development of an emergent theory to explain these findings. The coding process helped me to define what was happening and to deal with meanings and description of the process described through the lens of research participants. According to Charmaz (2014), grounded theory coding creates the basis of the analysis and therefore, it is beyond the beginning because it shapes the analytic frame to build the analysis toward theory development. To help to find the answers to my research questions and to develop a substantive theory of engagement in SCM for individuals living with DFU, coding data was undertaken according to the process described by Charmaz (2014). The process of coding in grounded theory studies involves at least the following two hierarchical phases: 1) an initial phase (open) line-by-line coding, and 2) a focused phase (selective and conceptual coding) (Charmaz, 2014) as described next.

3.9.1.1 Open coding. Grounded theorists start coding as the emerging data is collected. Thus, open coding is the first step in grounded theory analysis and helps the researcher to continue to be open to the data and to see distinctions in it. This form of coding requires examining each of the transcripts from the participants’ interviews, as well as their stories, line by line (Charmaz, 2006). By coding early in-depth interview data, the researcher gain a close look at what participants say and likely battle with (Charmaz, 2004). Thus, in this study, open coding helped me to identify implicit concerns and explicit statements, and engaging in open coding since the first interview helped me to keep focused throughout all data collection and analysis.

According to Charmaz (2006), line-by-line coding may be the most common type of open coding among grounded theorists. I intended to code line-by-line for the initial coding, but due to the nature of the interviews and robust responses, it became clear that line-by-line was not helpful. Rather, I took more of an idea-by-idea approach to open coding and coded interviewees’ responses with more than one code if more than one idea was implied within the response. For example, participants’ responses to my question about how they take care of their foot ulcer resulted in the development of many concepts ranging from the need
to have support from family or healthcare providers and descriptions of their self-care actions and limitations, to more deeply thoughtful ideas about the process of engagement in SCM. In this phase of coding, the words or codes assigned to each response were action words describing thoughts, actions, meaning, and feelings, for example. If appropriate, participants’ own words (in vivo coding) or gerunds (words ending in *ing* that reflect process rather than topic) were employed to keep the codes as close to the data as possible. This open coding identified the participants’ perceptions of not controlling diabetes very well, which was coded with participants’ own words of “being a bad diabetic.” The excerpts below indicate text that was coded as “being a bad diabetic” from interviews in the early stages of coding. The code “being a bad diabetic” was later elevated to a concept.

**“Being a bad diabetic”:**

*I’m a bad diabetic.* (Junior).
*I’m not a very good diabetic, that’s for sure.* (Shelby)
*Very little. I’m bad.* (Sam)
*I still don’t do a heck of a lot of it.* (Finn)
*I know I am a strange diabetic.* (Duke)

Eating unhealthy food:

*I stopped watching what I ate…* (Jona)
*I used to eat a lot of fast food… a lot of Pepsi.* (Kobe)
*I was just pumping the sugar in with the Coke.* (Duke)
*It was just the amount of food that I was eating.* (Charlette)
*I have an addiction to food and I’m an emotional eater.* (Maverick)

Having insufficient physical activity:

*I wasn’t getting up and moving around much.* (Anita)
*I do not do much exercise.* (Charlette)
*I need to try to do a little more exercising and walking.* (Paul)
*Exercise is virtually out of the question.* (Junior)

Smoking and drinking alcohol:
Smoking would be my number one thing…(Kobe)
I smoke two packs a day. (Junior)
I’m not ready to quit smoking. (Janet)
I started drinking alcohol again. (Sam)
I never smoked but I drank a lot of beer. (Butch)

In summary, participants’ perception of “being a bad diabetic” was related to not following a strict diet, not doing exercise, and continuing smoking or drinking alcohol. This coding process allowed me to explore the processes of engaging in SCM by using the words of the research participants that describe and categorize their experiences of having and taking care of their DFU. Eventually, these codes and categories were utilized to develop “generalizable theoretical statements that transcend specific time and places and contextual analyses of actions and events” (Charmaz, 2006, p. 46). During this initial coding, I perceived that the number of codes do not have a special significance, as this was an interactive process used to uncover the data. For example, many of these codes were synonymous with each other but coded with slightly different names such as “keep an eye on my ulcer” and “inspect it regularly.” I also found this tip of using action words very helpful to a novice in grounded theory study. Open coding takes form with the different sources of data, which allows a start to define and categorize the data (Charmaz, 2000).

In the process of coding I also compared events, actions, and interactions reported by participants with similarities or differences in their experience that were organized into categories. For example, while a significant number of participants stated that DFU has a great effect on their lives such as preventing them from walking (12/30), another significant group said it does not impact their lives too much (8/30). Thus, after following these strategies closely I observed that I was immersed with the process, which provided me direction and great understanding to develop theoretical categories.

3.9.1.2 Focused coding or selective coding. Focused coding is the second stage of analysis in the Charmaz (2006, 2014) model of grounded theory. Focused coding was used to synthesize and explain larger segments of data. This type of coding is more directed, focused, and conceptual than the initial coding process. The purpose of focused coding is to select significant codes or concepts from the initial codes to sort and synthesize a large portion of data (Charmaz, 2006, 2014). Because this type of code summarizes
and shapes what the researcher has already highlighted a priori, it advances the theoretical direction of the study. Thus, focused coding is more conceptual than the open coding (Charmaz, 2006, 2014; Glaser, 1978). Although focused coding is straightforward and happens rapidly, it means more than only selecting and going forward with the code. Through the process of constant comparison and after the initial coding phase, codes were compared with codes and some of them were collapsed into one code that best described them. For instance, in relation to the code “being a bad diabetic” I looked at all the sources of data to see how each participant spoke about taking care of diabetes. The constant comparison method of code with code, statement with statement, and so on helped me to refine the code of “being a bad diabetic.” I was led to look at the factors associated with “being a bad diabetic”; the effect of being a bad diabetic on the development of first DFU; the ways the participants responded to their experience of controlling diabetes; the activities they used in daily life to control diabetes (e.g. diet, exercise, taking oral medication or insulin); and the support they had in place to help them in taking care of diabetes. The initial code of “being a bad diabetic” was then elevated as a concept of the category titled: “Perception of Illness” in Phase 1 of my theory described in Chapter 4.

Following Charmaz approach, I used categories to explain the core category “The Journey Toward Engagement in SCM” and showed the link between them in the process of engagement in SCM of DFU through the lens of participants. As Charmaz states, this process of using core categories and categories and links reflects how I made sense of data. Therefore, after focusing and collapsing codes and elevating them into concepts I placed them into categories that best described a group of concepts to explain the theory and the contextual factors affecting participants’ journey toward engagement in SCM of DFU.

A category is a classification of concepts or themes grouped together to create a higher level of concept and aims to make sense of what the participant has said. Categories clarify ideas, events, or processes in the data and are tools to build context (Charmaz 2006, 2014). Concepts are abstract ideas related to the data and have specifiable properties and limitations. For constructivist grounded theorists, concepts provide abstract understanding of the process of interest. Concepts are located according to the conditions of their construction in time, place, individuals, and the context of the research process.
The initial categories were labeled with temporary titles because, in keeping with the grounded theory method, it was important to remain open to further analytic possibilities. Constant comparative analysis, conceptualization, and literature review resulted in some modifications in the initial coding and a need to collapse redundant codes or to elevate them at the conceptual level. For example, the early codes “initial diagnosis” and “noticing diabetes symptoms” were further developed to “discovering diabetes” and also became part of the category “Perception of Illness” in Phase 1. This was in recognition that part of the process of engagement in SCM would have occurred upon to the discovery of diabetes.

3.9.2. Constant comparative analysis. Constant comparative analysis is a key method in data analysis of grounded theory studies. This method was first developed specifically for grounded theory to make analytic distinctions at each level of data analysis. The constant comparative method involves comparison of data with data to find similarities and differences (Charmaz, 2014). This constant comparative method helped me to understand the process embedded in participants’ journey toward engagement in SCM instead of imposing my preconceived ideas related to how individuals with DFU engage in the process of taking care of their ulcer. This inductive method of analysis that is ideal for constructivist grounded theory studies helped me to unfold meanings and experiences and to develop concepts from data while analyzing at the same time (Charmaz, 2014). Therefore, meaning, motivations, actions, and reactions of the participants were drawn from data after it was critically analyzed. Memo writing was also associated with this comparison process; and I wrote a number of memos about my interpretations and analysis throughout the process.

The constant comparative analysis process in this study included four stages. The first stage involved coding and comparing each interview. For example, I compared interview statements (e.g., the ability to manage diabetes with the ability to manage DFU) and incidents (e.g., reactions of seeing a foot ulcer with the first action taken after noticing this issue) within the same interview and with different interviews. The second step included comparison of codes with codes, codes with categories, and categories with categories. Coding the information and organizing them into categories helped to identify patterns...
within data and provided a foundation for concepts to emerge from the coded information. The third step involved the analysis of the concepts for identification of the core category and theory development. In this stage the theory materialized from the gathered concepts. The fourth and final stage in constant comparative analysis was writing the concepts, sorting them into categories, and comparing them with the literature. During this process, the data were constantly sorted in regard to participants’ perceptions and experiences to look for concepts that became the foundation of the theory. The benefit of using this constant comparative method was found to be important to understand the processes involved in the journey toward engagement in SCM through the lens of participants. The raw data found in each participant’s interview was examined and through a labor-intensive analysis produced an inductively derived theory that explains the process of engagement in SCM of DFU.

3.9.3. Memo-writing and conceptual categories. Memo-writing was used during data analysis to support the process of coding and development of categories toward generating a substantive theory. Memo writing is a pivotal step between data collection and writing drafts of analysis in grounded theory studies. This is where researchers stop and analyze their ideas about their codes and emerging categories (Charmaz, 2014). Hence it is essential to write the memo immediately after reading and coding the interviews. Thus, notes of my thoughts, insights, and ideas about what I saw in the data were written down in the NVivo sources with the purpose of helping to capture and explore similarities and differences to sort into categories. As Charmaz (2014) states, title your memo as specifically as possible to identify what you are talking about. Thus, every time I wrote a memo I started by providing a title to it and then writing my insights and ideas and including raw data into most of them.

Grounded theorists acknowledge that the sorting of memos helped them in the generation of the theoretical outline or conceptual framework for the study (Charmaz, 2014; Ford, 2010; Gorra, 2007). This process also assisted me in looking for similarities and connections within the data, where to locate codes and categories, and in the resultant theoretical higher order of conceptualizations. Charmaz states, “Memo writing forced me to stop and engage different categories — my memos formed a place for exploration and discovery around the ideas I had about what “I had seen, sensed, heard and coded” (Charmaz, 2006, p. 164).
The same happened with me. Throughout my data coding I needed to stop many times to write my ideas and insights while reading and coding idea-by-idea or engaging in focused coding to understand the processes associated with The Journey Toward Engagement in SCM from participants’ experience of having and taking care of their DFU.

Charmaz emphasized the practical importance of labeling memos as specifically as possible. That helped me to organize my memos and to identify what I was interpreting from the data, which in turn served to guide my analysis. Although memos may serve different purposes at different points in the research, Charmaz advises that the following be included in a memo: 1) Define each code and category by its analytic properties; 2) Spell out and detail processes subsumed by the codes or categories; 3) Make comparisons between data and data, data and codes, codes and codes, codes and categories, categories and categories; 4) Bring raw data into the memo; 5) Provide sufficient empirical evidence to support your definitions of the category and analytic claims about it; 6) Offer conjectures to check in the field settings; 7) Sort and order codes and categories; 8) Identify gaps in the analysis; and 9) Interrogate a code or category by asking questions of it (2014, p.171).

Using memo-writing was also very helpful in this study to create an interactive space where I could maintain a conversation with myself about the data, codes, ideas, and intuitions and lead the development of my analysis and theory construction as stated by Charmaz. An example of my memo-writing is provided below:

**Memo**

After coding some interviews of participants such as Junior, Butch, and Toby who have faced many consequences of diabetes, I perceived that they see the disease of diabetes as a “death sentence” and they seemed prepared to lose their life to diabetes one day. They also admitted that they were not a “good diabetic” because they did not follow a strict diet or manage it as they were told. Another common thing among them was that they had not taken it seriously since the beginning, and that the lack of SCM knowledge and support led them to not being able to keep up with it on a daily basis. Now they seemed to accept that they are going to die due to the consequences of diabetes and are preparing their loved ones to accept this diabetes outcome as well. On the other hand, those who had faced less severe damages of diabetes seemed to be aware of the consequences of it to their body, but still felt that they could control it and live well and long with their disease. (July 31, 2017)
3.10 Theoretical Sufficiency

In grounded theory data collection is terminated when theoretical saturation is accomplished. In this study it occurred when themes and sub-categories in the data became repetitive and redundant such that no new information could be gathered by further data collection (Charmaz, 2014; Polit & Beck, 2014). Constructivist grounded theory differs in the use of this commonly held term of data saturation. For this study, data saturation was achieved when two situations occurred. First, the theoretical categories were robust and full of data (Charmaz, 2006). This occurred when no new properties for the core category “The Journey Toward Engagement in SCM” was obtained. The theoretical saturation was aligned with the theoretical sampling technique used during the research to guide the need for additional interviews and follow-up interviews and gathered additional information regarding emerging categories. These follow-up interviews and new interviews continued until no new properties of the patterns emerged to inform theoretical categories full of strong data.

Second, data saturation was achieved when the data gathered accounted for the patterns seen in the categories and findings (Charmaz, 2014). This type of data saturation not only established firm patterns in the data, but also developed theoretical relationships and the understanding of participants’ trajectory toward the process of engagement in SCM of DFU. Therefore, in this study data saturation occurred when new data did not alter the concepts that had been discovered. Instead, new data only continued to confirm and promote the well-known patterns. In summary, data saturation in constructivist grounded theory study is better established with high-quality interviews instead of large amounts of interviews (Charmaz, 2006). For this study data saturation occurred after I had interviewed 30 participants with active DFU. For this reason, every attempt was made to gather as much information from each participant as possible about the process of living with and taking care of their DFU.

3.11 Theoretical Sorting

Theoretical sorting is the last stage of the research process of writing a grounded theory study whereby the researcher sorts memos in preparation for writing the theory. During this process the researcher
can generate more memos to increase the conceptual level and integration of emergent theory. In this phase, the researcher has often finished interviews and coding to the point of saturation (Glaser, 1998). Sorting, diagramming, and integration of memos were an interrelated process. This process helped me to find my direction toward the theory building. The sorting of memos served the emerging theory and provided means for creating and refining theoretical links (Charmaz, 2014). Diagraming offered concrete images of my ideas and helped me to visualize and show the representation of the properties of the theory, their relationships, and how each property fitted together. Sorting and diagraming provided me with a logical way for organizing my analysis and integrating the properties of the theory (Charmaz, 2014). The sorting, comparing, and integration of memos was a bit complicated by the fact that more than one process was identified and several categories were present – so it was not a clear-cut process (Charmaz, 2006). I tried several different sorting strategies, drew numerous diagrams, and compared categories to categories many times until I had a good visual representation of their links and fit together. To that end, I followed the following recommendation provided by Charmaz to assist me with this process (Charmaz, 2014):

- Sort memos by the title of each category
- Compare categories
- Use the categories carefully
- Consider how their order reflects the studied experience
- Think how their order fits the logic of the categories
- Create the best possible balance between the studied experience, the categories and the theoretical statement about them.

The practical activity included trying several different arrangements of memos using diagram/model with the title of the different categories and using the NVivo word frequency and maps to visualize relationships between different categories and concepts. Considering that there were numerous categories, the process of sorting and diagramming needed to demonstrate how the different categories fit together and connected their relationship with the process of engagement in SCM of DFU.
3.12 Conceptualization

Conceptualizing is essential to achieve theorizing. Thus, researchers play an important role in moving from the coding stage of analysis to raising main categories to concepts (Charmaz, 2014). Following Charmaz’s recommendation in this grounded theory study, the most substantial categories become concepts of the theory. The process of choosing and determining which categories could be raised to theoretical concepts required identification of categories that represented the data most effectively and that supported “substantial analytic weight” (Charmaz 2006, p. 139). The categories that were raised to concepts were seen to have “theoretical reach, theoretical centrality, generic power and relationship with other categories.” The process of raising higher level categories to concepts included exposing them to “further analytic refinement and involved presenting their relationships to other concepts” (Charmaz, 2014, p. 247).

The identification of categories began with the initial coding process (Charmaz, 2006). During this process I coded data into a variety of categories that best represented the data. As I advanced with my initial coding I perceived two levels of categories: major (higher level) and minor. Major categories presented high frequency of mention, and were connected to many other emergent categories. The process of choosing major categories to elevate them to concepts requires that the researcher remain open to exploring the substantive studied area (Holton, 2007). Therefore, it is important to recognize a potential danger of choosing major categories before finishing data collection and analysis. The analytical process that happened over time and moved from initial coding to focused coding helped the process of determining which categories were connected to others and thereby which could be elevated to concepts. Concept development was essential to develop the theory “The Journey Toward Engagement in SCM.” In summary, the theoretical concepts were developed through the repeated processes of moving back and forth between the data, to the point at which it was becoming progressively more focused and the categorizations of the data were becoming increasingly more abstract.

3.13 Integrating the Data and Developing a Substantive Theory
A grounded theory is directly generated from the data it has created; it is therefore grounded in the data. Most grounded theorists develop substantive theories to explain and manage problems in a substantive (Charmaz, 2014) area such as in this study to understand the process of engagement in SCM of DFU. To move into the dominion of a formal theory, which means creating a theory applicable to various areas, it is necessary to develop multiple substantive theories (Charmaz, 2014). However, the central purpose of this study was to develop a substantive theory to explain the processes of engagement in SCM of DFU and the contextual factors influencing such engagement. It is important to highlight that the process of developing this substantive theory was not linear as it may suggest. The data collection and analysis happened in alternating sequences and in an interactive cycle as demonstrated in Figure 3.2.

3.14 Theoretical Sensitivity and Reflexivity

Theoretical sensitivity refers to the attribute of having the necessary insights to give conceptual meaning to data. It also reflects the investigator’s ability to use personal and professional experiences to discover, understand, and interpret a research context and data in such a way that allows the investigator to
explain the potential of the information for developing theory (Charmaz, 2006, 2014). The author states that sensitizing concepts allows the investigator to expand perception and provide a departure point for constructing analysis. Studies concerned with theory generation might require sensitizing concepts but no hypotheses (Blaikie, 2000). Instead of starting with a hypothesis to analyze the data, qualitative research uses the inductive process, which means extracting patterns, concepts, and categories from the data rather than them being imposed prior to data collection (Thomas, 2006). For instance, when I started to collect and analyze my research data I needed to go back and do constant reflection on my personal and professional experience by using a reflective journal or diary. This allowed increased understanding of what the data was telling me compared to what I know from my experience about the situation.

3.15 Chapter Summary and Conclusion

This chapter provided an overview of the methodology and methods employed in this grounded theory study. The philosophical and theoretical aspects of grounded theory were presented and the general background of the grounded theory method explained. The research design was influenced by a constructivist grounded theory approach and guided by a central research question and six sub-questions. The design of the data collection methods included an intensive semi-structured interview and was driven by theoretical sampling, as is the traditional procedure for a grounded theory study. The study’s participants were recruited by the investigator according to the inclusion criteria, and the recruitment process followed the procedures specified within ethical approval. While all participants were willing to share their experiences, their focus varied according to the topics. For instance, while some provided great detail about their experience in taking care of their wounds, others focused mostly on their personal struggles in navigating in their social world with diabetes and DFU or the impact of DFU on their lives. The forms of questioning used in the interviews included the use of prompts that assisted in eliciting the participants’ experience, reactions, actions, motivations, and meanings. The field notes and reflective journal provided extra sources of data that described the participants’ actions, attitudes, and behavior that I observed during the interview. Constructivist grounded theory provided the framework used to guide the analytic process of developing this substantive theory. The iterative process of developing this grounded theory study was in
fact complex and abstract in nature, as suggested by Charmaz. In providing detailed explanation of the steps taken to develop this grounded theory study, the methodology chapter shows the rigor of the research activity and supports the validity of the findings.
Chapter 4

Findings: Presenting the Context and the Theory

4.1 Overview of the Chapter

This chapter presents a description of the research findings. It begins with an overview and summative introduction of the theory “The Journey Toward Engagement in SCM”. As a researcher and wound care nurse, my goal was to understand the process of engagement in SCM of DFU from individuals’ experiences and perspectives as well as their context. Of particular interest was to describe participants’ experience of having and taking care of their DFUs on a daily basis. Listening to participants’ voices helped me to understand their efforts to engage in SCM of DFU, their struggles, and their needs. Therefore, the substantive theory “The Journey Toward Engagement in SCM” is also the title of the core category representing the whole theory. This theory explains how the participants of this study engaged in the process of SCM from the discovery of diabetes to the development of a DFU. The theory is represented by five categories and fifteen meaningful concepts grounded in the data. This chapter also describes the internal and external factors affecting participants’ engagement in SCM of DFU. These factors were seen as limiting or facilitating conditions that advanced or postponed participants’ ability to take care of their foot ulceration on a daily basis.

4.2 Overview of the Theory: The Journey Toward Engagement in SCM

The primary objective of this study was to develop a theoretical model explaining the phases of the processes of engagement in SCM for individuals with active DFU. My theory “The Journey Toward Engagement in SCM” explains how individuals with DFU engaged in the process of taking care of their diabetes in the beginning and foot ulceration that followed. It meets the definition of substantive theory because it is developed for a substantive area, provides explanation for a delimited problem in a particular field (Glaser & Strauss, 1967; Charmaz, 2014), and is grounded in data (Glaser & Strauss 1967, p. 32). My theory also follows the flexible methods of constructivist grounded theory (defined in chapter 3) because it
takes the “researcher’s position, privileges, perspectives and interactions into account as an inherent part of the research reality” (Charmaz, 2014, p. 13).

The theory “The Journey Toward Engagement in SCM” is also a social process described as a progressive movement reflected by phases (Strauss & Corbin, 1990). It “consists of temporal sequences that may have identifiable markers with clear beginnings and endings and benchmarks in between” (Charmaz, 2014, p. 17). These temporal sequences are linked in a process that occurs in a series of stages that occur over time and involves changes over time (Charmaz, 2014; Gibson, 2007; Glaser 1978). It also represents the transition of participants moving toward the process of SCM to achieve the healing of their DFU. The components of the theory are comprised of five phases, their respective categories, and set of concepts. The phases and categories are organized as follow: 1) Phase 1: Perception of illness; 2) Phase 2: Noticing foot changes; 3) Phase 3: Realizing seriousness; 4) Phase 4: Beginning to learn SCM; and 5) Phase 5: Engaging in SCM.

Each phase and category represents a process within itself and can stand alone with its set of concepts that are also components of the theory and therefore constitute the “theoretical bones of the analysis” (Dey, 2007, p. 168). The concepts allowed me not only to frame key characteristics of individuals’ experiences, but also to communicate a meaningful representation of them grounded in their everyday terms, as well as to construct relationships among the diverse components of the theory (Dey, 2007). The theory with its phases, categories, and context is depicted below in Figure 4.1.
Aging and/or living with multiple chronic diseases

Motivations

Self-efficacy

SCM Knowledge

Access to services and resources

Phase 1: Perception of illness
- Discovering diabetes
- Learning about diabetes
- Giving meaning to diabetes
- Being a bad diabetic

Phase 2: Noticing foot changes
- Just a small callus or blister
- Trying different salves

Phase 3: Realizing seriousness
- Fears of amputation
- Frustration and guilt
- Sense of life change

Phase 4: Beginning to learn about SCM
- Observing and asking questions
- Following instructions
- Relying on wound care team to make decisions

Phase 5: Engaging in SCM
- Keeping on top of it
- Being a SCM leader
- Making own decisions

The Journey Toward Engagement in SCM of DFU

Figure 4.1. Model representation of the theory depicting the phases and the context.
4.3 Summary of the Phases Involved in the Process of SCM of DFU

As discussed in Chapter 1, the onset of DFU is often gradual. It represents the consequence of uncontrolled diabetes mellitus over a long period of time associated with a lack of awareness and appropriate foot care practices that placed the participants’ feet at high risk to develop ulceration. As a result, individuals started on the path of developing foot ulceration shown by several foot changes including neuropathy (e.g., loss of sensation, weakness/atrophy, foot deformity, callus formation, dry skin) and peripheral arterial/vascular disease (e.g., poor circulation, peripheral edema, and ischemia). These signs and symptoms in their feet developed slowly and maybe went unnoticed for years mainly by individuals unaware of the consequences of diabetes to their lower extremities (Al-Rubeaan et al., 2015; Wagner, 1981).

For some of the study’s participants, the gradual development of DFU also led to a gradual process of engagement in SCM. Therefore, the theory “The Journey Toward Engagement in SCM” entailed a progressive movement and consisted of five phases. Each phase is represented by a category (the component/skeleton of the theory) and its respective set of meaningful concepts grounded in the data. Table 4.1 presents an outline of the core category, categories, concepts, and remarkable quotes.