A Focused Ethnography of Iranian Canadian Women's Experiences of Diabetes

by

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ABSTRACT

Living with diabetes is challenging. Achieving optimal blood sugar balance involves major lifestyle choices and changes that can be difficult to sustain over time. When a woman with diabetes immigrates to a new country with very different social and cultural customs, religion, values, norms, and expectations, effective diabetes self-care becomes even more complex. Despite a growing number of Iranian immigrants in Canada, there is a paucity of empirical research on how Iranian Canadian women integrate their diabetes with their original and new cultural and social habits. The purpose of this qualitative focused ethnography study was to explore the experiences of Iranian Canadian women living with type II diabetes. Transition Theory and Shifting Perspective Model formed the study's conceptual framework to explore and understand the nature, conditions, and processes of these women's health-illness transitions associated with diabetes and how immigration influenced their diabetes transitions. 15 women were recruited using purposive and snowball sampling at a local Iranian community center in a large Western Canadian city. Most women were aged 42 to 48 years and were diagnosed 3–17 years prior to my study, the majority being diagnosed with diabetes in Iran. They arrived in Canada 3-25 years ago. Four women were fluent in English and the rest understood English to some degree. Data collection consisted of 21 individual semi-structured interviews conducted in Farsi. Interviews explored their life journeys in learning to live with diabetes and how their culture, social context, religion and immigration experiences influenced this journey. Six participants were interviewed twice to verify the researcher's emerging analysis. Data analysis occurred concurrently with data collection. The analytic approach employed constant comparison, including open and in vivo coding, categorizing, identifying themes and writing memos. Verification strategies built into the inquiry process ensured research strategies adhered to principles of inductive qualitative inquiry and the results were trustworthy.

Experiences of having diabetes are contextualized by aspects of illness identity, socio-cultural and religious commitments and practices and immigration journeys for the women in my study. Iranian culture was intertwined with Islamic beliefs that impact diabetes self-care management directly and indirectly as women selectively chose which cultural and social customs to retain or adopt. Each woman had a unique transition trajectory in diabetes, but there were some common phases: 1) “Dark days of diagnosis” started with the reactions to diagnosis and included a search for meaning and cause; 2) “Struggling to live with diabetes” reflected each woman’s personal journey as she learned how to integrate diabetes into daily life and was faced with challenges and choices to attend to diabetes or adhere to transitional cultural, social, family norms and expectations; and 3) “Recognizing their life road with diabetes” which included two sub themes of experiencing diabetes as “Life as a bumpy road” and “Life as an uphill battle.” These phases were not linear, but cyclical and often repetitive. Some women were stuck in experiencing life as an uphill battle and they struggled to meet their diabetes needs within their current roles and commitments. Their socio-cultural and religious backgrounds and immigration journeys strongly shaped how they experienced their diabetes journey, lifestyle behavior options, relationships with others, their perceptions, interpretations, and self-management behaviors. For some women their beliefs led to more passive behaviors, while for others they were a source of power and motivation. Traditional roles within the family and the Iranian immigrant community were important in either supporting their self-care or functioning as a justification for being unable to manage their diabetes effectively.

This study provides significant insight into the realities of a largely hidden diabetic population. Clinically, religious, cultural and social norms and values must be considered in self-care planning. Involving family and individual socio-cultural and religious commitments in education and support strategies will enhance the quality of care and the interaction and trust between Iranian Canadian immigrants and the health care system. The findings also have implications for interventions incorporating a role for the support group within the diabetes clinic and Iranian community. This role would not only address issues of socio-cultural and religious support in diabetes self-care, but would also serve as a means to educate individuals with diabetes, their families, and the community about improving diabetes management.

PREFACE

This thesis is an original work by Zahra Komeilian. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “A Focused Ethnography of Iranian Canadian Women’s Experiences of Diabetes”, No. MS6_Pro00016340 Date: 26/3/2013

DEDICATION

In the name of Allah, the Gracious, the Merciful.
Praise be to Allah, Lord of all the worlds.

The Most Gracious, The Most Merciful,

Master of the Day of Judgment.

It is You we worship, and upon You we call for help

Guide us to the straight path

The path of those You have blessed, not of those against whom there is anger, nor of those who are misguided.

Quran (The opening)

“We shall not cease from exploration, and the end of all our exploring will be to arrive where we started and know the place for the first time.” -T.S. Eliot

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The honor of fulfilling my doctoral education should also be shared with my parents, whose unfailing support was invaluable.

May Allah accept this humble effort in pursuit of knowledge.

Amen.

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CHAPTER 1 - INTRODUCTION

Background

Living with diabetes is a challenge on a daily basis. Each and every day without fail, individuals living with diabetes must face the complex process of maintaining their blood sugar levels within reasonable parameters so that they can live their lives and avoid complications in the near and distant future. Unfortunately, achieving optimal blood sugar balance may involve major lifestyle choices and changes which can be difficult to sustain over time. Women in particular, may face unique challenges by virtue of their mothering and partnership roles, as often the needs of the family supersede their own needs. Moreover, when a woman with diabetes immigrates to a new country with very different social and cultural customs, religion, values, norms, and expectations, effective diabetes self-care becomes even more complex. In such instances, daily life may be affected by particular cultural practices that would not necessarily be conducive to good diabetes management. These individuals may then struggle to balance acknowledging and respecting their fundamental cultural values and norms against adequately managing their diabetes.

This is the case in the sizable Iranian immigrant population in Canada. Despite a growing number of Iranian immigrants in Canada, there is a paucity of empirical research on how Iranian-Canadian women integrate their original and familiar cultural and social habits within the constraints and opportunities of the new cultural context of Canada. Clinical diabetes nurses know anecdotally how these multiple challenges make effective self-care management much more complex. Yet, there is a lack of empirical evidence to foster an appreciation of the unique challenges Iranian immigrant women face, or to guide tailored clinical care to meet their unique needs. The goal of this study was to explore the experiences of Iranian Canadian women who live with diabetes. This study may enhance the understanding of health care professionals as to how the interlinking of Iranian Canadian socio-cultural and religious background shapes women's responses to their chronic illness.

Iranian culture is intertwined with Islamic beliefs that impact diabetes self-care management directly and indirectly. For example, religious and socio-cultural factors strongly influence dietary habits among Muslim people. The month-long fasting in Ramadan and five daily prayers, examples of spiritual practices for Iranian-Muslim people, may also affect diabetes management. For many Muslims in Iran, religious beliefs are an integral part of their daily lives and appealing to Allah forms part of their daily conversation. Culturally-based lifestyles, beliefs and expected behaviors influence health practices and subsequent health outcomes, even when they immigrate to a new country. For example, gender role expectations, such as shame and honor, highlight women's need for modesty so that Iranian Canadian women prefer to see female health care providers, and often choose not to exercise in mixed-sex environments. As people react to the world around them through cultural processes, cultural differences due to immigration can cause many barriers for immigrant people, especially when they are living with a chronic illness such as diabetes.

Canada, as one of the top immigration-friendly countries, is home to the third largest immigrant Iranian community with over 125,000 Iranian Canadians. Immigration is obviously a major life transition. When people immigrate to Canada, they may choose to keep their lifestyle practices from their home country. It is difficult for people in general to understand differing languages, norms, values, and expectations implicit within new social structures and particularly within the health care system. Cultural differences can also affect how immigrants react to illness, respond to symptoms, seek medical care, and work with members of their health care team. Cumulatively, these factors have a significant influence on how they are able to manage their diabetes self-care.

My goal in this research was to create a contextual basis of understanding how women's socio-cultural and religious context influenced their experience of living with diabetes; and to identify areas so that nurses could tailor nursing care more effectively for these individuals. This research took place within a conceptual framework that helped me remain sensitized to important concepts of self-care management and transition, as well as the concept of shifting perspective in the foregrounding and backgrounding of chronic illness.

The Conceptual Framework of the Study

Several major concepts and theoretical approaches have contributed to my study. Two important theoretical approaches that guided me were (a) the idea of "Illness in the foreground/background" based on the Paterson's (2001) shifting perspective model of chronic illness; and (b) the concept of "Transition" as conceptualized in transition theory (Meleis, Sawyer, Im, Schumacher, & Messias, 2000). Transition theory is particularly relevant as it is informed by the notion that religious and socio-cultural beliefs are fundamental to understanding how people make lifestyle choices. There were also other major concepts such as chronic illness, self-care, and culture which further enriched my study. In the next section of this chapter, I will provide a brief overview of the concepts that I found important in my study and then frame them within the shifting perspective and transition theory models.

Chronic Illness

Chronic illness refers to a persistent incurable condition that must be controlled, lived with, and adapted to within the everyday life challenges and realities of people's lives. A chronic illness and management of its symptoms can affect personal and social relationships. It also influences personal and social identities of those living with it (Tilden, Charman, Sharples, & Fosbury, 2005). These effects can be portrayed by exploring how people with a chronic illness express their feelings about life experiences, such as changes in their daily activities, re-ordering their priorities, and relationships with others. To do so, health care professionals need to look at their clients as individuals with unique understanding and perception of the illness (Paterson & Thorne, 2000).

Self-Care Management

Self-care management of chronic illness refers to the daily activities that people with a chronic illness employ to control their illness. Lorig, Mazonson and Holman (1993), as leading researchers in this area, note that "self-management is about enabling participants to make informed choices, to adapt new perspectives and generic skills that can be applied to new problems as they arise, to practice new health behaviors, and to maintain or regain emotional stability" (p. 440).

Although self-care is a main component of diabetes management, religion and socio-cultural practices are also important elements that influence self-care. As such, in order to adequately assist individuals with diabetes, health professionals need to appreciate the socio-cultural contexts impacting their clients' self-care behaviors. In this study, I explored several socio-cultural and religion components that impact diabetes self-management practices in immigrant Iranian Canadian women with diabetes.

Culture

Helman (2007) defines culture as a way one views the world and how one behaves in relation with others. Culture is the way in which we understand our life. Kleinman (1980) argues that cultural values shape the concepts of health and illness and health seeking behavior by people with chronic illnesses. Cultural factors, such as health and illness beliefs as well as personal and social factors play important roles in finding meaning and understanding of chronic illness and decision making through their journey with their illness. Hains et al. (2006) suggest that cultural beliefs of people with diabetes have the greatest amount of control over their decisions to abandon or accept the treatment regimen. Therefore, culture was a key concept in my conceptual framework because it was essential to understand how Iranian culture affected tensions between traditional values and the demands of diabetes self-management as well as health seeking behaviors.

Different aspects of culture, such as values and beliefs, can influence our patterns of daily life. Cultural beliefs concerning the source of health and illness (e.g. the “evil eye”), cultural guiding health and illness behavioral norms (e.g. use of humoral ‘hot /cold’ theory in food consumption or herbal remedies) all have major implications in the health status of people with Iranian cultural background. Differences in cultural explanatory models between client and practitioner cause difficulty in illness management. The explanatory model used has an interactive approach, emphasizing variations between clients and practitioner models of illness (Cohen, Tripp-Reimer, Smith, Sorofman, & Lively, 1994). Overall differences between clients and health care professionals reflect emphasis on different domains of explanatory models of diabetes.

Religion

There are numerous definitions of religion, but generally religion is a set of beliefs or worldviews related to supernatural power or God. Islam is the main religion practiced in Iran and it is a keystone of many Iranian people’s lives. The beliefs originating from Islam influence multiple dimensions of Iranians’ daily life from the food they eat or avoid, to norms about women's roles in the family and community, and beliefs about the meaning of chronic illnesses as an ordeal from God. After migrating to Canada from Iran, many immigrants may retain some of their lifestyle socio-cultural and religious norms while choosing to adopt others from their current Canadian context. In the current study, my aim was to explore how religion and socio-cultural context influenced living with diabetes.

Shifting Perspective Model

The shifting perspectives model described by Paterson (2001) assumes that the experience of living with a chronic illness continually changes. In this model, perspectives of illness and wellness are represented by overlapping circles; sometimes one perception is dominant over the other and then may revert back to the previous view. Paterson (2001, p.23) notes "perspective is representative of beliefs, perceptions, expectations, attitudes, and experience about what it means to be a person with a chronic illness within a specific context."

According to Paterson, a person with a chronic illness can assume one of two perspectives; illness in the foreground, or wellness in the foreground. Although individuals may have a preferred view about the chronic illness, they are likely to shift between these two standpoints several times over the course of their illness experience. Patterson developed this model through a meta-synthesis of 292 qualitative research studies on experiences of people living with chronic illnesses. I selected this model as a part of my sensitizing conceptual framework because it illuminates how perceptions of diabetes can rapidly change according to ever-evolving personal circumstances. According to this framework, when people with a chronic illness feel their disease is out of control, lack disease management skills, experience stigma, or are dependent and hopeless, they shift to the "illness in foreground" perspective. In contrast, when they focus on positive aspects of life and try to disconnect from their illness, they put wellness in the foreground. However, at any time, changes in their personal circumstances or even inexplicable changes in their blood sugars can move them back to an illness in the foreground perspective. I will describe this model in more detail in the next chapter.

Transition

Transition has been theoretically defined in various ways. Transition is described as an alteration at the individual, family or organizational level such as changes in a person's health condition, family roles, relationships and expectations, or organizational structure or function (Schumacher & Meleis, 1994). Kralik and Van Loon (2010, p. 22) state "transition involves a process of inner reorientation as the person learns to adapt and incorporate the new circumstances into his or her life." The difficult part of the transition, as evidenced in the literature, is considered to be the adjustment to the identity a person had before the onset of the chronic illness (Kralik, 2002; Bridges, 2004). I used the concept of transition as explicated by Chick and Meleis to frame my study:

> A passage from one life phase or status to another…transition refers to both the process and the outcome of complex person-environment interactions. It may involve more than one person and is embedded in the context and the situation. Defining characteristics of transition include process, disconnectedness, perception and patterns and response. (Chick & Meleis, 1986, p. 230)

Based on this, I conceptualized a very contextual approach that incorporated ideas of religious beliefs, socio-cultural influences in shaping the perceptions, experiences, values, norms, and behaviors of Iranian Canadian women living with diabetes. For many immigrants, how their family adopted and adapted themselves to Canadian customs around cultural norms, such as food preferences, was an important transition that significantly impacted their ability to make effective diabetic meal choices. The individual's illness experience could not be separated fully from the experience of other family members, especially close family in Canada. In the next chapter I will explain the use of this conceptual approach in my study in more detail. In summary, health professionals supporting individuals in their chronic diseases self-care management need to consider that:

> There is no singular way to live well with a chronic condition, that the learning process is complex and incremental, and that the role of medical science must be contextualized within an understanding of the living that is taking place. (Thorne, 2008a, p. 12)

People living with a chronic illness often learn that their responses to their illness do not follow the patterns described or prescribed by health care professionals, but rather, they begin to find their own self-care practices that fit within the context of their lives (Kralik, Koch, Price, & Howard, 2004). In essence, in order to improve our clinical interventions and support, first we need to discover what our clients think and know about living with diabetes, and seek to understand our clients' actual experiences. Understanding the belief system of our clients and how it influences health seeking behaviors is crucial to meeting the health care needs of people with chronic illnesses in general and women in particular. When it comes to a multicultural country such as Canada, health care professionals encounter even more complex issues.

My Dissertation Journey

The work described in this dissertation reflects my personal journey in appreciating the complexity of living with diabetes. Having conversations with the women in my study helped me appreciate the importance of the individual, often hidden from health professionals, experience of self-care management. My interest in the experience of people with diabetes in general and women in particular began from this question, 'what is their real experience like?' As a nurse educator in a diabetes clinic in Iran, I tried different ways to promote and tailor our client education plans. I designed some booklets covering different aspects of diabetes education and organized educational classes and camps. After many years, I came to the realization that in spite of my best efforts to provide guidance, direction and education, our clients with diabetes did not seem to be able to achieve optimum glycemic control. It seemed particularly challenging for women with diabetes. The specialist physicians and Endocrinologists labeled most of our clients "non-compliant."

A few years later, I started to question whether or not my educational goals and advice was achievable or relevant to their everyday lives. When I entered the doctoral program at the University of Alberta, I focused my study on concepts of chronic illness and self-care management. I began to understand that the personal experience of living with a condition such as diabetes may be largely hidden from, and misunderstood by health professionals. I realized that perhaps I needed to find out from our clients with diabetes what it is actually like to live with diabetes. I wanted to understand how my educational plans missed the target and why my advice was ignored. I believe these questions in diabetes self-care management are relevant to any chronic illness, or any geographical transition, that involves different cultural and social contexts. I decided to pursue this path throughout my dissertation research. As my own country of origin contains such interrelated aspects of religion and socio-culture, I wanted to explore how cultural and religious beliefs and diabetes management intersected.

This dissertation is the first step in my journey. As an Iranian woman who has lived in Canada for several years, I had the advantage of insider access to this cultural group who traditionally may not be very vocal about their experiences, needs and challenges within the mainstream health care system in Canada. I was uniquely positioned to hear their experiences and, as a Registered Nurse, also had an etic, or outsider experience that could, when integrated with the emic perspectives offered by my participants, make a contribution to similar diabetes care situations in Canada. By completing this study, I enabled women with diabetes who immigrated to Canada to express themselves in their own words and through the story of their lives with diabetes.

Research Questions

The overall research question guiding this study was conceptualized as, "what is the experience of living with diabetes for Iranian women who immigrate to Canada?" As I lived through the study, the research questions evolved to match my growing appreciation of my participants' emic perspective. I explored different domains of experience guided by the following more specific questions:

- Over time, how did Iranian Canadian women learn to live with diabetes? How have these women learned to integrate diabetes into their daily lives?
- How has immigration affected Iranian Canadian women's perceptions and experiences of living with diabetes?
- How have socio-cultural and religious values influenced Iranian Canadian women's experiences of living with diabetes?
- How has their perception of themselves as woman, mother and community member been influenced by their diabetes?
- What are the socio-cultural, religious, and family challenges to illness management for Iranian Canadian women with diabetes?

Significance of the Study

This study represents the first step in my research initiatives aimed at improving clinical interventions and support for Iranian women with diabetes who live in Canada. Understanding the experiences of living with diabetes when people come from different cultures and societies may help health professionals provide comprehensive and optimal care for clients who may not be very vocal about their needs and preferences. In this study, I explored and strove to understand how Iranian Canadian women perceived, experienced, and engaged in diabetes self-care. The knowledge gained from this study provides a description of the emic experience of these women in the context of their socio-culture and adaptive lifestyle as immigrants. This study may increase understanding by health care professionals and thus their ability to appreciate how Iranian Canadian socio-culture context and religious beliefs shape women's responses to their illness and the challenges they face in accommodating the requirements of diabetes care into their daily lives.

In the following chapter, I will discuss the background literature about diabetes self-care management, culture, and religion. In Chapter Three, I will describe the design and methods I used to collect and analyze data as well as the strategies I used to ensure the rigor of the research. In Chapter Four, I will present my results based on the main themes such as diabetes as a 'ball and chain.' In Chapter Five, I will discuss my results within the context of existing research on self-care in diabetes and immigrant experiences with health and illness. In this chapter, as well, I will explore implications for practice, future research and education.

CHAPTER 2 - LITERATURE REVIEW

The goal of this study was to investigate how immigrant women from Iran, living in Canada, experienced receiving a diagnosis of diabetes and describe their beliefs about health and the impact on how they live with diabetes. To provide a context for this study, I present a literature review of topics relevant to this research. The purpose of this literature review was to explore theoretical approaches and empirical knowledge about diabetes management within personal, family, social and cultural contexts, with particular focus on chronic disease self-management. I further explored the role of illness perception and identity within the specific context of Iranian Canadian women and the impact of their culture and religion on diabetes self-management behavior. I will also discuss the impact immigration has for people with chronic illness, such as diabetes.

Diabetes

Diabetes is a chronic metabolic disease, in which the body either cannot produce insulin or cannot properly use the insulin it produces. Diabetes is characterized by macrovascular and microvascular complications along with the dysfunction of fat and protein metabolisms (Canadian Diabetes Association (CDA) 2012, para. 2). Diabetes has both genetic and environmental causes and affects virtually every organ system of the body. Through its impact on the microvasculature, diabetes compromises the function of the eyes, kidneys, and nervous system.

There are three main types of diabetes. Type I diabetes, usually diagnosed in children and adolescents, occurs when the pancreas is unable to produce insulin, a hormone that controls the amount of glucose in the blood. Approximately 10 percent of people with diabetes have type I diabetes. The remaining 90 percent have type II. Type II diabetes usually develops in adulthood, although increasing numbers of children in high-risk populations are being diagnosed. Type II diabetes is a progressive disease associated with significant morbidity and mortality. The third type of diabetes, gestational diabetes, is a temporary condition that occurs during pregnancy. It affects approximately two to four percent of all pregnancies and involves an increased risk of developing diabetes for both mother and child (CDA, 2012, para. 6).

The onset of type II diabetes may be prevented or delayed, through increased physical activity, healthy eating and weight loss. According to National Institutes of Health (NIH, 2012, para. 8), people at risk of type II diabetes were able to reduce their risk by 58 percent by exercising moderately for 30 minutes a day and by losing five to seven percent of their body weight. In people age 60 and older, the risk was cut by almost 71 percent.

International Diabetes Federation (IDF, 2015) estimated that 415 million people worldwide are affected by diabetes and 7 million people develop diabetes each year. The number of those with diabetes is expected to hit 642 million by 2040 (Figure 2.1). There has been a dramatic increase in the prevalence of diabetes in Canada over the last decade and current projections are that the same will occur in the decade to come. The total population with diabetes is estimated to be 2.7 million (7.6%) in 2010, and is projected to rise to 4.2 million people (10.8%) by 2020. Today nearly one in four Canadians (almost 9 million) either has diabetes or pre-diabetes (CDA, 2005). According to Health Canada, type II diabetes is one of the fastest growing diseases in Canada, with over 60,000 new cases yearly. It has an increasing prevalence due to sedentary lifestyles and changes in forms of nutrition.

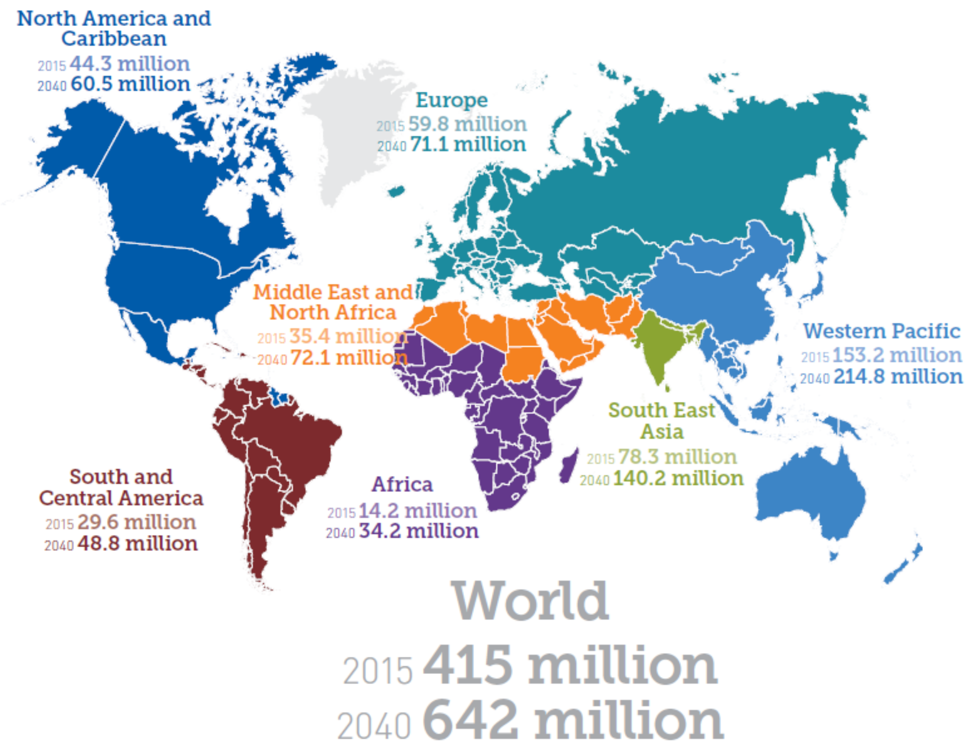

Figure 2.1 Estimated number of people with diabetes worldwide and per region in 2015 and 2040 (20-79). Reprinted from IDF diabetes ATLAS, 7TH edition, 2015, Retrieved from http://www.idf.org/sites/default/files/EN_6E_Atlas_Full_0.pdf Copyright (2015) by International Diabetes Federation (IDF). Reprinted with permission.

Indeed, the Center for Disease Control (CDC, 2012, para. 11) reported that in the15.7 million people with diabetes in the United States more than half (8.1 million) are women. The report also indicates that the prevalence of type II diabetes is at least two to four times higher among Black, Hispanic, American Indian, and Asian Pacific Islander women than among white women.

In all forms of diabetes the goal of treatment is to keep the blood sugar close to as normal level as possible and to try and prevent or minimize complications that occur when there is too much sugar in the blood. The recommended treatment to ensure this glycemic control and prevent complications includes meal planning, physical activity, oral anti-diabetic/ insulin treatment, self-blood-glucose monitoring, and diabetes self-management education (CDA, 2012, para. 10). This treatment requires considerable effort and cost. Thus, diabetes presents a significant health and economic burden, not only for clients' families, but also for industry and society (Tuncell et al., 2000).

The Cost of Diabetes

The personal costs of diabetes may include a reduced quality of life and an increased likelihood of complications such as heart disease, stroke, kidney disease, blindness, and amputation. Life expectancy for people with type II diabetes may be shortened by 15 to 20 years (CDA, 2013, para. 1). The financial burden of diabetes and its complications for individuals and society is enormous. People with diabetes encounter medical costs that are two to three times higher than those without diabetes (CDA). A person with diabetes can face direct costs for medication and supplies ranging from $1,000 to $15,000 a year. New statistics from the CDA (2013, para.4) indicate the economic burden of diabetes in Canada could escalate to nearly $17 billion by 2020, an increase of more than $10 billion from 2000, and the number of Canadians diagnosed with diabetes will have approximately tripled. Diabetes is not only a personal crisis for people living with the disease and their families. There is good evidence that intensive glycemic control reduces the development and progression of complications in people with diabetes. Appropriate chronic illness management system, self-care management in particular, can reduce the cost of diabetes significantly. In the following sections, I will describe the concept of chronic illness and self-care management.

Chronic Illness Management

Given the high cost of managing chronic illnesses, the development of cost-effective systems for chronic disease management is vital (Forbes & While, 2009). Wagner et al. (2001) used the following analogy to explain the nature of chronic illness management. They stated that:

> Living with chronic illness is like flying a small plane, if the plane is flown well, one gets where one wants to go with the exhilaration of mastering a complicated set of challenges. If it is flown badly, one either crashes or lands shakily in the wrong airport, reluctant to ever leave the ground again. The client must be the pilot, because the other possible pilot, the health care professional, is only in the plane a few hours every year, and this plane rarely touches ground. If chronically ill clients must pilot their planes, then the role of health care is to ensure skilled pilots, safe planes, flight plans that safely get the pilots to their destinations, and air traffic control surveillance to prevent mishaps and keep them on course. Medical care then must assure that persons with chronic illness have the confidence and skills to manage their condition; the most appropriate treatments to assure optimal disease control and prevention of complications; a mutually understood care plan; and careful, continuous follow-up. (p. 66)

Chronic disease management has been improved through the use of chronic care models. The components of chronic disease management identify the essential elements as self-management support, clinical information systems, delivery system design, community resources and policies, and health care organizations. Effective chronic illness management calls for a delivery system design that encourages and enables productive interactions. The multiple tasks involved are more likely to be accomplished with the coordination of care among health professionals in the team. Moreover, increasing access to effective programming in the community through linkages with the relevant agencies is a cost-effective way to obtain important services such as nutrition counseling or peer-support groups.

Concentration on these components fosters productive interactions between clients who take an active role in their care and proactive providers who offer expert advice, constant encouragement and guidance to the individual in his/her efforts to manage their condition through effective self-care (Forbes & While, 2009). According to Holman and Lorig (2004), self-management support systems help individuals with chronic illness gain self-confidence in their ability to control their symptoms and understand how their health problems affect their lives.

For diabetes in particular, self-care management skills can help clients competently manage their new condition over time. It is estimated that 95 percent of diabetes management is self-management which requires people with diabetes to make multiple daily self-care decisions within the context and constraints of their everyday lives (Ruston, Smith, & Fernando, 2013). Diabetes self-management is considered an integral component of comprehensive diabetes management. In the following section, I will describe traditional diabetes management and the concept of self-care and self-management.

Standard of Diabetes Management

In standard clinical approaches to diabetes management, the condition is viewed through a biomedical lens with a focus on controlling blood glucose through monitoring blood sugar levels. The recommended regimen is taking the right drug doses, monitoring dietary intake and structuring lifestyle to maintain optimum health (Cooper & Geyer, 2009). Frustration for people with diabetes stems from problems and complications still arising even when they have done all the right things (dosages, diet, exercise). For the person with diabetes, understanding their condition solely through this lens, guilt can be a frequent companion.

Diabetes, like any other long-term illness, needs new management boundaries (Cooper & Geyer, 2009). It has become clinically clear that the traditional biomedical perspective of diabetes treatment as control of the symptoms and blood glucose is no longer adequate on its own (Ononeze, Murphy, MacFarlane, Byrne, & Bradley, 2009). Chronic disease management does not happen outside of complex human lives (Thorne, Paterson, & Russell, 2003). As Humphrey (2006) notes, this change in thinking "is not a direct product of complexity thinking, but reflects the general shift away from the orderly framework that is going on throughout the fields of science, medicine and public policy" (p. 606). According to new standards of care, diabetes requires continuous medical care with multifactorial risk reduction strategies beyond glycemic control (American Diabetes Association (ADA), 2014). Ongoing client self-management education and support are critical to prevent diabetes chronic complications People with diabetes need a variety of strategies and approaches to live effectively with their illness on a day-to-day basis. In other words, although glycemic control is still the goal, there is increasing recognition that this may be a significant challenge for many people. Understanding how people perceive or understand this condition within the context of their lives is important. In the following section, I will discuss living with chronic illness and the concept of self-care and self-management followed by associated concepts that impact self-care management processes.

Living with Chronic Illness

People with chronic illness appear to move through a complex, dynamic and multidimensional trajectory. Essentially all chronic conditions present a common set of challenges to clients and their families—dealing with symptoms, emotional impacts, complex medication regimens, and difficult lifestyle adjustments (Kralik, 2002; Ambrosio et al., 2015). Having a chronic illness can have a profound emotional and physical impact on daily living. One factor that determines people's experiences in living with a chronic disease is their illness perspective. Illness perspective, or lived experience, includes the individual's attitudes, beliefs, and values about living with the disease (Paterson, 2001). One approach to better understanding the barriers to and facilitators of adopting self-management behaviors is to explore the lived experience (Protudjer, Dumontet, Jonathan, & McGavock, 2014). Understanding the lived experience of people with chronic illness can help health care professionals address concerns and tailor their advice accordingly. Further, it can aid in developing interventions which will facilitate the adoption of effective self-care behaviors (R.M. Taylor, Gibson, & Franck, 2008). According to Aujoulat, Marcolongo, Bonadiman and Deccache (2008) most people with chronic illness express the need to not only become knowledgeable about their disease and treatment, but also to assign meaning to their illness experience. Understanding one's illness is not created only "through the assimilation of medical information, but also through the acknowledgment and interpretation of bodily sensations and emotional states linked to the very experience of being ill" (Aujulat et al., 2008, p. 1230). A better understanding of clients' perspectives on chronic illness could also be expected to minimize conflict and frustration in our clients (Ockleford, Shaw, Willars, & Dixon-Woods, 2008).

Living with diabetes is a complex balancing act and life events can impact on diabetes management (Youngson, Cole, Wilby, & Cox, 2015). According to Youngson et al., the lived experience of diabetes is a multifaceted and complex balance between the person (their self-identity), their environment (physical, social-cultural, religious, lifestyle, and life events), and their relationships with health care providers. People with diabetes expect to have negative outcomes and experience a profound amount of suffering (Wennick & Hallstrom, 2007). To understand the lived experience of having diabetes, we need to recognize how diabetes is viewed within the social-cultural environment, and how that image of diabetes impacts a person's experience of the illness. The significance of personal meaning in the experience of adapting to, and managing, chronic illness in general and diabetes in particular, has been well documented in the literature.

Reviewing the literature there appears a predominantly negative as well as a positive view of having diabetes. The larger themes which seem to emerge from the literature include loss, suffering, prolonged stress, fear of having diabetes for the rest of their life, and having difficulty coping with self-care (Stiffler, Cullen, & Luna, 2014). Participants in Penckofer, Ferrans, Velsor-Friendrich and Savoy's study (2007) experienced feelings of depression, anxiety, and anger, which affected their health and overall quality of life. Grief at the loss of current and future expectations for their life (Ford, Havstad, Brooks, & Tilley, 2002), loss of individuality (Wennick & Hallstrom, 2007) and loss of well-being and social support (Westaway, Seager, Rheeder, & Van Zyl, 2005) are the most salient aspects of feeling loss in people with diabetes. Diabetes is also commonly interpreted as continual suffering due to isolation, loneliness, fatigue, depression, and fear. In Heuer and Lausch's (2006) study of Hispanic immigrants with type II diabetes, the impact of suffering the physical and emotional symptoms of diabetes are described by their participants. Fear of long-term complications was another major concern of individuals in this study. Subjects also faced challenges related to eating and living with fear of potentially devastating complications. The participants in Lakshmi, Ganesan, Mohan Anjana, Balasubramanyam and Mohan (2014) study also expressed negative views about having diabetes including: perceiving diabetes as a serious medical condition; the cost of managing diabetes; or a feeling of victimization and stress associated with the management of the condition. Another study by George and Thomas (2010) elucidated experiences and perceptions of self-management as narrated by older people with diabetes. The majority of their participants' experiences were described as painful, full of conflict and a huge change in their lives. For example, experiences of hypoglycemia generated fear of sleep. The disconnection between participants and health care professionals is also captured in this study. A study by Abdoli, Ashktorab, Ahmadi, Parvizy, and Dunning (2011) on Iranian people with diabetes in Tehran, the capital of Iran, indicates that the majority of people in this study experienced prolonged stress because of fluctuation in blood glucose levels, negative perceptions of diabetes, and grief, making it difficult to cope with diabetes. Individuals who believed in the power of religion and faith, regarding doctors as holy men, believing diabetes was God's plan for them (God's will), and that their body is a gift from God, appeared to have less stress related to their perception of chronic illness. The importance of peer and family support in the participants' lived experiences also emerged in this study. Other studies by Farahani, Ghofranipour, Ahmadi, and Emami (2008) and Alavi, Ghofranipour, Ahmadi and Emami (2007) also elucidate negative views of having diabetes in Iranian people with the illness.

Alternatively, in some studies, having diabetes became an opportunity for individuals to start living a healthier life (Hörnsten, Sandström, & Lundman, 2004). Hörnsten et al. also investigated lived experiences of 44 adults residing in Sweden who have type II diabetes. Their participants saw trying to incorporate diabetes into daily life as a demanding task, which often took time and involved the family and other relatives. Taking control over the new situation appears to be an active way of managing the disease. Establishing personal routines for handling the new situation also facilitated incorporation of diabetes into daily living. Planning for the future was mentioned by the majority of their participants, and they believed it was important for achieving meaning in life. The findings also indicated that participants' personal understanding of their illness differ to a certain degree from how professionals view diabetes. The researchers suggested that it is crucial that health professionals understand how diabetic people from different populations understand their illness in order to help tailor their presentation and treatment of diabetes to suit the population being served (Hörnsten et al., 2004). Another study of 15 Iranian people with type II diabetes, by Karimi Moonaghi, Namdar Areshtanab and Jouybari in another city in Iran (2014), indicates that the majority of the participants had a positive view of having diabetes and considered it as an opportunity for changing unhealthy lifestyles. Diabetes was also seen as an agent in devoting more attention to spiritual issues. They believed that a closer relationship with God and greater spirituality could help them better tolerate the illness. It can be concluded that, despite the difficulties of having diabetes, it may also have positive effects for those diagnosed. The manner in which clients perceive positive or negative implications of their illness can influence various psychological consequences (Currier, Hermes, & Phipps, 2009). The participants who realized positive changes following type II diabetes diagnosis do so because of the meaning they ascribe to it (Karimi-Moonaghi et al., 2014). Studies have shown that how the individual cognitively processes information plays an essential role in coping with illness (Kashdan & Kane, 2011). These different perspectives of having diabetes may remain when they immigrate to another county with different cultural and religious traditions and practices.

Immigration to a new country poses many new challenges for immigrants diagnosed with type II diabetes. These challenges also affect lived experience of having diabetes. Hjelm, Bard, Nyberg and Apelqvist (2003) studied lived experience of three different populations of Swedish women, among which were Arabic speaking immigrants with diabetes. According to their study, these women explained the cause of diabetes as fate, “Allah’s will,” but also referred to individual factors, such as sorrow and emotional stress, related to their immigration experience, thoughts about relatives left behind, as well as being linked to some incident just before the onset of diabetes. Other factors were psychosocial such as social isolation, alienation, limited social support, “mental discomfort,” and severed relations with family in their country, as well as disturbed relations to other people and to dead family members. Supernatural causes were also described by the Arab immigrant women. These women emphasized adaptation and a lot of dietary obligations and showed a lower threshold for seeking assistance from nurses and physicians. They also showed a lack of knowledge of the consequences of diabetes and effects of insulin, and discussed general symptoms. The study shows the importance of religion, and its influential role in self-care management and care seeking behavior, regardless of whether they are practicing their religion or not. The study’s use of focus groups consisting of three different ethnic groups in the clinical setting may have influenced their responses. Instead, in-depth interviewing conducted in these women’s natural setting would have provided richer data that may have shed more light on their experience with diabetes in the new country.

A study by Uzochukwu (2008) was designed to understand how African immigrant adult males who have type II diabetes experience this disease in their lives. The first-hand information provided by the eight men indicates their lack of knowledge of type II diabetes before their diagnosis and the acquisition of extensive knowledge afterwards; their negative initial reactions when they were diagnosed; the perception that their lives had been changed forever; their strong emotional connections to their original homes and their perception that coming to the United States caused them to develop type II diabetes; their persistent problem with the dietary aspect of their diabetes self-management because the dietary part of the diabetes education materials provided to them did not include their cultural foods which they prefer; and finally, the advice they offered as their obligation to help protect their future generations from type II diabetes. It is also obvious from the literature that men and women have different perspectives of having diabetes (Gucciardi, Wang, DeMelo, Amaral, & Stewart, 2008).

Plato was, perhaps, one of the first to recognize that women's worlds are different to men's (Vickers, 2001). Women’s experiences should not be subsumed under those of men. Differences have been found in health-related behavior in males and females (Hjelm & Nambozi, 2008; Sleskova, Salonna, Dijk, Geckova, & Groothoff, 2005).

Overall, the lived experience of having chronic illness in general and diabetes in particular, is an essential aspect of understanding the illness. Without it, health care professionals will not fully understand how the illness impacts the person and what it means to the individual. The meaning of having diabetes differs from person to person, and from day to day. There is a need for studying lived experience in individuals with different cultural and religious backgrounds and immigrant or non-immigrant experiences. Whilst all of this literature is important, informative and useful, there is no attempt to explore the issues of having diabetes for Iranian women who immigrated to another country. Much research has been done in North American, European or Arabian contexts. It is difficult to know how transferable this knowledge is to the Iranian immigrants. My goal in this study is to highlight information about Iranian Canadian women’s perspective of having diabetes. Contributing such knowledge of the lived experiences of women with diabetes as a first step can lead to the development of appropriate treatment and educational programs as well as better support of our clients. Studies have shown that interventions that target clients’ belief systems are effective in improving self-management behaviors in diabetes (Petrie, Broadbent, & Meechan, 2003). Lastly, I believe, as Thorne (2008b, p. 12) challenges, that “armed with socially and culturally specific and appropriate knowledge, we can challenge the traditional approach to diabetes care, and ultimately improve care, so that diabetes cease to be a “disease” to be contained, but allows a life to be fully lived.” Lived experience of having chronic illness affects self-management behaviors (Liddy, Blanzkho, & Mill, 2014). In the following section, I will review the concept of self-management in the literature.

The Concept of Self-management

In contemporary thought, the concept of self-care, self-care management and self-management, are interchangeable (Barlow, 2013), but self-management is the most common term. Self-management is a dynamic, interactive, and daily process in which individuals engage to manage a chronic illness (Lorig & Holman, 2003). Self-management in chronic illness is a certain set of tasks, skills and behaviors in partnership with health care professionals to manage and prevent symptoms and move towards empowerment (Funnell et al., 2009; Sarkar, Fisher, & Schillinger, 2006; Siguroardottir, 2005).

Diabetes self-management is a lifelong matter which takes shape through an individual’s own personal self-management strategies within the context of a unique life, including day-to-day disease management by individuals and with the help of health-care professionals (Moser, Van Der Bruggen, Spreeuwenberg, & Widdershoven, 2008; O. Ogundipe, Blandford, & Ogundipe, 2006). In diabetes, self-care often refers to behaviors such as following a specific exercise regime, managing one's diet, carrying out personal care (e.g. foot care) and self-monitoring of blood glucose. In order to optimise well-being and quality of life, diabetes management activities need to be shared between the individual and their health care providers. Self-care activities designed to promote well-being and improve quality of life are vital (Cochran & Conn, 2008). A person diagnosed with diabetes needs to learn how to monitor glucose levels and to adjust medication accordingly, to follow an appropriate diet, and to be aware of the complications associated with diabetes (e.g. damage to vision, cardiovascular system and kidneys). There is no doubt that diabetes self-management remains one of the crucial factors that assists individuals with diabetes to achieve great success in controlling their illness.

Self-management is not just about learning about illness and adhering to therapeutic recommendations to reach a desired goal. At the heart of a self-management approach is empowering people and building self-efficacy so people have the skills and confidence to better manage their chronic diseases and interact with the primary health care system (Johnston, Liddy, Mae Ives, & Soto, 2008). People with chronic disease can reach their greatest self-care potential by integrating their personal experiences, understanding their illness and perceptions of the illness (Coulter, Parsons, & Askham, 2008). Self-management activities have a positive effect on HbA1C (Mahmoodi, 2006; Mohebi, Azadbakht, Feizi, Sharifi- Rad, & Kargar, 2013), but some studies also indicate self-management behaviors are insufficient in people with diabetes (Jafarian- Amiri, Zabihi, Babaiaesl, Eshkevari, & Bijani, 2010; Johnston et al., 2008). People living with long-term illness often learn that their responses to illness do not always follow the patterns described or prescribed by health care professionals (Kralik et al., 2004). They begin to find their own self-care behaviors based on the context of their everyday lives (Kralik et al., 2004).

Self-management has a crucial role in improving quality of life in people with chronic illness, but supporting people to effectively self-manage their illness is complex and must move beyond merely delivering information by health care professionals (Bodenheimer, Lorig, & Holman, 2002). Education alone does not improve glucose level in diabetes; other additional factors are needed (Norris, Engelgau, &Narayan, 2001). There needs to be interplay of cognitive and practical skills in self-management processes, collaborative decision-making and goal setting especially in type II diabetes (Thorne et al., 2003; Moser et al., 2007).

According to new standards of care in diabetes, health professionals’ recommendations alone cannot improve clients’ lives (ADA, 2014). Successful self-management needs ongoing support from health care professionals, family and friends, and their community (ADA). According to ADA, self-management is an ongoing process of facilitating the knowledge, skill, and ability necessary for diabetes self-care. This process incorporates the needs, goals, and life experiences of the person with diabetes. When health care professionals do not consider spiritual and cognitive demands, outcomes will diminish (Gallant, Spitze, & Grove, 2010). According to D. Anderson and Christison-Lagay (2008), self-management differs from traditional diabetes education in that it focuses less on educational topics and more on attitudes and behaviors. Cultural and ethnic differences can also determine self-care behaviors. These factors, including cultural and religious understanding of health and illness, spirituality, low literacy, limited English proficiency, socio-economic status, and social relationships are domains that present additional considerations to promoting diabetes self-management (Abdoli et al., 2011; Becker & Newsom, 2005; Gallant et al., 2010; Jafari, Farajzadegan, Loghmani, Majlesi, & Jafari., 2014).

In the following section, I will discuss these facilitators and inhibitors of diabetes self-management.

Facilitators and obstacles for optimum diabetes self-management. Various factors have been identified as obstacles or facilitators for optimum diabetes self-management across the population. These factors include: increased age as an obstacle (Alberti, Boudriga, & Nabli, 2005), social and family support as a facilitator (Alberti et al., 2005; Karter, Ferrara, Darbinian, Ackerson, & Selby, 2000; Piette, Heisler, & Wagner, 2004), lower educational level as an obstacle (Karter et al., 2000), limited English proficiency in immigrant people to Western countries (Heerman & Wills, 2011), and cultural values and traditions (Gallant et al., 2010; Galdas, Ratner, & Oliffe, 2011; Jafari et al., 2014).

In the case of Iranian and Muslim people with chronic illness, Abdoli et al. (2011) listed the facilitators to optimum diabetes management behaviors in Iranian people as: (a) the power of religion and faith, (b) the concept of the doctor as holy man, (c) acceptance of diabetes as God's will, (d) care for the body because it is God's gift, and (e) support from family, especially daughters. Another study in the Iranian population by Sharfi Rad, Azad Bakht, Feizi and Mohebi (2013) aimed at determining the relationship between social support, dietary habits, family support, and self-care management behaviors offers insight. The results indicated that there is a positive relationship between self-care behavior and social support in clients with diabetes, and that social support can predict the health promoting behaviors in people with diabetes.

Supporting clients to master skills of self-care and changing their behavior is also essential for optimum diabetes self-management (C.J. Wu & Chang, 2014). Behavioral changes are complex processes that are influenced by such factors as knowledge, beliefs, attitudes, skills, motivation, and social support (Al-Khawaldeh, Al-Hassan, & Froelicher, 2012). According to Bandura (1997), one of the key factors in attaining behavioral goals is self-efficacy. Self-efficacy proposes that individual beliefs about personal capabilities predict specific behaviors, such as self-management activities. Usually people avoid tasks and situations when they believe that they exceed their capabilities. Based on Bandura (1982), individuals show higher behavior change when they have higher self-efficacy. Thus self-efficacy is an important construct in undertaking successful self-management behaviors (Mohebi et al., 2013).

A growing body of research has identified self-efficacy as a predictor of self-management behaviors in people with diabetes or any other chronic illness (Heerman & Wills, 2011; Sarkar et al., 2006; Mohebi et al., 2013). For example, there is a positive association between self-efficacy and healthy diabetes self-management and glycemic control (S. V. Wu, Lee, Liang, Lu, Wang, & Tung, 2011) and a self-efficacy program improved diabetes self-efficacy and self-management behaviors (Ha, Hu, Petrini, & McCoy, 2014; Shi, Ostwald, & Wang, 2010). Most likely, diabetes self-management behaviors require different types of knowledge, skills, as well as different levels of motivation and confidence (self-efficacy) (Wattana, Srisuphan, Pothiban, & Upchurch, 2007; Al-Khawaldeh et al., 2012). Individuals with diabetes can reach optimal outcomes when they can capably integrate knowledge, personal experience, their belief system, and self-understanding of their illness (illness-identity) (Ogden & Parkes, 2013). According to Thorne (2008b):

> Living as well as possible with a chronic condition requires an increasingly sophisticated and integrated capacity to weigh alternatives, make choices, attend to evidence, listen to one’s unique body cues, and develop an individualized system by which to know whether one is doing better or worse over time. (p. 11)

In recent literature, clients’ views about their chronic illness are cited as an important facilitator or inhibitor of diabetes management behaviors (Morton, Tong, Howard, Snelling, & Webster, 2010; Hjelm & Nambozi, 2008; Lakshmi et al., 2014). Research based on psychological theory has highlighted the importance of clients’ personal beliefs about their illness and treatment in the self-management of a range of chronic illnesses (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002; Miller & Rollnick, 2002; Barnes, Moss-Morris & Kaufusi, 2004). When people with diabetes find meaning in their illness they then can either adapt to the process of illness, increase self-efficacy and better self-management, or consider diabetes as a tremendous loss, decreasing self-efficacy (Ohman & Soderber-Lundman, 2003; Thorne et al., 2003).

There are other factors that are considered as positive facilitators of diabetes self-management including: knowledge about diabetes, social support from others, and spirituality (J. Shaw, Brow, Khan, Man, & Dillard, 2013). On the other hand, there are also negative factors, such as lack of knowledge about self-management skills and social difficulties caused by dietary changes (Shaw et al., 2013). Despite many studies that focused on diabetes self-management in different countries, including people in Iran, there is little documented diabetes-related research exclusively on Muslim immigrants with diabetes in general, and Iranian people in particular, indicating a need for research on diabetes self-management in this growing population. In summary, behavior change is clearly a key factor in optimal self-management. In this regard, many variables such personal belief systems influence these behavior changes. In the next section I will focus on belief systems in diabetes self-management.

Belief System in Diabetes Self-management

Over the past decade there has been a growing amount of research focused on individual or family experience of chronic illness in which the findings point to the strong influence of belief systems on experience and perception of chronic illnesses (Horne & Weinman, 2002; Chacko, 2003; Lewis, 2008). Belief system refers to the stories individuals tell to define their personal sense of reality, ideals and values (Uso-Domenech & Nescolarde-Selva, & Gash, 2015). Using this definition, every human being has a belief system and it is through “this mechanism that we individually, make sense” of “the world around us” (p. 2). Cultural and religious beliefs influence illness perception, illness identity and empowerment (Abdoli, Ashktorab, Ahmadi, Parvizi, & Dunning, 2008).

Culture, religion and ethnicity (personal belief system) are particularly important in shaping the way people interact with a health care system; their participation in prevention and treatment programs; and their understanding of health, illness and lifestyle choices (Larsen, 2006). Thus, according to Larsen, people from a different culture may not consider health care in the host country as ‘quality care’ because the health care professional does not take into account the individual’s religious beliefs and values. Sometimes the demands of diabetes management, such as controlled dietary intake, can conflict with personal belief systems based on religious requirements, such as fasting during the month of Ramadan. Petrie et al. (2003) noted that interventions that align with clients’ belief system are more effective in improving self-management behavior in diabetes. This finding by Petrie et al. supports the importance placed on the role of belief system in chronic disease management. Individual belief systems influence satisfaction with the consultation and future health care use, and can affect the quality of self-management activities as well as the client’s quality of life (Petrie, Jago, & Devcich, 2007). Considering belief system in individuals with chronic illness can help health care professionals understand why some people do not respond to educational and treatment efforts (Petrie et al., 2007).

In the literature there are also dissimilarities between ethnic groups in their experiences of diabetes or any other chronic illness. Iranian worldview, spiritual and philosophical values are reflected in their social structure. The religion of Islam is believed to have played a significant role in the development of Iranian worldviews. In Iran, Iranian culture and Islamic religion are intertwined. Islam is practiced by the majority of Iranians and directs many aspects of their personal and social lives. In Iran, the family is the basis of the social structure and the concept of family is more private. Cultural values and religious beliefs are crucial keys in their belief system. In the following section, I will describe two important aspects of belief system: culture and religion.

Culture. Culture is a common pattern of behaviors and interactions that are learned through a process of socialization (Deaux, 2006). Culture includes arts, beliefs, manners, dress, language, religion, rituals, and norms of behavior of a population that are passed down from generation to generation (Sue & Sue, 2003). According to Rovner, Casten and Harris (2013), culture is always mutually influenced by religious, economic, social, political and geographical elements. Health and illness also have different meanings in every culture and thus culture influences diabetes management, response to diabetes education or recommendations on medication, diet and lifestyle (Barnes et al., 2004; Fleming, Carter, & Pettigrew, 2008; Rovner et al., 2003). In this regard, Kleinman (1980, p. 24) argued that “in every culture, illness, the response to it, individuals experiencing it and treating it and the social institutions relating to it are all systematically interconnected.” Culture is also a contributor to the beliefs about disease etiology, interpretation of symptoms, appropriate treatments, proper self-care, preventive treatment and health care beliefs, attitudes and perception of chronic illness and health–seeking behaviors in general, and about diabetes self-care in particular (J.L. Shaw et al., 2013; Larsen, 2006; Rovner et al., 2013).

Cultural differences between health care professionals and individuals with chronic conditions can cause barriers for self-care management in people with diabetes (Nam, Janson, Stotts, Chesla, & Kroon, 2012). According to Singleton and Krause (2009, p. 12) the “culturally bound beliefs, values, and preferences a person holds influence how a person interprets health care messages." Thus, effective treatment plans for diabetes must fit with local, cultural beliefs, values and practices (Smith, Rodriguez, & Bernal, 2011). Culturally adapted self-care education can significantly improve HbA1C and is a strong predictor of medication adherence (S. E. Choi & Rush, 2012; Miller & Rollnick, 2002; Nam et al., 2012; Petrie et al., 2007).

In the literature, role and responsibility within the family and community, the structure of family and social support, food customs, the use of herbal remedies, supernatural causes for life events, and language are the main determinants in culture that may influence behaviors of people with chronic illnesses. In the following section, I will discuss the literature for each of these determinants.

Role and responsibility within the family and community. Roles within the family and community influence self-management practices. Razee et al.'s study (2010) is an example of how women's self-care was neglected when they chose to prioritize family needs. They assessed cultural notions and expectations of being a good mother and wife in Australian women with a history of gestational diabetes from different cultural backgrounds, including Arab and Chinese cultures. Women in their study felt bound to honor their role by taking care of the family's needs first while their own needs came last. The notion of hospitality also affected Arabic speaking women's ability to follow a healthy diet. As a result, they had low levels of healthy lifestyle behaviors. As gestational diabetes is a temporary condition for women in this study, it needs further exploration whether these role challenges remain the same in immigrant women with diabetes. The consequences of role alteration for women within the family and among their friends are also poorly addressed in the literature.

Family and social support. Family and social support are considered important cultural determinants in coping with negative experiences and improving quality of life in people with chronic illness (Oftedal, 2014; Miller & DiMatteo, 2013; Abdoli et al., 2008; Razee et al., 2010; Lundberg & Thrakul, 2011; Singleton & Krause, 2009). Some authors supported the concept of *familism* and *individualism* to explain different roles of family in different cultures. In familism, problem-solving classically occurs within the family, especially with elderly people, and family has priority over the individual. Individualism, on the other hand, concentrates on independent problem solving (Singleton & Krause, 2009). A study by Oftedal (2014) on adult with type II diabetes revealed the importance of family and friends support on diabetes management. The participants perceived support from family and friends in different way: mixed practical support, non-constructive emotional support, and intrusive informational support. Furthermore, the findings indicated receiving mixed practical support, e.g. diet and exercise, from family and friends was very valuable in diabetes self-management. Intrusive informational support (overwhelming and irrelevant information) was perceived as disturbing and did not meet their needs for support in diabetes management and non-constructive emotional support (overwrought response and negative attitudes) demotivated the participants' self-management activities. What was unclear from this study was whether ethnicity played a role in perception and importance of support.

In general, Iranian families are strongly patriarchal with a hierarchical structure. Usually in Iranian cultural structure, males are the head of the household, with women subordinate to men, and youth subordinate to elders (Dhami & Sheikh, 2000, Darvishpour, 2002). The wife does have some influence, particularly on matters related to home and children. The extended family is quite important in Iranian culture and may also play an important role in the medical decision-making process. There are many studies in Iran that indicate the importance placed on family members in everyday decision making, either in health or in illness situations. In terms of diabetes, family support from spouses in particular had a positive effect on controlling blood sugar level and HbA1c (Abdoli et al., 2008; Morowati-Sharifabad & Rouhani-Tonekaboni, 2008). As in many cultures, having an ill family member affects other members of the family especially when a woman (the mother of the family) is the one with a chronic illness. Some aspects of family life change and these changes affect other family members. The life of a woman with diabetes may also be complicated by feelings of guilt and not being “perfect” because of problems in sexual performance, tiredness and so on. The negative aspect of family support needs to be explored more in further studies. Another important question is: do the family structure and roles remain the same when they immigrate to a different country?

Food. Food is an essential part of any culture. What we eat, how we eat, how much we eat, and when we eat reflect the complexity of wide cultural arrangements around food (Koc & Welsh, 2002). Food preference acts as a border that can potentially separate people from different cultures (Naidu & Nzuza, 2013). Like culture, food habits acquired from childhood are long lasting and there is often a resistance to change (Naidu & Nzuza). For example, rice is viewed as an essential food for people in the Middle East and Asia. Some people believe rice is not just a food; it is a fundamental part of their culture. According to Naidu & Nzuza (2013), when a food is a staple for some clients with specific cultural backgrounds, we cannot easily replace it as our clients feel they would be “doing away with their home identity” (p. 200). Food changes in the dietary plan is a major challenge in diabetes self-management in people with different cultural backgrounds; for example, exchanging white rice to brown rice (Lawton, Ahmad, Hanna, Douglas, & Hallowell, 2006; Holmboe-Ottesen & Wandel, 2012). Food challenges in community feasts have been given little attention in the literature.

Supernatural causes for illness. People with chronic illness hold a wide variety of beliefs concerning the causes of illness. Such beliefs vary in every culture and are influenced by many factors, including level of education and cultural background. Belief in supernatural forces, which inflict illness on humans, sees illness as a punishment, or test, from God or the evil eye. This is another aspect of culture that should be considered in a multicultural society. References to the evil eye have been recorded in all countries. It is a widespread belief found in countries such as India, Iran, Turkey, Greece, Italy, Romania, Vietnam and some African countries (Andary, Stolk, & Klimidis, 2003). Examinations of more traditional societies suggest that supernatural beliefs are common (Minas, Klimidis, & Tuncer, 2007). Thus, in many cultures, belief in the evil eye serves as a primary explanatory model for chronic or acute illnesses. Explanatory models include beliefs and expectations about health and illness. Explanatory models of illness are influenced by culture and include how the individual and their family think about the cause, timing and onset of illness, the nature of the pathology, the severity and course of illness, and its treatment (Kleinman, 1980). Belief in supernatural forces, such as the evil eye, is a cultural and religious belief and not only belongs to Islam and Iranian culture. In a study by Minas et al. (2007), causal beliefs of a Turkish immigrant community were assessed for the relative frequency of natural, supernatural, persistence of supernatural beliefs, as well as the frequency of natural beliefs. Several belief types are regarded as causing both mental and somatic illness. Their study also showed that supernatural beliefs are subject to variation within the community studied, based on demographic, modernizing, and acculturative factors and the presence of illness. Understanding the person's explanatory model is very important clinical practice for health care professionals. An understanding of supernatural beliefs is important for the design of a culturally appropriate care plan for diabetes. Moreover, the evaluation of supernatural beliefs on diabetes self-management, or how people expose their supernatural beliefs when they immigrate to a different county, needs further exploration.

Language. Language in its many forms is a primary symbol of culture. There is a close relationship between language and culture; as culture is transmitted through language (Yule, 2010). Knowing about a client's language and culture helps understand their health literacy (Singleton & Krause, 2009). In the health care system, language and literacy barriers adversely affect clinical effectiveness, medical decision-making, medication adherence, and clients' understanding of and access to services (S.P.Taylor, Nicolle, & Maguire, 2013). The concept of health literacy in approaching and improving self-management skills for diabetics is mentioned in many studies (S. Kim, Love, Quistberg, & Shea, 2004; Sarkar et al., 2006; Berkman et al., 2011). Exploring a client's health literacy levels may provide a better understanding of the client's potential barriers to self-management of disease and health-promoting behaviors (Ishikawa, Takeuchi, & Yano, 2008).

Gender differences. Culture determines to a significant extent, gender roles. Researchers indicate that there are some differences in men and women's perception of illness and barriers or facilitators in diabetes self-management. Both within and across different cultures, there is a great difference in standards of desirable gender-role behavior. This gender difference has been found among people with diabetes in some studies. Svenningsson, Marklund, Attvall and Gedda (2011) conducted research to compare obese and normal-weight people with type II diabetes, with a focus on their attitudes towards the disease, quality of life, and treatment, from a gender perspective in Sweden. According to Svenningsson et al. (2011), there is a gender difference in the perceptions of quality of life of people with diabetes. Women generally experience poorer health and quality of life than men. The difference between genders is greater among people with diabetes compared to the general population and is not affected by age. The result also indicated that women with diabetes felt the disease to be overwhelming and difficult to handle, which may cause difficulties that prevent women from achieving metabolic control. Further investigation is needed to identify the relationship of illness perception in different genders within a culture.

Addressing cultural beliefs and practices in health care interventions can lead to better self-management outcomes. According to Kandula, Khurana, Makoul, Glass, & Baker (2012, p. 1308), while “culturally targeted messages” are appropriate, focusing on the surface characteristics of culture, such as food or language, is not a powerful way to change behaviors. It is suggested that health promotion interventions impact behavior change by deep exploration of a culture and insiders’ view about the causes of health, perceptions of symptoms and emotional states, and facilitators or barriers that are unique in each culture, such as religious beliefs, values and gender norms (Kandula, et al., 2012). This is reinforced in a study by Weller, Baer, de Alba Garcia, & Salcedo Rocha (2013), who compared client and physician beliefs about diabetes using an explanatory model framework and tested whether differences in beliefs affect self-management and glucose control in Mexican clients with type II diabetes. They measured the congruence between each client’s responses and an aggregation of the physician responses and then compared the degree of congruence with client self-management practices. The results indicated that greater congruence between a client’s and providers’ beliefs predicted more self-management behaviors. The researchers commented that finding and fostering common ground between clients and physicians in understanding the disease, and establishing shared goals and outcomes for treatment, may help in diabetes management. In other words, a health care professional’s inability to understand the client’s worldview and take into account various aspects of health beliefs and cultural practices can fundamentally undermine effective self-care management support. When forced to choose, people will adhere to basic cultural norms and find it difficult to adapt to recommendations that violate those norms and expectations. The results of this study, and other similar studies, highlight a need to explore the consequences of different explanatory models between people with diabetes and health care professionals from different cultural and religious backgrounds on diabetes self-management.

Culture, thus, can be shaped by many factors including but not limited to religion, race, economic status, level of education, and environmental factors. Although it is wise to avoid underestimating the role of various other factors, Islam is undoubtedly the main factor responsible for shaping Iranian culture. In the following section, I will describe the influence of religion in general, and Islam in particular, and their relationship to health beliefs and behaviors.

Religion. Religion, faith, and spirituality are essential components of one's life experience and identity (Bussema & Bussema, 2000; Daaleman, 2004). In the literature faith, spirituality, and religion sometimes used interchangeably, but in practice are different concepts. According to Jenkins and Pargament (2008, p. 53) religion refers to "organized systems of belief and practice and spirituality is viewed best as efforts to consider metaphysical, or transcendent aspects of everyday life as they relate to forces, supernatural and otherwise, that exist outside of the person". "Spirituality encompasses religion as well as many beliefs and practices from outside the normally defined religious sphere" such as belief in evil eye (Jenkins & Pargament, 2008, p. 53). A person's worldview is closely linked with their personal beliefs and this has profound health care implications (Juckett, 2005). For example, believe in fatalism (i.e., predetermined fate) often caused less adherence to treatment, because people with an illness believe that medical intervention cannot affect their outcomes.

Faith can give all persons in general, and a chronically ill person in particular, a framework for finding meaning and perspective through a source stronger than themselves, and it can provide a sense of control over feelings of helplessness (Koenig, 2002). Many people turn to their faith beliefs when faced with a crisis, such as a chronic illness (Shelton & Mabe, 2006). Religion, faith and spirituality are understood as being essential components of one's life experience and identity (Bussema & Bussema, 2000; Daaleman, 2004). Levin (1994) reviewed the studies linking religiosity measures to a large number of health outcomes, making the relationship increasingly difficult to deny. Levin notes that the validity of this association is substantiated by the literally hundreds of published studies and the positive findings for nearly all ethnic groups and different segments of the population. Aranda (2008, p. 9) defined religious involvement as "encompassing formal, public and collective involvement at worship-related services as well as more informal activities such as private prayer." In the literature, religion is considered a significant factor in individuals' health belief systems, thereby exerting powerful influence on personal perceptions, attitudes, and beliefs toward health care (McAuley, Pecchioni, & Grant, 2000). Mok, Martison, & Wong (2004) in their exploration of the empowerment process in people with chronic illness stated that religious beliefs, in particular belief in the presence of God, are a useful source for their participants. The relationship with God also helped them to accept their illness.

Religion appears to play an essential role in how people with chronic illness understand their illness and positively affects physical and psychological well-being (Schnittker, 2001; Lee & Newberg, 2005; Lauder, Mummery, & Sharkey, 2006). There is evidence in the literature that adherence to religious practices and beliefs may be of great importance to clients with health problems (Halligan, 2006). According to Vonarx & Hyppolite (2013, p. 69) people with chronic illness “endeavor to deepen their religious and spiritual practice and knowledge” and it helps them to confront their suffering. Casarez, Engebretson and Ostwald’s (2010) qualitative study explored the spiritual dimensions of diabetes self-management behaviors in 18 African Americans living with type II diabetes. They indicated how spiritual practices were integrated into spiritual orientation and how spiritual practices in each orientation could be integrated into a diabetes self-management program. The researchers showed how certain spiritual practices affect self-management.

There are some studies that indicate spiritual practices are a major facilitator in self-management of diabetes among different ethnicities (Utz et al., 2006; Jones et al., 2006). Both these researchers conducted focus group interviews with people with type II diabetes to identify barriers and facilitators to self-management. Participants reported that prayer and faith helped them make daily decisions, such as deciding what foods to eat. Prayer also gave them the daily strength in caring for their diabetes. Polzer and Miles (2007) conducted a grounded theory study to examine how spirituality affected self-management of diabetes. The core construct identified was self-management through a relationship with God. Within this broad construct there were three categories of how participants managed their diabetes through a relationship with God: God is in the Background (participants accepted personal responsibility for self-management), God is in the Forefront and God is Healer. For the group in God in the forefront, they participated in their relationship with God by performing diabetes self-management activities, performing spiritual practices, and having faith that God would give support in managing the illness. When their participants considered God as a Healer, they believed that if the person with diabetes had enough faith, God would cure them and that self-management was not necessary.

These participants did perform self-management activities, but said they were working toward having the level of faith needed to cure the illness.

Although there is much literature that indicates spiritual and religious beliefs help people with chronic illness to confront their daily life challenges, an understanding of religious involvement on health outcomes is still incomplete. We also have some counter arguments in the literature that revealed the negative effects of religion on people's experiences and perception of chronic illness. Some studies (Zwingmann, Wirtz, Muller, Korber, & Murken, 2006; Nelson, 2009; Flannelly, Ellison, & Strock, 2004), for example, mentioned that certain religious beliefs may lead people with chronic illness to interpret their illness as a sanction or punishment from God, causing feelings of abandonment, guilt and emotional distress, resulting in a reduction of self-management behaviors. More work is required to understand fully when religion is a facilitator and when it is a hindrance to self-management.

Islam in Iran. Islam is the main religion for Iranian people around the world. Islam provides a way to live life through a number of commands and prohibitions covering every aspect of individuals' lives. The Islamic teachings and laws basically come from two sources, the Quran (the Holy Book revealed to Allah's last messenger) and the Sunnah (sayings and sanctions of the Prophet Mohammad; peace be upon him). The five pillars of Islam are the announcement of faith, praying five times a day, Zakat (giving to the poor), fasting during the month of Ramadan, and the Hajj (pilgrimage to Mecca once in a lifetime) (Al-Oballi Kridli, 2011). Muslims believe that throughout life they are tested and challenged by Allah and that one's consistent and unwavering faith will lead them to their reward, which is the gift of Junnah (Paradise): "Peace be upon you because you have persevered in patience! Excellent indeed is the final home (Paradise)" (Quran, 13:24, trans. 2001).

Muslim perceptions of health and health practices find their basis inIslam. Islam views health from a holistic perspective and advocates primary health by prescribing guidelines and regulations for cleanliness, food consumption, modesty and almost every other aspect of life. Muslims view Allah as the source of both health and illness (Kulwicki, Miller, & Schim, 2000). Based on Islamic teachings, injury and illness can happen for many reasons, however it is important to acknowledge and accept that nothing happens in this world accept with the permission of God (Stacey, 2009):

> And with Him are the keys of the unseen; no one knows them except Him. And He knows what is on the land and in the sea. Not a leaf falls but that He knows it. And no grain is there within the darkness's of the earth and no moist or dry [thing] but that is [written] in a clear record. (Quran 6:59)

Islamic faith encourages healthy lifestyles, and the family has a central role. Muslim communities, based on their interpretation of Islam, may also share meanings and cultural worldviews associated with illness and healing (Laird, Amer, Barnett & Barnes, 2007). The physical body has rights in Islam and Muslims are encouraged to seek medical treatment. Illness and health have a spiritual or "heart" dimension, and illness may be construed as a divine test or an opportunity to purify the soul (Laird et al., 2007).

> Blessed is He in Whose hand is the Sovereignty, and, He is Able to do all things. Who had created life and death that He may try you, which of you is best in conduct; and He is the Mighty, the Forgiving. (Quran 67:1, 2)

The Prophet Mohammad (pbuh) said, "no fatigue, no disease, nor sorrow, nor sadness, nor hurt, nor distress befalls a Muslim, even if it were the prick he receives from a thorn, but Allah expiates some of his sins for that" (Khan, 1994, p. 934).

My literature search revealed relatively little research published on Muslim health beliefs, in particular from the perspective of Muslims with chronic illness. However, examining the perceived roles of God (or Allah) is important, because for Muslim people who have strong religious convictions, God plays a major role in health belief systems, which, in turn, might influence health behaviors (McAuley et al., 2000). For many Muslims, their religious beliefs are an integral part of the way they live their lives, and invoking Allah forms part of their daily conversation (Ott, Al-Khadhuri, & Al-Junaibi, 2003). In Yehya and Dutta's study (2010) of elderly women in Lebanon, health was intrinsically tied to their faith. Their participants believed modern medicine was an invader that spoiled the sanctity of the sacred space. Farahani et al.'s (2008) study in Iran indicated some clients are not willing to be educated because they think that their illness has been determined by God, and therefore they do not consider themselves to be involved in the eruption of the disease or in the prevention of its progress. In other words, disease was a divine determination. Ypinazar and Margolis (2006) found in their research that concepts about the origins, nature, cause, consequences, and interventions of health, illness, and disease among older Arabian Gulf Arabs appear heavily influenced by their strong connections to Islam and their traditional culture. Their study provides an insight into how elderly Muslim Arabian Gulf Arabs understand and perceive health and illness, with a focus on the place and impact of Islam on their health care beliefs. In this study, the two major themes of the role of religion and the meaning of health and illness were identified. In the participants in this study, religion is considered as a significant factor in individuals' health belief system. Religion also had a powerful influence on personal perceptions, attitude, and beliefs toward self-care. Ott et al. (2003) also state that for many Muslims in health or illness, religious beliefs are an integral part of the way they live their lives. Although Ypinazar and Margolis' study provide us with a comprehensive insight into the perception of Muslims with chronic illness, more investigation is needed in this area because this research was limited to elderly Muslims with different chronic illnesses. Having a chronic illness in different stages of life may produce different perceptions of illness, even when there is a common belief system such as Islam. In other words, the Muslim population cannot be considered a homogenous group, as it has a diversity of cultures and customs (Daar & Al Khitamy, 2001; Rassool, 2000).

Among the five pillars of Islam, fasting in Ramadan is related to health and illness among Muslims. During this month, Muslims abstain from eating and drinking from sunrise to sunset. Fasting in Ramadan provides an opportunity for Muslims to learn self-restraint from everyday pleasures and practice self-discipline, as it is an important spiritual practice (Al-Oballi Kridli, 2011). Fasting also helps to purify the body; feel compassion and empathy towards the poor and control our desires (Cross-Sudworth, 2007; Zaidi, 2003). As stated in Quran; "O you who have believed, decreed upon you is fasting as it was decreed upon those before you that you may become righteous" (Quran; 2, 183).

Based on Islamic law there is an exemption from fasting during Ramadan for the sick, menstruating women, people who are traveling, elderly, those breastfeeding infants and pregnant women, and those unable to understand the purpose of fasting during Ramadan (Ertem, Kaynak, Kaynak, Ulukol, & Gulnar, 2001; Pearce & Mayho, 2004; Robinson & Raisler, 2005; Zaidi, 2003). Despite their illness, the Muslim client may try to fast during Ramadan regardless of medical advice (Ahmad, 2004). Many Muslims with diabetes may not perceive themselves as sick and are keen to fast (Hui et al., 2010). Quran states:

> ".... and whoever is ill or on a journey—then an equal number of other days. Allah intends for you ease and does not intend for you hardship and [wants] for you to complete the period and to glorify Allah for that [to] which He has guided you; and perhaps you will be grateful" (Quran; 2, 183).

Diabetes is the most commonly studied disease in Ramadan due to the complicated management of this disease while fasting (Al-Oballi Kridli, 2011). Studies indicate that many diabetic Muslims do not seek medical advice regarding managing their illness during Ramadan for fear of being discouraged from fasting (Pathy, Mills, Gazeley, Ridgley, & Kiran, 2011; Pinar, 2002). There are many recommendations given in managing diabetes during Ramadan in the literature regarding management of diabetes for these people who are willing to fast. For example, Hui et al. (2010, p. 1408) mentioned some people with diabetes are able to fast during Ramadan, if they receive “Ramadan focused education” for diet management while fasting, such as considering a pattern of eating at night rather than through the day. The desire to fast by people with diabetes may be difficult to understand for health care professionals who are outside of the Muslim socio-cultural and religious contexts. It seems this issue is a very challenging one for health care providers. Accordingly, nurses and other health care providers are faced with a difficult task of providing medical advice to Muslims with diabetes regarding health issues related to fasting during the month of Ramadan (Josooph, Abu, & Yu, 2004).

In summary, beliefs and value systems about health and illness influence individuals’ interpretation of illness, experiences with illness, and the actions they take in response to illness. Belief systems also influence health care seeking and help people cope with life. Illness perception is also considered important for predicting self-management behaviors and perceived control of illness (Hagger & Orbell, 2003; Hjelm et al., 2003; Lakshmi et al., 2014). Lack of understanding of an individual’s belief system and illness identity (illness perception) may cause failure in the management of chronic illness and have a major impact on the individual and family’s adjustment and ability to manage the illness. In the following section, I will explain more about illness identity in relation with diabetes self-management.

Illness Identity (Illness Perception)

Illness identity is different from person to person, even within the same culture. Tyler and Blader (2003) stated that “an individual’s feelings about themselves are based on their sense of self (personal identity) and their feelings about the status of the groups to which they belong (social identity)” (p. 220). Leventhal, Leventhal, & Contrada (1998) defined illness identity as the label people place on their health threat. According to Paterson (2001), an illness perspective is a combination of the individual’s belief, perception, expectation, attitude and experience about a particular chronic illness. Illness identity is about perception of how long the illness will last (timeline), how serious it is or is likely to become (consequences), what might have caused it (cause), and whether it can be treated or controlled (control-cure) (Leventhal et al., 1998). Illness identity is influenced by factors such as cultural and religious beliefs and social relationships.

The relationship between perspectives about illness and health-related outcomes has been broadly studied. According to Abdoli (2011), illness perceptions are modifiable risk factors for depression and anxiety in some people with chronic illness. Morgan, Villiers-Tuthill, Barker, & McGee (2014) stated that negative illness perception negatively influences emotional adjustment and health-related outcomes in people with chronic illness. Many studies demonstrate that contradictory identities, such as feeling unable to maintain social roles or functions, have a negative effect on medication adherence (Kucukarslan, 2011; Searle, Norman, Thompson, & Vedhara, 2007) including making alterations to treatment regimens, skipping doses or splitting tablets when not advised to do so (Aflaksheir, 2012; Chen, Tsai, Lee, 2009). A sense of threatened identity was the main social problem that the people with diabetes experienced (Abdoli, Ashktorab, Ahmadi, Parvizy, & Dunning, 2014) and it is suggested that social roles might be impossible to maintain with diabetes (Aujoulat, Luminet, & Deccache, 2007). Another study that was conducted in Iran also indicates that diabetes can be a threat to self-identity (Abdoli, Mardanian, & Mirzaei, 2012). They noted that having diabetes for their participants meant being different, with loss of control over one's body and life, fear of disability and diabetes complications and being dependent on insulin. Alavi et al. (2007) found in their study that most people with diabetes in Iran declared that they preferred to hide their disease and that this had caused them unnecessary stress. Farahani et al.'s study (2008) also highlights this behavior. They stated one of the major challenges for health team members in Iran is the concealment of disease diagnosis in people with chronic illnesses. As noted above, in Iran a client may not be informed of the diagnosis of chronic illnesses, such as cancer, because in Iranian culture it is the physician who tells the client's family about the diagnosis and the family may believe that the client should not know the diagnosis. Alvai et al.'s study also shows that diabetic people in Iran tend to equate diabetes with complications such as amputation or blindness. Thus, there is some evidence that illness identity has a profound impact on individuals' self-management behaviors.

Overall, studies in Iran indicate that the cultural norms around the role of the family in the context of illness may result in delaying communication of the diagnosis to the person concerned, which inevitably increases the possibility of complications. It would appear that part of understanding how people respond to differing states of health is not only dependent on their family and social support, and their personal belief systems, but it is also dependent on whether or not they feel empowered to adapt and change to their new situation. A question remains unanswered about whether Iranian people still hide their diabetes and its symptoms when they immigrate to a different country.

A different group of people with diabetes may view having diabetes as a reason for a healthier lifestyle, encouraging them to change their habits. Yamakawa and Makimoto (2008) explored the existence of positive experiences in clients with type II diabetes amongst Japanese people. The positive experiences resulting from the development of diabetes included: (1) positive appraisal of the stressor (opportunity for lifestyle change, feeling secure, pleasant surprise); (2) diversion (participants divert their attention from diabetes to cope, pursuing an individual way of life and enjoying a healthy life); and (3) bonding to a new social network or improved relationships with their family. According to the researchers, regardless of the duration of illness, age, and presence of other complications, all their participants had positive experiences of developing type II diabetes. Sometimes people in the first group (illness has negative and destructive effect) try to restore their previous identity by various strategies. Abdoli et al. (2014) indicated at the beginning, some individuals with diabetes selected doubt or silent trust, but eventually they admitted there is no escape from reality and they need to accept diabetes in their life.

In summary, the way individuals view their illness and how it affects their lives is central to understanding how they respond to health professionals' advice and treatment plans. Illness identity is not a fixed perspective, it tends to change over time and is influenced by the individual's life experience, significant others, their social environment, ethnicity, culture, gender and spirituality as well as psychosocial, biological, education level, and economic factors (Abdoli, 2011; Downe-Wamboldt & Coulter 2006; Mu'Mina Chowdhury, Helman, & Greenhalgh, 2000; Bhushan Gupta, 2010; Thompson & Gifford, 2000; Poss & Jezewski, 2002; Fleming et al., 2008). A better understanding of the types of beliefs that are associated with diabetes self-management is very crucial for health care professionals. The relationship between immigration and diabetes self-management is addressed in many studies (Park, Nam, & Whittemore, 2015; Cha et al., 2012). In the following section I will explain more about immigration, acculturation and the relation to health.

Immigration, Acculturation and Health

Immigration is a significant component of globalization and remains an important force shaping Canadian identity (Gushulak, Pottie, Roberts, Torres, & DesMeules, 2011). In recent years there has been a marked increase in the numbers of immigrants coming to Canada from different countries and cultures. According to statistics Canada, about two-thirds of the population growth in Canada in 2013 was because of immigration, up dramatically from one-third in the mid-1970s (Statistic Canada, 2016, para.4). Statistics Canada in 2015 indicated 3.2% of the population identified themselves as Muslim. Many Muslims in Canada are new immigrants from a wide variety of countries including Arab and non-Arab countries (Statistic Canada, 2015).

Immigrating to a new country and living with people from a different cultural background with no shared past, leads to numerous changes. Immigrants leave their countries for a variety of reasons including studying, economic hardship, or political unrest. Immigrants have to make new connections between their past and their present and make it meaningful for their future (Lago & De Abreau, 2008). Often when people immigrate to a different country, they may continue to rely on their own unique and long-standing cultural beliefs, practices, and support systems and these may not be the same as those in the host country. Their concerns and the ways of addressing needs may also be different.

When immigration is layered with a chronic illness, coping with the illness becomes more complicated. Health care practices in immigrants usually are shaped by their homeland values, cultural attitudes and traditional health practices (J. Y. Choi, 2008). The problems that individuals who immigrate to different social and cultural contexts may encounter include language barriers and lack of culturally adapted programs (Ngo-Metzger, Legedza, & Phillips, 2004). Barriers to an appropriate use of the health care system by immigrants may also include language insufficiency, lack of same-sex providers (McKeary & Newbold, 2010; Ng & Newbold, 2011; Grondin, 2007), and limited knowledge about available services for immigrants (Donnelly & McKellin, 2007). Research specific to Iranian Canadian people identifies key barriers as lack of knowledge of the Canadian health care service and lack of trust in Canadian health care services (Dastjerdi, Olson, & Ogilvie, 2012).

Gender is an integral part of the migration process (Boyd & Grieco, 2003) and it plays a significant role in managing a chronic illness following immigration. The migration experiences of women fundamentally differ from those of men, and women’s health seems to deteriorate more than men’s (Vissandjée, Hyman, Spitzer, Apale, & Kamrun, 2013). The interaction of women's roles, status, and age within a particular socio-cultural context can affect immigration experience (Boyd & Grieco). Family roles and relationships in type II diabetes in the Van Dam et al. (2005) study are recognized as vital to effective management and quality of life in immigrants. According to Wynaden et al. (2005), all cultures have a health belief system that determines how people will respond to illness and seek help in a different country with a different cultural background.

In the following section, I will discuss how immigrants and members of minorities deal with acculturation issues. I will also examine these issues through presenting different studies on people with chronic illness who immigrate to different countries.

Acculturation

Acculturation is defined as behavior and attitude changes that occur as a result of interaction among different cultures (Kottak, 2012). These changes include language, food, clothing, values, and beliefs (Yoost & Crawford, 2015). In acculturation, elements of two cultures have mutual influence on each other (Maxwell, 2002). In Berry, Trimble, and Olmedo's (1986) seminal work, four variations of acculturation are: (a) assimilation (movement toward the host culture or society), (b) integration (holding on to or maintaining cultural integrity), (c) rejection (reaffirmation of the traditional culture or withdrawal from the larger society), and (d) marginalization, or de-culturation, which means alienation from both cultures so that the group or individual is out of cultural and psychological contact with either their traditional culture and the host culture. Contemporary research has primarily focused on different strategies of acculturation and how variations in acculturation affect the ability of individuals to adapt to their host society. There are many factors that can contribute to these variations, including the level of acculturation of a particular group (Maxwell, 2002). Many studies have been conducted to examine the relationships between acculturation and health behaviors. Associations between acculturation and increasing rates of diabetes, obesity, coronary artery disease risk, and poor diet have been identified in various studies on different ethnic groups. For example, higher levels of acculturation were significantly associated with higher BMI in Latino-Americans (Hubert, Snider, & Winkleby, 2005) and Asian-Americans (Novotny, Williams, Vinoya, Oshiro, & Vogt, 2009; Deng, Zhang, & Chan, 2013).

Acculturation is also significantly associated with diabetes self-management (Xu, Pan, & Liu, 2011; Mainous, Diaz, Geesey, 2008; Venkatesh, Brown, & Bala, 2013). Another study by Xu, Pan, and Liu examined the level of acculturation and its relationship with diabetes self-management behaviors among Chinese Americans with type II diabetes. The results indicated that the majority of participants were born outside the U.S. and had a low level of acculturation. Women and older individuals were less acculturated, and those who had higher social economic status and lived in the U.S. for a longer period were more acculturated. The authors found increased acculturation was associated with increased help seeking behaviors and increased use of professional services. A study by Chesla, Chun and Kwan (2010) also examined how acculturation affects type II diabetes management and perceived health for Chinese American immigrants in US. The results indicated that cultural adaptation experiences affected diabetes management in different ways: (a) utilizing health care, (b) maintaining family relations and roles, and (c) establishing community ties in the U.S. Kandula et al. (2008) indicated as well, that acculturation was associated with the prevalence of diabetes. This multi-ethnic study reported that higher acculturation was significantly associated with the increased prevalence rate of diabetes in non-Mexican-origin Hispanics in the United States. Huang et al. (1996) also showed a higher prevalence of diabetes in Japanese-American men who were acculturated to a Western lifestyle compared to those who retained a more Japanese lifestyle. Jaber, Brown, Zhu and Herman, (2003) reported that lack of acculturation was an important risk factor for poor control of diabetes in 542 Arab Americans. The researchers believed lack of education, little social activity, not being employed outside the home and following an Arabian meal plan, with heavy foods, and high in fat and sugar caused low acculturation across the participants. Therefore, the illness-acculturation link may depend on the characteristics of the host country situations as well as the immigrant group from different cultures.

There is growing body of research identifying the challenges to illness management for immigrants such as dietary habits, language difficulties and education. There has not been any research yet to determine the interaction between levels of acculturation and diabetes for Iranian Canadian people or for women in particular. There is a need to integrate these considerations in health education for immigrants living with diabetes. It seems obvious that health educators who understand and take into account the level of acculturation in a target population will be better able to design effective programs of self-care behaviors.

Conceptual Framework of the Study

Coming to terms with a diagnosis of a chronic condition is a major transition. It is another major transition to acknowledge, accept and integrate it. Having a chronic illness is a major life transition because it profoundly alters one's sense of self and requires constant lifelong adjustment in managing the condition and living as well as possible. Changes are often necessary in all aspects of life including one's s physical, mental, social, spiritual and emotional self, as well as relationships with others, in particular family. In essence, people with chronic illness need to find a new way to live.

Over the past 50 years, several theories of chronic illness have been proposed to conceptualize the experience of living with chronic illness and to understand and predict lifestyle and behaviors. In this section I present a review of literature relating to some of the more common theories and models, and outline the central elements of the more prevalent conceptualizations. These cognitive theories or models include: Health Belief Models (HBM) (Hochbaum, 1958), Trans Theoretical Model (TTM) (Prochaska, 1979), The Theory of Planned Behavior & Theory of Reasoned Action (TPB) (Ajzen, 1985; Ajzen & Madden, 1986), Shifting Perspective Model (Paterson, 2001), and Transition Theory (Shumacher & Meleis, 1994).

The Health Belief Model (HBM) is a psychological model that attempts to explain and predict health behaviors by focusing on the attitudes and beliefs of individuals (Rosenstock, 1990). The Health belief model (HBM) has 4 constructs (perceived susceptibility, seriousness, benefits, and barriers) that are proposed to vary between individuals and predict engagement in health-related behaviors (e.g., getting vaccinated, getting screened for asymptomatic diseases, exercising). Self-efficacy was added to the four components of the model in an attempt to better explain individual differences in health behaviors. Self-efficacy in this model refers to an individual's perception of his or her competence to successfully perform a behavior (Rosenstock, Strecher, & Becker, 1988; Glanz, Rimer, & Viswanath, 2008). These constructs are further supplemented by an additional component referred to as “cues to action” which trigger actual adoption of behavior. Nisbet and Gick (2008) summarize the model as follows:

> In order for behavior to change, people must feel personally vulnerable to a health threat, view the possible consequences as severe, and see that taking action is likely to either prevent or reduce the risk at an acceptable cost with few barriers. In addition, a person must feel competent (have self-efficacy) to execute and maintain the new behavior. Some trigger, either internal ... or external ..., is required to ensure actual behavior ensues. (p. 297)

There are a number of reviews and studies that use this model as a framework (Rutter and Quine, 2002; Munro, Lewin, Swart, & Volmink, 2007; Nisbet and Gick, 2008; Webb, Joseph, Yardley, & Michie, 2010). While the HBM attempts to forecast health-related behaviors, it does not account for other factors that influence health behaviors, such as habitual health related habits like smoking, and environmental factors outside an individual's control (Janz & Becker, 1984). Furthermore, the health belief model is inadequate as a basis for understanding the impact of emotions on health-related behavior (Glanz et al., 2008; Jackson 2005). Thus this model does not explain all aspects of people’s behavior while they struggle to learn to live with diabetes within the context of immigration transitions.

Trans Theoretical Model (TTM), or the Stages of Change model, is a cognitive based, and sub-divides individuals between five categories along a continuum of behavior change. These stages are (1) pre-contemplation (not ready), (2) contemplation (getting ready), (3) preparation (ready), (4) action, and (5) maintenance (Prochaska & Velicer, 1997). The authors stated that the research related to the Trans Theoretical Model shows that interventions to change behavior are more effective if they are “stage-matched,” that is, “matched to each individual's stage of change.” Questions regarding what these stages actually are and whether an individual must move through each (and not jump stages) are common. This model does not explain how individuals change or why some change more effectively or quickly than others (Morris, Marzano, Dandy, & O’Brien, 2012). In addition, the model does not focus on the social context in which change occurs, such as socio-economic status and income (Nisbat & Gick, 2008).

The theory of planned behavior (TPB) is also a cognitive approach to explaining behavior which focuses on individuals’ attitudes and beliefs. The key component to this model is behavioral intent. Behavioral intentions are influenced by the attitude about the likelihood that the behavior will have the expected outcome and the subjective evaluation of the risks and benefits of that outcome (Fishbein & Ajzen, 1975). This theory has been applied in studies on the relations among beliefs, attitudes and behavioral intentions. The theory of planned behavior model is thus a very powerful and predictive model for explaining human behavior (Liou & Bauer, 2007). The theory of planned behavior overlooks, however, emotional variables such as threat, fear, mood and negative or positive feeling (Dutta-Bergman, 2005). It also assumes that behavior is the result of a linear decision-making process, and does not consider that it can change over time. Thus it cannot explain behaviors over time.

I explored the above theories as they sought to illuminate how and why people chose to change their behavior. I was looking for a model or models that would help me to have a holistic view of my participants' experiences. I discovered that these frameworks, though useful, would not help me to understand the whole picture of living with diabetes in immigrant Iranian women. I needed to search more broadly.

I thought about how diabetes poses many challenges due to its characteristic pattern of controlled or uncontrolled blood glucose and how it affects all aspects of one's life, and how one's perception of disease and one's self-management behaviors change over time. I also recognized that immigration and the experience of living with diabetes in a different country could be described as an ongoing transition process. This led me to look at transition theory as espoused by Meleis et al. (2000). Transition theory can provide an appropriate framework for exploring the experience of individuals with diabetes who immigrated to Canada. The concepts and assumptions in this model reflect the kind of sensitivity and transformative understanding that does not assume there will ever be a linear-rational adaptation to diabetes, but that there will be shifts back and forth depending on the context of people's lives. At the same time, I also saw that the Shifting Perspectives Model by Paterson (2001) could also help me to provide an explanation of why there is variation in attention to symptoms over time, "sometimes in ways that seem ill-advised or even harmful to their health" (p. 25). Concepts inherent in both these models are culturally sensitive, so one can appreciate not only the changes that diabetes brings to these women's lives, but also the cultural contexts that frame so many of their understandings about daily life. For these reasons, I have selected these two models as the conceptual framework for this study: transition theory (Meleis et al., 2000; Meleis 2010) and the shifting perspective model developed by Paterson (2000). In the following sections, I will describe these models in terms of their main concepts and underlying assumptions, their empirical support and contributions to chronic illness research.

Transition Theory

Transition theory explains the experience of moving from one status or condition to another. Transitions are complex, multidimensional processes, which can include health and illness experiences as well as life transitions, such as immigration (Meleis et al., 2000; Meleis, 2007). All transitions are characterized by flow and movement over time and can cause changes in identities, roles, relationships, abilities, and patterns of behavior. Major concepts of the middle range theory of transition include the following: (a) types and patterns of transitions including situational or health/illness; (b) properties of transition experiences including multiplicity and complexity; (c) transition conditions (facilitators and inhibitors); (d) process indicators; (e) outcome indicators; and (f) nursing therapeutics (Schumacher and Meleis, 1994; Alligood & Marriner-Tomey, 2010; Meleis, 2010) (Figure 2.2). The primary study by Meleis et al. (2000) focused on gaining a rich description of the nature of the transition, including types, patterns and properties.

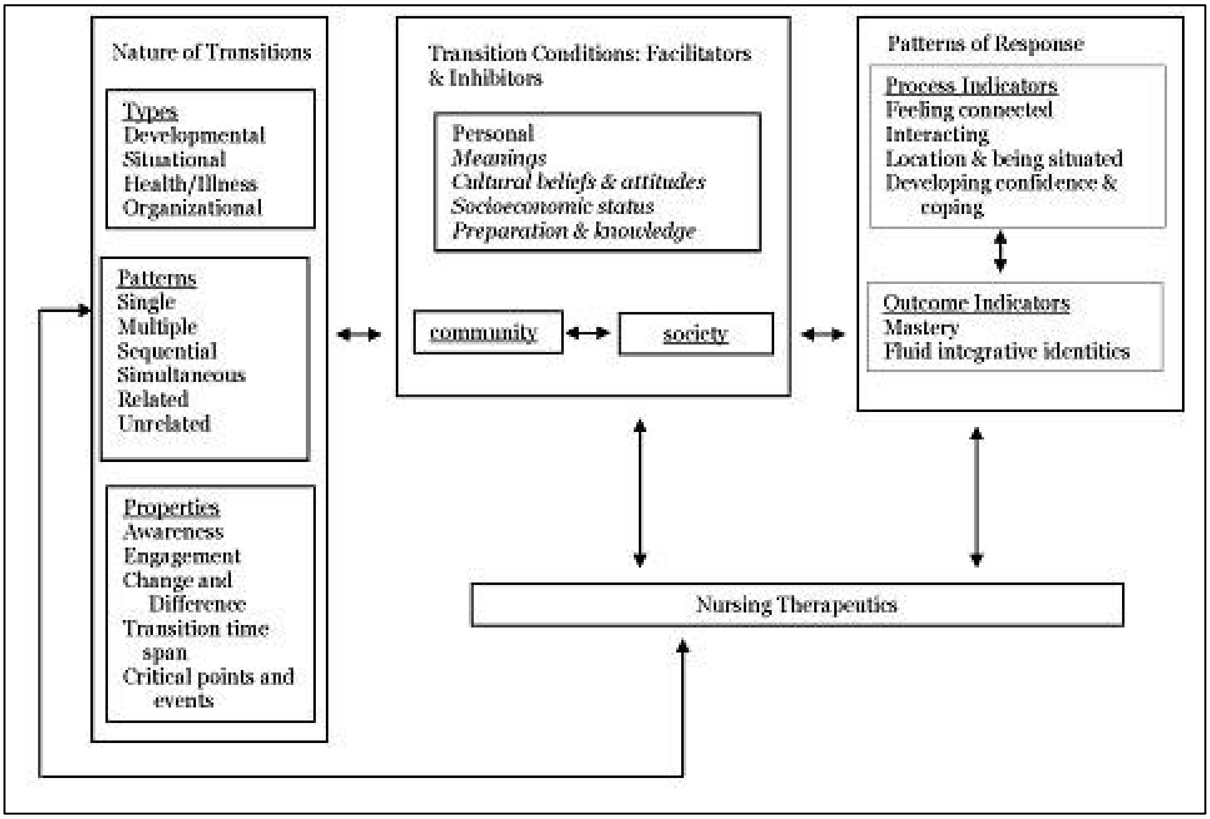

Figure 2.2 Transitions: A middle-range theory. Adapted from: Meleis, A.I., Sawyer, L.M., Im, E.O., Schumacher, K., and Messias, D.K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science, 23*(1), 17. Reprinted with permission.

Types and patterns of transition. Meleis et al. (2000) propose four different types of transitions. The types of transition that individuals and families encounter include developmental, situational, health and illness, and organizational. Examination of the patterns of transition indicates that transition experiences are complex, and often associated with multiple transitions (Meleis et al., 2000), occurring sequentially or simultaneously. It is important to consider whether multiple transitions are related or unrelated to each other (Meleis et al., 2000).

Properties of transition. Transition experiences are unique to individuals. However, there are five interrelated components, or properties, that can be identified in all transitions. These include awareness, engagement, change and difference, time span, and critical points and events (Meleis et al., 2000).

Awareness. According to Meleis et al. (2000), awareness is an individual's recognition and perception of the transition. An individual’s level of awareness will greatly impact the transition experience. Awareness is often gauged by comparing what the individual perceives about his or her transition with an established set of parameters experienced by other individuals undergoing a similar transition (Meleis et al., 2000).

Engagement. Based upon a foundation of awareness, the individual may become involved, or engaged, in the transition. Engagement is demonstrated by active participation in preparing for and facing challenges through seeking information and altering activities (Meleis et al., 2000).

Change and difference. Two closely related properties of transition are change and difference. According to Meleis et al. (2000) and Kralik (2002) change and difference are essential properties of transitions. Change may be associated with disruptions in routines or with a specific “critical or dis-equilibrating event” (Meleis et al., 2000, p. 19). Difference is “exemplified by unmet or divergent expectations” (Meleis et al., 2000, p. 20).

Time span. Transitions are “characterized by flow and movement over time” (Meleis et al., 2000, p. 20). Some transitions have a clearly defined beginning and end, but many transitions are not amenable to clear boundaries (Meleis et al., 2000; Skärsäter & Willman, 2006).

Critical points and events. Most transition experiences include a number of critical points. These critical points often involve an event where an individual’s awareness of changes and differences is increased, or where the individual becomes more engaged in the transition (Meleis et al., 2000).

Transition conditions. Transition theory provides ‘‘conditions’’ that influence the way people move through a transition and the conditions can be conducive to a smooth transition (facilitator), or they may place the person at risk for a difficult transition (inhibitor) (Meleis et al., 2000). These conditions include meanings, expectations, level of knowledge and skill, environment, level of planning, and emotional and physical well-being. Meleis (2007) concluded that identification of conditions that facilitate or inhibit progress toward 'achieving a healthy transition' is crucial (p. 20). For Meleis people have a "healthy transition" when they were feeling connected, being settled and developing confidence, and coping and mastering new skills (Meleis et al., 2000). It is obvious that different transitions, or changes, can impact an individual's health in different ways. Recognizing these impacts can help health care professionals in designing appropriate interventions.

Patterns of response. Patterns of response are conceptualized as process indicators and outcome indicators. These process indicators and outcome indicators characterize healthy responses.

Process indicators. The process indicators suggested by Meleis et al. (2000) include feeling connected, interacting, being situated, and developing confidence and coping. The need to feel and stay connected is a process indicator of a healthy transition.

Outcome indicators. The outcome indicators suggested by Meleis et al. (2000) include mastery and fluid integrative identities. A healthy completion of a transition can be determined by demonstration of the mastery of the skills and behaviors that are needed to manage their new situations or environments.

Application to chronic illness research. Transition theory, cited as the theoretical foundation for many studies, has provided the basis for a number of situation-specific theories related to transitions (Hattar-Pollara, 2010; Meleis, 2010). This theory assists us in understanding the complexity and multidimensional nature of living with chronic illness. Transition theory provides a comprehensive view of people’s experiences with chronic illnesses, in particular during periods of change in their lives while emphasizing the contexts within which people are experiencing their transition (Shumacher & Meleis, 1994; Shaul, 1994).

Transition theory has been used in many studies that addressed changes or processes in participants; for example, clients’ experiences of health transitions in pulmonary rehabilitation (Halding & Heggdal, 2012), transitions in women with rheumatoid arthritis (Shaul, 1997), perceived readiness for hospital discharge in adult medical-surgical clients (Weiss et al., 2007), Swedish elders admitted to rehabilitation following hip fracture (Olsson, Nystrom, Karlsson & Ekman, 2007), the transition towards end of life experienced by cancer clients in palliative care (Larkin, Casterlé, Dierckx, & Schotsmans, 2007) and a study by Kralik (2002) with midlife women living with adult onset chronic illness. In Kralik’s study, 81 women were asked to tell their stories of living with a chronic illness over a one-year time frame. The results revealed that when women are first confronted with a chronic illness they appear to move through a complex trajectory that involves an extraordinary phase of turmoil and distress; however, they might then make the transition toward an ordinary phase that involves incorporating chronic illness into their lives. The most important finding was that transitions in a chronic illness experience involve movement from extraordinariness to ordinariness and sometimes back again. These transitions were found to be processes that are nonlinear, sometimes cyclical and potentially recurring throughout a woman’s life. Women in Kralik’s study mentioned that their “lives characterized by changes in feelings and behaviors that evolved over time” (p. 151). Although transition was dynamic for participants they experienced episodes of uncertainty and exacerbation of illness, as well as times of illness stability. Kralik concluded that understanding illness transitions offers a framework that will enable nurses to move beyond traditional chronic illness management towards a holistic approach to the provision of nursing care. There is also a need for knowledge of the transition of learning to live with diabetes in order for health care staff to understand how to facilitate the transition process to help people with diabetes to be more active and feel responsible for their health and care.

The transition framework was also tested in a number of studies to describe immigrants' transitions. Im, Meleis and Lee (1999) conducted a study guided by transition and feminist approaches to explain symptom experience during menopause in low-income Korean immigrant women. One of the transition conditions–emotional and physical well-being–was operationalized as a symptom in their study. Through interviews the data showed that a major conceptual category that emerged was neglecting and ignoring the menopausal transition because of other imminent demands in the women's lives, such as immigration, new work experiences, and the patriarchal cultural heritage that makes women's experiences invisible and inaudible. The findings also indicated that the women's symptom experience was different according to other contextual variables including family income, education, and work satisfaction. The results revealed cultural differences in symptom experience during menopausal transition, and the importance of immigration transition and above contextual variables.

Overall, based on the research of people with chronic illness, there was no single recognizable end point at which the health and illness transition is complete (J.M. Anderson, Blue, & Lau, 1991). Transition is not linear and people with chronic illness may go forward and backward in the transition process. In contrast, transition theory does seem to suggest an almost linear trajectory that involves distinct start and finish points. Kralik (2002), however, proposes that transition does not follow a chronological trajectory. Likewise Paterson (2001), who explained a 'shifting perspectives' model of chronic illness, also challenges the notion of a linear trajectory in transition. Patterson (2001) proposed that learning to live with chronic illness is an ongoing process involving movement in many directions. As an illness trajectory is not straightforward, the Shifting Perspectives model can help us to understand these changes and movements better. The Shifting Perspective model may also be helpful to describe different experiences through the life journey with chronic illness. In the following section, I will describe this model.

Shifting Perspective Model

The Shifting Perspective Model helps us to explain different perspectives of having chronic illness. Paterson (2001) developed the Shifting Perspectives Model of Illness following a meta-synthesis of 292 qualitative studies of chronic illness. Based on this synthesis, Patterson suggests that the experience of living with a chronic illness is an “ever-changing process” (Paterson, 2001, p. 22). The Shifting Perspectives Model of chronic illness considers living with chronic illness a process of continually shifting between the perspectives of wellness in the foreground and illness in the foreground, “in order to make sense of one’s world at the time” (Paterson, 2003, p. 987). Although individuals may have a preferred or fixed outlook, they are likely to shift between the two several times over the course of their illness experience. According to Paterson, when people with chronic illness assume an illness in the foreground, they focus on the sickness and the burdens, suffering, and loss associated with it. At this time, their illness is considered as negative to self and to others in their lives. This is frequently seen in individuals who have been newly diagnosed. When people have this perspective, they may have difficulty considering the needs of significant others. Paterson believes that when people assume this perspective, they are able to learn about their disease. Focusing on the illness may also help people with chronic illness seek attention from their family or health care professionals (Paterson, 2001).

The second perspective that people may consider is wellness in the foreground. In this perspective, individuals consider the illness as an opportunity for meaningful change, focusing on the self by considering other aspects of life (Paterson, 2001). They are able to accept the limitations within their illness, and view themselves as healthy beings (Paterson, 2001). Paterson mentioned that in viewing himself or herself as healthy, a person with chronic illness "is not misleading reality, but re-examining what is possible and normal" (p. 23). Shifting from illness in the foreground to wellness in the foreground may happen either gradually, or as a result of a sudden situation, such as having new complications or getting rid of previous problems related to their illness process. According to this model, sometimes people who assume an illness in the foreground can resume a wellness in the foreground perspective by reframing the situation to appear less discouraging. As a result, the individual may have a renewed sense of appreciation for life (Paterson). In other words, the shifting perspectives model illustrated complex dynamics and interactions between individuals with chronic illness and their environments based on taking into account people's situational needs, major life events like diagnosed with new complication, and the larger socio-culture context (Williamson, Koro-Ljungberg, & Bussing, 2009).

Application to chronic illness research. Although Paterson's shifting perspective model has been cited in many, often qualitative, research studies, there is at present, a paucity of research indicating its utility as an explanatory model. Paterson (2003) believes there are some difficulties and limitations encountered when researchers attempt to define the experience of living with chronic illness through the lens of a single perspective. There are some studies that use this model as a framework for explanation of the results of their studies. The patterns of illness transition among adolescents with ADHD, as described by Williamson et al. (2009), supported a model of shifting perspectives of illness and wellness similar to Paterson's description. People in this study had different perspective from time to time. Audulv, Asplund and Norbergh (2011) conducted a phenomenological study to explore people's illness perspectives and related self-management of chronic disease. They found two illness perspectives; being life-oriented meant to focus upon how to live a good life with disease, whereas a disease-oriented illness perspective emphasized the medical and physiological aspects of disease. The participants usually held one of the two illness perspectives as primary, although they shifted between the perspectives under specific circumstances. People with life-oriented illness perspective (wellness in foreground) are able to perform self-management in order to continue their normal activities. When their participants had a disease-oriented illness perspective, they focus upon controlling their illness including symptom and new complications. The results indicate that illness/wellness perspective had a major influence on chronic illness self-management activities and ability. It was also clear that people continually shifted perspectives triggered by particular events or conditions.

Overall, these two models, Transition and Shifting perspective can promote new ways of thinking about self-care behavior, attitudes and beliefs in the context of chronic illness. Transition theory looks at larger processes and shifting perspectives model looks at internal and relational processes. Both are about identity evolution in some way.

Chapter Summary

Diabetes is a lifelong condition in which one needs to constantly monitor blood glucose levels and lifestyle changes, such as diet and exercise. Self-management is crucial for diabetes management and many factors, such as culture, religious beliefs, and socioeconomic context, influence it. When individuals with diabetes immigrate to a different country, their lives became more complicated. Health professionals involved in chronic disease management need to consider that there is “no singular way to live well with a chronic condition, that the learning process is complex and incremental, and that the role of medical science must be contextualized within an understanding of the living that is taking place” (Thorne, 2008(a), p. 12). Understanding the belief systems of our clients and how they influence health beliefs and behaviors is crucial to meet the health care needs of people with chronic illness. In multi-cultural countries such as Canada and US, health care professionals encounter the variety of belief systems in their clients. Health care professionals need to consider cultural aspects that influence people’s understanding of chronic illnesses.

Iranian socio-cultural values and beliefs are the central to Iranians’ lives. Perception and experiences of diabetes can be influenced by these socio-cultural values. Some of the same values may be also embedded in Iranian people who migrate to other countries. Therefore, it is important to consider women‘s socio-cultural contexts, as well as personal beliefs, when examining the experiences of living with diabetes in Iranian Canadian women. To date, there is no published qualitative research specifically about the experiences of Iranian Canadian women with diabetes. This study is necessary to begin to fill this gap in the literature by describing these experiences and perceptions.

CHAPTER 3 - METHODOLOGY

When I was planning this research, I had one purpose in mind; to understand what it was like for women to live with diabetes. Being a diabetes educator for more than eight years and having never been diagnosed with this chronic condition, I was asking the question as an outsider peering into a world that was hidden from my view. During my PhD studies, I came to understand the critical value of appreciating our clients' beliefs, understanding and appreciating their personal experiences of their condition; and recognizing that diabetes may fundamentally influence the individual's existence. I also learned that by listening to women with diabetes talk about their illness experience, one can gain better understanding about the ways in which individuals construct the meaning of diabetes.

The context of immigration was a crucial issue to take into account: how does immigrating to a very different country and socio-cultural influence their ability to live with diabetes? I recognized that this experience couldn't be limited to a single cause and effect relationship; it must take into account their history, background, and the inherent cultural values and beliefs each person holds as well as their individual experiences. Knowing that I needed to obtain an in-depth understanding of living with diabetes, I chose to approach the issue from a qualitative perspective. This method provided the flexibility to change my research strategies as I incrementally came to understand my participants' perspective. I employed both "emic" and "etic" perspectives to understand my participants' experiences and perceptions.

The data collection strategy I chose was a semi-structured interview format as this would allow each participant to share her experience of living with diabetes and of immigration in her own way, as well as to explore whether cultural assumptions, cultural explanatory models concerned with health and illness, social roles, and family and social relationships influence how a woman lives and attends to her diabetes on a daily basis. By doing these interviews, my goal was to illustrate the largely hidden nature of the diabetes experience, while looking for similarities and differences that existed across my participants. Although I did not assume that all Iranian women hold the same cultural and social beliefs, norms and values, I did want to become aware of the kinds of issues health professionals need to recognize and address when working with immigrant women who live with diabetes.

At the beginning of my dissertation journey, taking a qualitative approach to health research was a new path for me. However, after exploring the research on living with chronic diseases, I realised that I was not among the first to assume this perspective in studying chronic illnesses. There are many studies exploring the lived experiences of various diseases such as rheumatoid arthritis, multiple sclerosis, cardiovascular disease, cancer, and diabetes to name a few.

In this chapter, I describe the research design employed to meet the purpose of the study as well as the specific strategies I employed in recruiting participants and collecting and analysing data. I also describe how I ensured rigor was maintained throughout the study and how I employed and maintained research ethics standards to its completion.

Methods

In order to understand the holistic or contextualised experience from the perspective of the women living with diabetes, I needed an inductive and flexible design that would facilitate movement between an emic and etic viewpoint. Qualitative designs, as Schwandt (1994, p. 118) states, help us "understand the complex world of lived experience from the point of view of those who live it." My starting position was that an individual's perspective of having diabetes is tied to their socio-culture and religious realities.

As such, investigating the “everyday life” of women with type II diabetes can be approached by using an anthropological approach of ethnography.

The aim of ethnography is “to understand another way of life from the native point of view” (Spradley, 1979, p. 3). Spradley stated that ethnography is concerned with developing an in-depth description of “[the] meaning of actions and events to people” (p. 5). According to Agar’s (1986, p. 12) seminal work, “ethnography is a description of the patterns of behavior of individuals and groups of people within a particular culture.” Researchers employing qualitative ethnographic approaches need to discover and interpret the cultural meanings found within a particular group. Roper and Shapira (2000, p. 3) state that, from a cognitive perspective, “culture is the ideas, beliefs and knowledge that are used by a group of people as they live their lives”. According to Roper and Shapira, the synthesis of these two perspectives of culture will help to explore “what people know and believe and what they do.” In essence, ethnography offers “thick” descriptions of understanding and practices of a group of people. Based on these assumptions, my study provides a description and interpretation of the women understands and experiences in managing illness within the context of their Iranian Canadian cultures.

Focused Ethnography

Focused ethnography is a specific form of ethnography. Classic or “traditional” ethnography aims to study all aspects of a culture. In a traditional approach, the researcher enters the field with minimal direction or purpose. In contrast, focused ethnography is based on a clearly delineated and often predetermined research question related to a specific phenomenon (Muecke, 1992; Roper & Shapira, 2000). I wanted to concentrate specifically on how women lived with diabetes within their cultural and social environments. Further, in contrast to classic ethnography, which requires the researcher to participate in people’s daily lives over an extended period of time through immersive fieldwork (Hammersley & Atkinson, 1995), focused ethnography may employ only one data collection strategy, often interviews, which permits inclusion of people from the same cultural group or having the same characteristics but who might be widely dispersed. This approach was ideal for Iranian Canadian immigrants who have settled and lived throughout the Greater Vancouver area. These participants were bound by their shared Iranian Canadian cultural experiences as well as their diabetes, although there were considerable variations in their experiences and points of view. Data collection was very intensive, over a short period of time. Thus, by selecting a qualitative approach that would evolve as I delved deeper into understanding my participants' experience, I aimed to create an interactional communication between the participants and myself to explore their feelings about living with diabetes within the immigration context.

Setting and Access Procedure

This study took place within the Iranian Canadian community in Greater Vancouver. However, before starting to describe the setting of my study, I will draw a cultural picture of my participants so that readers might have a glimpse of life for the Iranian Canadian community and my participants.

The Iranian Canadian community in Greater Vancouver. Iranians have settled in Vancouver since the 1950s. Since 2002, the Iranian population in Vancouver has tripled. Iranians come to seek a new life in the place that is described as the "Promised Land" (Shahrvand, 2012, p. 23). After Iran's 1979 revolution, Iranians seeking economic opportunities and political refuge from the new Islamic Republic also started to arrive in Canada. Further political and religious chaos in Iran saw more middle-class and skilled Iranians looking to Canada for a new home, in particular those from religious minorities (e.g. Baha'i). Some people may have left Iran to live in a society that has fewer restrictions. After the 1990s, the focus for many Iranian immigrants was education, especially for young people. Cultural norms meant that when a child moved to Canada for educational purposes, at least one parent would accompany the child. Now more than 10,000 Iranian Canadians live on the North Shore, where they search for a new life and a new identity (Todd, 2010).

Iranians who immigrate to British Columbia cluster in the University of British Columbia (UBC) campus area, Burnaby, Coquitlam, and North Vancouver. There is a significant Iranian presence in North Vancouver, across the water from Vancouver proper. Some people say this is because the North Shore is resonant of the mountainous region in Northern Tehran (Shomal). North Vancouver has many coffee shops, bakeries, Persian supermarkets and restaurants (Figure 3.1) that specialise in a variety of Iranian traditional foods such as Persian rice and spices.

Figure 3.1 One of the Persian stores in North Vancouver that sells varieties of nuts and sweets.

The list of Persian recipes, appetizers and desserts is extensive and are served in many Persian restaurants across Greater Vancouver, in particular North Vancouver, with more than 10 fine restaurants. Iranian cuisine includes a wide variety of foods ranging from Chelow Kabab (rice served with roasted meat), Khoresht (stew that is served with white Iranian rice), kuku (vegetable soufflé), and polo (white rice alone or with meat and/or vegetables and herbs, including green beans called loobia). White rice is considered a 'golden food' in Persian cuisine (Figure 3.2). It is impossible to separate it from everyday food for most Iranian people.

Figure 3.2 A typical Iranian food table. Retrieved from http://www.chn.ir/Nsite/FullStory/Print/?id=99678 (Reprinted with permission)

Besides restaurants and markets there are also Iranian institutions, like the recently opened Iranian school allowing children to study Farsi and Persian history on the weekend or after school. The Iranian community has its own media in Farsi. There are five Persian magazines and newsletters that publish weekly. Not all Iranians who live in Vancouver are Muslims and also some Iranian Muslims do not practice Islam. Although individuals in my study have similar cultural backgrounds, they have different degrees of attachment to their religion and cultural beliefs and practices. Some follow Islamic rules in their everyday lives and they attend every single religious program; others selectively follow these rules and they may not participate in these programs. For example, Hijab encompasses more than just a dress code; it is concerned with moral boundaries and respect for women and is part of community cohesion and modest behavior (Khan, 2015). Some Muslims take a relativist approach to hijab. Hijab is a veil that covers the head and chest, which is particularly worn by a Muslim female beyond the age of puberty in the presence of adult males outside of their immediate family. Some Muslims believe it must be interpreted with regard to the surrounding society. In my study some women do not wear Hijab (four women) nor practice daily prayer, while others wear Hijab (11 women) and were very thoughtful about daily prayers (Salat).

There are two mosques and many Islamic and cultural centers in Vancouver. Some people only attend these centers for cultural feasts and others go to mosques and cultural centers for both religious and cultural events. Iranians have many cultural and religious feasts around the year. The most common cultural feasts are Nowrouz, the Persian New Year that falls on March 21, also called the First Day of Spring (13 day celebration of Spring); and Yalda, the winter solstice festival celebrated on December 21. Family is very important in Iranian culture and according to Islamic beliefs; divorce is considered the most despicable of all legal things by God. The historical, social, political, and religious history in Iran has led to a culture of cautiousness when communicating with people outside their immediate community. They do not usually speak about their problems even when faced with many challenges. One of the main reasons is politics and fear of being misunderstood. They especially refuse to discuss politics in Iran, fearing repercussions (Todd, 2010).

Context of the study. The context of my study was primarily within two key Iranian community organizations: the Al-Ghadir and the Az-Zahra Islamic and cultural centres. These formal organizations are the hubs of cultural and religious traditions within the Iranian community in Vancouver. The Al-Ghadir Islamic and Cultural Center is active in organizing weekly programs based on the Islamic calendar (lunar calendar) and cultural celebrations, such as Nowrouz (the First day of spring celebrated as Persian New Year). Almost all people who attend this center are Iranian and programs are offered in the Farsi Language. The Az-Zahra Islamic Centre has "Friday prayer" every week and they also organise Islamic celebrations. The people who come to this mosque are from different cultures and countries, and lectures are usually in English and sometimes in Urdu (native language in Pakistan).

Even though I identified myself as an active member of the local Iranian community, it was important to get support from these centres for my research. I contacted leaders and administrators of these two organizations through e-mail, phone calls and in-person meetings. For Al-Ghadir mosque, I introduced myself, explained my research objectives, and asked for their permission to post advertising posters and information in order to recruit potential participants. After several meetings and discussions, they agreed to support my research in their centers and I officially started to recruit my participants.

Sample

The participants of my study were Iranian women with type II diabetes, whether diagnosed in Iran or Canada, who immigrated to Greater Vancouver, BC, Canada. The Greater Vancouver (also known as Metro Vancouver) area includes the cities of Vancouver, North

Vancouver, West Vancouver, Burnaby, Richmond, Surrey, and a few other smaller cities. In this study I considered the definition of an immigrant as any person who had been granted residence in Canada, whether permanent or temporary, for at least one year. In the following section I will discuss the way I determined the sample size and how participants were identified and recruited.

Inclusion and exclusion criteria. The inclusion and exclusion criteria for my participants were as follows:

1. Women aged 30-60 (midlife women) who identified themselves as living with adult onset diabetes (type II). I did not include women over 65 years of age because aging (between 60-65, WHO, 2015) can shape a woman's experience of living with a chronic condition. The same reason holds true for those women under 30 as they are transitioning into adulthood. In this study, I focused on women who are likely to be actively engaged in multiple roles of worker, wife, or mother. I did not limit the time since diagnosis because I wanted to have a wide range of illness experience, including women who have just been diagnosed as well as those who have had it for many years.
2. Have type II diabetes managed by diet, oral medication or insulin, and exercise. The reason for choosing variation in treatment regimens was availability of the participants in each group. It also provided me with access to a wide range of experiences of women with different treatment approaches.
3. Non-pregnant women.
4. Willing to participate.
5. Ability to communicate clearly: Potential participants were excluded if they were not willing to participate or able to speak Farsi, as that is the language in which I am most conversant.

6. Available for at least one interview.
7. Immigrated to Canada at least one year prior to the interview.

Sampling strategies and participant recruitment. I employed purposive and snowball sampling methods in this study. Purposeful or purposive sampling is "selecting information-rich cases for study in-depth" (Patton, 2002, p. 242), and can be used when the researcher wants to understand something about a particular topic without expecting to generalize to all (McMillan & Schumacher, 2006). My initial efforts recruiting participants focused on those who belonged to the Iranian spiritual organizations such as Al-Ghadir and Az-Zahra. I attended the community gatherings of the Al-Ghadir center at least twice a month. I explained the study to secretaries and coordinators of the center and asked them to explain my study to the women attending the center. I asked them to convey the following message to potential participants: "There is a nurse researcher studying at the University of Alberta who lives in Vancouver. She is conducting a study about what it is like for women to live with diabetes. She is interested in talking to women aged 30-65 who have type II diabetes. Would you be interested in learning more about the study?" In addition, I attended other events arranged by the Iranian community at the UBC family housing Commons Block and tried to find appropriate people to participate in my study by discussing the project. Interested participants were asked to contact me by phone or email. If the person met the inclusion criteria, we determined a mutually agreeable time for an interview.

In order to recruit participants from a wider range of the community and to reach the people who do not attend those two centers, I distributed more advertisements in Persian supermarkets in North Vancouver, downtown Vancouver, and Burnaby districts. The poster contained a brief introduction to the research, the voluntary nature of participation, and my contact information. All advertisement materials were in Farsi. Both Farsi and English versions of my posters are in the appendices (Appendix A). I also tried to find more participants by talking to bus riders on the # 240 route that goes to North Vancouver, as this area has many Iranian immigrants as well as many Persian supermarkets and Restaurants.

As the study proceeded, I used the technique of snowball recruitment to identify other potential participants. In nominated or snowball sampling, participants already in the study recommend other persons to participate. Thus, at the end of each interview, I asked participants to identify those who might meet the criteria and be interested in participating in my study. I gave participants information to pass on to potential new recruits and asked them to contact me. The recruitment was initially slow, but after I started snowball sampling, the recruitments speeded up. I recruited six participants through snowball sampling.

Sample size. The sampling size principle in qualitative research focuses on the richness of the data rather than representativeness, to accurately “portray the full context of the piece of reality through which the research focus is addressed” (Germain, 1986, p. 152). An appropriate sample size for a qualitative study is one that adequately answers the research question. This requires “a flexible research design and cyclical approach to sampling” (Marshal, 1996, p. 523). The number of required participants usually becomes obvious as the study progresses, when new categories, themes or explanations stop emerging from the data (data saturation or analytic redundancy). Data saturation is integral to naturalistic inquiry and as Strauss and Corbin (1990) state, saturation is the point at which no new insights are obtained, no new themes are identified, and no issues arise regarding a category of data. In other words, data saturation occurs when new patterns about the major constructs under study no longer emerge from the data and when concepts and relationships are validated with a variety of participants (Morse, 1995). In this study, participant recruitment continued until no new themes or concepts emerged.

From May 2013 to November 2013, I initially recruited nine participants, then six more through snowball sampling. The recruited women mainly did not have regular connections to the Iranian community centers. In total, I conducted 21 interviews with 15 women with diabetes in Vancouver to reach data saturation (six interviews were repeated interviews from my previous participants).

Sample profile. I obtained demographic data immediately after obtaining consent and before starting the semi- structured interview. Gathering demographic data was useful for two reasons. First, it helped me get to know the participants better. Second, it provided useful information to describe the group of participants in my study and helped me construct a profile of the sample. Demographic data I collected included: age, marital status, education, employment, family composition, time since diagnosis, management regimen, and how long they lived in Canada.

My participants were from the Iranian community living in the Vancouver area. As indicated in Table 3.1, most women were between 42 to 48 years old. Their marital status varied: Ten women were married, three were divorced, and two were widowed. In two cases, the spouse of the participant had diabetes too. Eleven participants were diagnosed with diabetes in Iran, while the rest learned about their diabetes in Canada. Most women had a diploma level of education. Only one person was non-Muslim (Zoroastrian - a religion based on belief in one universal, supreme God, Ahura Mazda, or the “Wise Lord”). Five women came to Canada to be with their children while they studied in Canadian Universities. The women who came with their children did not speak or understand English at all. Thus they could not participate in Canadian social activities and could not communicate with others; they were socially isolated. Four women were fluent in English and the rest of the participants understood English to some degree. Among the Muslim women, nine women practiced Islam as part of their everyday routine; they wore the

Hijab and participated in religious ceremonies regularly. Five participants did not practice all aspects of Islam, did not wear Hijab and did not participate in religious programs run by mosques. The duration of having diabetes was from three to 17 years. They immigrated to Canada from three to 25 years ago. Regular physical activity is an important part of diabetes management but only seven women had regular physical activity such as using a treadmill, walking, (a few) swimming, and eight women found themselves too busy to have regular physical activity, considering it a lower priority in their everyday lives.

Five women did not have a Care Card and were travelling to Iran for their check-ups. Four women went to the diabetes clinic, and 6 women went to a family physician.

Table 3.1 - Demographic Characteristics of the Participants

Demographic characteristics	Status	Number (Percent)
Marital status	Married	10 (67%)
	Widowed	2 (13%)
	Divorced	3 (20%)
Education	Limited (Less than grade 6)	5 (33%)
	High School	7 (47%)
	Post-secondary	3 (20%)
English proficiency	Fluent	4 (26%)
	Limited	6 (40%)
	No English	5 (33%)
Employment	Employed	8 (53%)
	Homemaker	7 (47%)
Religion	Muslim	14 (93%)
	Non-Muslim	1 (7%)
Number of children	0-2	11 (73%)
	More than 2	4 (27%)
Family composition in Canada (living in the same house)	Husband and children	5 (33%)
	Husband, children, and parents	3 (20%)
	Children	5 (33%)
	Husband	1 (7%)
	Alone	1 (7%)
The place of diagnosis	Iran	11 (73%)
	Canada	4 (27%)
Follow-up treatment	Family physician	6(40%)
	Diabetes clinic	4 (27%)
	In Iran with endocrinologist	5 (33%)
Health care insurance	Yes	9 (60%)
	No	5 (40%)
Physical activity	Regular (treadmill, walking, swimming)	7 (47%)
	Irregular (inactive)	8 (53%)

Informed Consent Procedures

At the beginning of my meeting with each participant, I invited her to have a cup of tea with me, and I started with icebreaking social talk on topics such as the weather, traffic, and their family (such as children or grandchildren). This is socially appropriate in Iranian culture. During data collection, I introduced myself as a doctoral student and a Registered Nurse. Then, I started the process of obtaining informed consent. I described the study and explained the aims of the project and the role of the participant in the research. I stressed that potential participants would have valuable knowledge, experiences, and insights to contribute to the study and that the study would have benefits for the Iranian community in Canada. I also mentioned that their experiences, concerns and needs would be communicated through my results to raise the awareness of health care providers, researchers, and policy makers to the needs of the community and population. I carefully explained the woman’s rights as a participant in the study in terms of confidentiality, and their right to withdraw or refuse to answer questions. I explained my obligations in terms of keeping participants’ identity confidential and secure, and what I would do with their information. After ensuring that all questions the participants had about the study had been answered, I obtained written informed consent in Farsi (Appendix B). All of the participants signed the consent form. The consent form contained the telephone numbers of the human subject review committee, as well as my supervisor’s, and my own, contact information in case participants needed to express any concerns about the research.

Data Collection

Data collection included collecting demographic data and conducting semi-structured interviews. I will describe each stage of these data collection activities.

Interview location. The participants' comfort was my main concern when I scheduled the interviews. I went to a place as suggested by participants including their house (n=3), meeting rooms in two Islamic centers, a meeting room at the University of British Columbia (UBC) Commons Block (n =5), as well as meeting seven people at a coffee shop (either outside or inside the coffee shop). I conducted five additional interviews with specific participants either by phone (n=3) or in-person, meeting at the UBC Commons Block (n=2).

Interviews. My primary form of data collection was the semi-structured individual interview. This form of interviewing is a conversation-based style of data collection, as opposed to a structured and more formal approach. This allowed me to establish rapport with participants and to explore participants' thoughts, beliefs, or perceptions about living with diabetes (Agar, 1980). Before conducting initial real interviews with study participants, I conducted a practice or mock interview with a trusted friend who pretended to be a participant. The goal of this practice interview was to rehearse my explanation of the study and informed consent procedures and to also check whether the question probes I had developed worked. I listened to the recorded interview in order to reflect on my interview style and to identify any issues that needed to be addressed with real participants. This interview was not transcribed.

The interview was conducted in Farsi (my native language) and always started with warm-up (grand tour) questions such as "*tell me about living with diabetes*?" From this, I used a variety of questions and probes to explore different aspects of their lives with diabetes. For example, I explored how diabetes was understood and managed within the context of their everyday life. I explored perceptions of good and poor control of diabetes, the factors that led to these, and how women balanced the demands of diabetes with other aspects of their lives. I used my conceptual framework to explore how religious beliefs and behaviors influenced the participants’ experience, norms, and behaviors. I explored how they balanced their life roles with diabetes by asking “*can you tell me how diabetes influences your life as a mother, a wife, a working woman, or any role you have played in your life before and after diabetes?*” I asked about how they managed specific religious activity that requires fasting (e.g. Ramadan). We talked about how moving to Canada had affected their lives with diabetes, either in a positive or negative way. The initial interview guide is included in Appendix C and the later interview guide that evolved over the course of my study, is posted in Appendix D.

The guiding principle was that the participants would control the conversation. I tended to ask questions that flowed from the information shared by the women and held specific questions until the end of the interview, to give as much time and opportunity for the participant to tell her story in her own way.

Overall, the questions covered various aspects of women’s lives, such as beliefs about illness, the effect of the illness on social relationships, perceptions of relationships with health professionals, help-seeking patterns, and daily management of diabetes. The interviews were flexible enough to allow the participants to tell about their experiences from their own perspective. The interview guide and questions evolved over time as I learned more about the experiences of my participants. For example: initially, I asked generally about diabetes, and over time, moved toward more specific exploration in particular domains, such as religion and culture.

During the interview, I took brief notes to help me keep track of important ideas I wanted to follow-up later in the interview. I asked the participant for permission to audio record our conversations. This made recalling the interview data easier. When two women declined permission to record the interview, I took brief notes during the interview, and wrote descriptive field notes immediately afterward. During the interview, my role was listening, but I was also constantly observing non-verbal cues as I actively explored and unraveled different aspects of their experiences. The interviews ranged from 60 to 90 minutes although most took around 70 minutes.

I used verification strategies in later interviews to explore emerging themes (e.g. "*some of the women I have talked to have told me that having diabetes is like a ball and chain. Does this resonate with you?"*). I will talk more about verification strategies in a later section.

At the end of the interview, I asked the participants for their contact information for a follow-up interview in order to clarify or explore issues if needed. I interviewed six participants for a second time, based on my analysis up to that point, both to verify my emerging analysis and to seek clarification on specific areas of interest. I interviewed my first, third, fifth, seventh, and 11th participants, twice. This allowed me to explore more deeply the themes and areas that were important in my analysis but for which I needed further details. In additional interviews, for example, I asked, "what are the milestones that affected your movement from early days of diagnosis to your current stage?" This question was added to interviews because I found in my initial analysis that most of the participants experienced distinctly different stages during their illness. At the beginning of the second interview, I reminded the participants again of their rights in their study and asked if they had any questions or issues prior to starting the second interview.

After finishing interviews, I offered the participant a gift as a token of my appreciation of their time and effort. I prepared $25 gift cards from Safeway supermarket. My last two participants were interviewed in North Vancouver so I gave them a gift card from a famous nuts store (Ayube) that carried a variety of nuts and dried fruits from Iran. The interview site for these participants was one block away from this store. The value of these gift cards was the same as other participants' gift cards.

The interviews were recorded via a digital voice recorder. This recorder featured folders that allowed for the creation of separate files for each individual interview. I reassured each participant that all personal identifiers such as names would be removed in the transcripts. Each participant was assigned a code that was used on the transcribed interviews and ensuing data analysis. The audio files were transferred to my personal password protected computer where they were stored and labeled with the interview number and the pseudonym of the participants (e.g. ABY 1). The use of a recorder also allowed for the creation of separate memo files for each interview, or for the recording of comments I thought were important to include at any interval point during the interview. Digital recording also assisted me in transcribing as it ensured that the participants' exact words and tone/speaking characteristics were captured.

Interview notes and memos. Interview notes and memos helped me record non- verbal observational data and contextual information from my interviews, and helped track my thoughts about the data as I analyzed it. Interview notes allowed me to record non-audible information about the participant and the context in which the data were created. The interview notes data helped me compare and contrast responses from participants to ensure a thick description of the context of the interview. I also found them helpful in aiding in the accuracy of interpreting data. Following each interview and throughout my data analysis I wrote personal notes that reflected on:

- What I saw, experienced, and perceived during the interview.
- The main topics and flow of the interview, including observations of non -verbal behavior.
- Main ideas/experiences that gave me some inspiration.

- My reactions to the participant and interview as a person, researcher, and nurse educator. For example I wrote the following journal after I finished my 15th interview:

> I never knew what was going to happen in each interview…I was waiting for my participant outside the Vancouver Public Library…I had never met her or talked to her before… I had a sense of fear of the known and the unknown …She was walking with crutch and her husband accompanied her. She was walking toward me with difficulty…they looked very serious to me…I stood up and said "salaam" …she replied back but her husband did not pay attention to me and did not immediately reply back…I thought it was because I was wearing scarf (my participant did not wear the Hijab) …I was not very surprised. It happened to me here in Vancouver a few time when I am among a group of Iranians who do not practice Islamic rules…I was guessing from their initial reaction that they did not expect somebody with Hijab…I introduced myself as a PhD student at University of Alberta….after that I felt their face became more welcoming …Although I have learned to not judge people before I know them very well but at the beginning of the interview I thought this participant seems very hard to interview but it went very smoothly…at the end of interview, surprisingly she was very pleased and asked my phone number if she had a question.

I discussed my field notes with my supervisors as a way to communicate the context of the interview data. I used memos to describe my impressions of the data, connections between data, possible interpretations, and to document themes as they emerged. Richards and Morse (2007) stated that in memos the researchers record information, ideas, insights, thoughts, and feeling about relationships of events observed. Memos were particularly important to explore my implicit assumptions about the data and my understanding of my participants' experiences. For example, I wrote memos on the nature of the 'evil eye' in Iranian culture and a religious notion of predestination (*Nasib*) in Islamic beliefs and how these may have influenced participants' perceptions and experiences of diabetes. These were discussed with my supervisors to help me in identifying gaps in the data that needed to be pursued in subsequent interviews. As part of my discussions with my supervisors and my attempts to describe the richness of Iranian life, I took photographs to illustrate the foods and feasts celebrated in the Iranian Calendar. I took a picture in the Iranian nut shop as well as the tables of food in some of the feasts at the Iranian Community Center. The choice of what I photographed was influenced by my participants descriptions of their experiences when shopping in Iranian shops at during feasts and celebrations but serve to illustrate the verbal descriptions.

Data Analysis

In qualitative inductive data analysis, data collection and analysis proceed concurrently from the very first interview (Richards & Morse, 2007). Overall, qualitative data analysis in this study consisted of recognizing the codes, sorting them into different categories, and comparing and refining these categories. Data analysis is a breaking up of the research materials into manageable pieces that the researcher then sorts, searching for patterns. I used the strategy of constant comparative analysis as my primary analysis strategy.

Data transcribing. To begin the process of analysis, all audiotapes were transcribed verbatim in Farsi. In order to maintain confidentiality, the transcriptionist signed a confidentiality agreement (Appendix E). I read the transcripts in conjunction with the audiotapes to verify the accuracy of the transcription and to correct any transcription errors. This also helped me become very familiar with the transcripts, as Sandelowski (1995) suggests, gaining a sense of the overall picture. I translated the first three interviews into English for review and analysis with my co-supervisors, Dr. Spiers and Dr. Allen. The rest of the transcripts were kept in the original language (Farsi). I prepared a summary of each interview which included the main themes and observations of the content, the participant’s attitudes and behaviors, and key quotes. This strategy helped me to review aspects of interviews that were not clearly understood or that needed further elaboration from the participants. This also greatly helped me in planning for subsequent participants.

Translation process. This research was conducted in two languages, Farsi, the language used with my participants, and English, the language used with my supervisors and to complete my dissertation. It is important to recognize that translation is an act of interpretation, and to be aware of how translation may affect my reflective analytic process.

The first major task in my study was to translate the interview questions into Farsi. To do this, I translated the English equivalents into Farsi, and then asked a native Farsi speaker to translate them back to English to compare the accuracy and wording. The second major task was to translate the first three interviews into English for my supervisors so that I could work with my supervisors on coding. They were first transcribed verbatim in Farsi. I performed the translation according to the following steps suggested by Chen and Boore (2009).

I was careful to identify ideas or terms that were not easily translatable into English, or where the English equivalent was not adequate to express the full meaning of the original term in Farsi. Once I had gained confidence in my coding practices, I continued to code in Farsi. I provided English summaries of my codes to my supervisors with exemplar quotes selected for translation. I included descriptions that enhanced the translation when needed. At all times, I recorded in memos instances where I struggled to find the English translation of an idea in Farsi and discussed those memos with my supervisors. As much as possible, I used Farsi for the code and category labels because this allowed me to keep the label as close to the data as I could. When I needed to translate codes or transcripts or quotes for my supervisors, I checked my translation with a Farsi-speaking colleague (who had also signed a confidentiality agreement). I translated the transcripts and asked another Farsi-English bilingual speaker (my colleague) to undertake a back-translation to check for accuracy. When I was writing my results chapter, I asked a Farsi speaking person to determine the adequacy of the Farsi-English translations, and when there were discrepancies with the person who back-translated, I discussed it with her, and then I determined the most appropriate word given the context. Lastly, I asked another person with Farsi/English translation experience to check and confirm the accuracy of English translation of Farsi quotes.

Constant comparative analysis. I used the strategy of constant comparative analysis to analyze my data. Glaser and Strauss (1965) originally developed this method for use in grounded theory. Charmaz (2000) notes however, that constant comparative analysis is an analytic approach that can be used with other methods. Similarly, O'Connor, Netting and Thomas (2008) and Fram (2013) stated that constant comparison analysis is not exclusive to grounded theory; it assures that all data are systematically compared to all other data in the data set (O'Connor et al., 2008). It also helps to maintain an emic perspective in qualitative studies (Fram, 2013).

Constant comparative analysis is a process in which data are compared with other data within a transcript, transcripts are compared with other transcripts within the same group (same experience), comparison of interviews within different groups (experience), and data are also compared with everyday life experiences to attempt to reflect the everyday life experiences of the participants as accurately as possible. I also compared codes to codes and category to category. The core activity is coding, which is the process of reducing data to specific groups. It consists of two activities, namely fragmenting and connecting (Dey, 1993). Both strands are necessary and keep each other in equilibrium. Charmaz (1983, p. 112) describes fragmenting and coding as:

> The process of fragmenting (open coding) lifts the coded pieces out of the context of the interview as a whole. Codes serve to summarize, synthesize, and sort many observations

> made of the data....coding becomes the fundamental means of developing the analysis....Researchers use codes to pull together and categorize a series of otherwise discrete events, statements, and observations which they identify in the data.

The process of data analysis is cyclical and repetitive, with the researcher going back and forth to the data for review and reconsideration, until the researcher is satisfied that it is complete. Data analysis consisted of the following steps: (1) open coding, (2) categorization, and (3) development of subthemes and themes.

Open Coding. After reading each transcript and my field notes, I started open coding of the data using the qualitative analysis software (NVivo 10) to manage the data. Open coding is the process for highlighting ideas or "*in vivo*" codes. The idea is to "see what is there" and to see what assumptions may be at work. Labels or codes were assigned to words, phrases or entire stories within the text, essentially any level that constituted a unit of meaning and therefore a unit for analysis. The codes were grouped into similar categories in order to make them more workable. Initial coding was based on what Glaser and Strauss call *in vivo* codes as well as on conceptually derived codes. *In vivo* codes were the category labels used by respondents themselves to organize their world (Rodriguez, 1998). For example, if my participant said, "in my family we have a set of routines for our meals. Being regular helps me keep my blood sugar constant" I used the word 'routine' as an *in vivo* label. As I continued my data analysis and data collection, I explored some of the important ideas with new participants and in second interviews to discuss whether or not the label and idea resonated with them. Thus, *in vivo* codes such as *ball and chain* and *dark days of diagnosis* were developed into main themes.

I then started to compare and contrast the codes and ideas within each interview. This allowed me to appreciate the context and richness of the data "as the interview parts are interpreted as a whole and the pieces of one case are connected" (Sivesind, 1999, p. 370). In the process of open coding, every passage of the interview was read to determine what exactly had been said and to label each idea with an adequate code. By comparing different parts of the interview, I examined the consistency of the interview as a whole.

Data analysis in a qualitative study, for me, looked like solving a puzzle. After coding (different pieces of puzzle) the next step was categorizing, or grouping small codes under larger ideas or labels.

Categorization. This process involved comparing and contrasting codes within and between interviews. Through this comparing, I formed categories that were the basis for the identification of a theme. Categories were like labels but fell under larger groupings that described regularities in behaviors and beliefs of women with diabetes in my study. Categories were meaningful both internally in relation to the data understood in context, and externally in relation to the data understood through comparison (Dey, 1993). For this step, I needed to identify and sort puzzle pieces into groups (e.g. codes such as “believe in God,” “God’s will,” etc.) that made a coherent picture. Codes that appeared related or linked were placed into categories of codes. Constant comparison was important to ensure that categories were mutually exclusive and covered the range of variations within the data (Baker, Wuest, & Stern, 1992). Throughout the coding experience, codes evolved as I collapsed smaller codes into larger categories, or realized that a code or category needed to be split. Over time, the names of the codes and categories evolved to reflect my emerging understanding and in the later part of the analysis, my use of the literature. For example, a key category in this study was the “bumpy road.” This idea was initiated when my 9th participant said: “Living with diabetes is not very easy…sometimes it is bumpy road…” I then created a category under the title of “bumpy road” and reviewed my earlier interview data to see which codes appeared to be similar and could be subsumed within it. Over time, “*bumpy road”* evolved into different categories: *bumpy road* and *uphill battle.*

Comparison between interviews was also crucial. In this process, I was seeking similarities and differences between the interviews and between the codes with regard to the experience of a specific phenomenon and combination of codes or concepts. The aim of this process was to further develop the conceptualization of the subject. To facilitate this, I used axial coding. Axial codes typically represent categories that describe the open codes (Glaser, 1978). In essence, axial coding consists of identifying relationships among the open codes, and open code is about identification and labeling.

Theme-ing. Following the descriptive coding and identification of categories and subcategories, I revisited the data in general, and abstracted themes from the data analysis. Doing abstraction is interpretive in nature compared to descriptive coding and categorization. DeSantis and Ugarriza (2000, p. 362) define a theme as: “an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole.” I was seeking to find the key ideas that would link the stories together. During analysis, themes around the diagnosis phase, *dark days*, *struggling to learn to live with diabetes,* and *ways of being with diabetes* as travelling on a *bumpy road* or mostly *struggling to climb up-hill in life* emerged. Over time and particularly as I was starting to write my results, the metaphor of a *life journey path* became useful in articulating the core similarities in my participants’ experiences.

The Role of analytic memoing. Memoing is an important part of constant comparison. Writing memos help me to keep track of the different ideas throughout the study. I initially read each interview several times before doing any type of coding. I made notes and memos during the study to record my ideas and impressions about portions of an interview and to record key ideas and insights as coding proceeded.

Rigor

Rigor is the means by which we show integrity and competence of our work (Meadows & Morse, 2001). I chose to employ the model of verification as described by Morse, Barrett, Mayan, Olson, and Spiers, (2002) to guide my research activities and to ensure the outcome was trustworthy. They recommend a set of verification strategies to ensure validity in the process of conducting qualitative research (Meadows & Morse, 2001; Morse et al., 2002). Using these strategies, I was able to identify the pitfalls of my research project during the process of the study and therefore had the opportunity to go back and forth to correct the problems as necessary. Verification involves "strategies to check for investigator responsiveness, methodological coherence, sampling accuracy, an active analytical stance, theoretical thinking, and theory development" (Morse et al., 2002, p. 17). Focusing on verification strategies enhanced my responsiveness to data and constantly reminded me to be proactive in addressing issues in my data collection and analysis. I used the verification strategies as explained below.

Investigator responsiveness. Morse et al. (2002) stated that the major threat to rigor is the lack of responsiveness of the investigator. Investigator responsiveness demands sensitivity, creativity, flexibility, and skill in using the verification processes. As such, I enhanced my responsiveness capabilities in terms of increasing my knowledge and improving my skills in the field of qualitative research in general as well as reinforcing my specific research skills, such as completing a practice interview. Further, in order to implement this strategy during data collection, I listened to the participants carefully without leading them toward my personal conclusion with my questions and comments. In my interview reflections, journaling and memoing, I tried to be conscious about when I was moving between an emic appreciation and an etic view of the data. I need to recognise my experience and assumptions gained as a diabetes nurse educator and differentiate these from what I was seeing in the data. During data analysis, I tried to be very reflexive about my decisions, and ensured I maintained an audit trail. Ongoing analysis resulted in the dynamic formulation of conjectures and questions. I had regular frequent discussions with my supervisors to discuss my interviews, data and coding. This provided the opportunity to question my interpretations and understandings of the data, and to appreciate how my assumptions and worldview may influence my data analysis. I also maintained a diary to write any new discoveries arising from the data and my impressions.

Methodological coherence. Throughout the data collection process, I used a variety of techniques such as face-to-face interviews, interview notes and telephone or face to face conversations with my participants for the second round questions. I recorded all my observations about the participants in particular and the environment in general. I also had a personal diary and wrote my feelings, thoughts and impressions before and after each interview, the process of the interviews and my interaction with the participants.

Using focused ethnography helped me to move through the data, develop ideas from the data, and then categorize and identify the main themes from the data. Although constant comparison has its origins in grounded theory, it is congruent with focused ethnography, and provided more direction for me as a novice researcher than the more generic thematic or content analysis often associated with ethnography.

Sampling adequacy and saturation. Sampling adequacy, evidenced by saturation and replication (Morse, 1991), means that sufficient data to account for all aspects of the phenomenon have been gained. Adequate and appropriate sampling means that I had to recruit the best people with the best kind of information to answer my research questions. Seeking negative cases was essential; ensuring validity by indicating aspects of the developing analysis that are initially less than obvious (Morse et al., 2002). As Richards and Morse (2007, p. 76) mentioned, “the scope of a project is bigger than its sample, for participants provide information about others like them or unlike them.” In order to find negative cases, I distributed advertising posters to some of my community contacts who could distribute them in the Zoroastrian and Baha’i community centers. Although my participants practiced Islam differently, they were all Muslim except for one participant who was Zoroastrian (Zoroastrianism is an ancient Iranian religion and a religious philosophy). I considered the religion of this participant as a negative case because her belief system (including religion) was different and she was “unlike” others in my study. Her experiences and ideas helped me tease out the difference between cultural and religious influences. For example, it became clear that beliefs such as ‘illness as a test from God’ or ‘illness as a punishment from God,’ the concept of the evil eye and even notions of predestination were common to participants from an Islamic tradition that she did not share.

An appropriate sample size for a qualitative study is one that adequately answers the research question. In my study, saturation was determined as when participants provided redundant consistent descriptions and experiences. Although there was wide variation in the articulation of some religious and cultural assumptions and practices, the core themes of phases of the diabetes journey, as well as diabetes as a ‘ball and chain’ were considered as reaching saturation.

Collecting and analyzing data concurrently. This strategy is a mutual interaction between what is known and what one needs to know (Morse et al., 2002). After conducting an interview with a new participant, I reflected on the interview and wrote reflective notes and sent the recorded interview for transcribing. Upon receiving the transcript, I began the analysis of the transcript. Completing the analysis of a transcript from one participant before starting another helped me to identify areas that might need exploration, ideas that needed clarification, or new questions to pose. This strategy helped me in increasing my understanding about what was happening and enabled me to focus on new participants. By consulting with my supervisors, focusing on, and continuously rechecking the data, I tied to ensure that the data I collected illuminated Iranian women's experiences of living with diabetes.

Ethical Considerations

We submitted this proposal for ethical review by Health Research Ethics Board at the University of Alberta. The proposal was also reviewed by the management of the recruitment sites, the Al-Ghadir and Az-Zahra Islamic and cultural centres. Qualitative inquiry brings with it special issues pertaining to participant consent and maintenance of participant anonymity that I will explore in the following sections.

Informed consent. Information that I provided to the participants for the purpose of obtaining informed consent included the title, purpose, explanation of the research and the procedures that followed. I shared with the participants my status as a past diabetes educator at a clinic (although not currently employed as a nurse) and a student researcher. I verbally explained the information sheet, consent form, and answered any questions the participant had about the research. The consent forms were signed prior to starting the interviews. I gave a copy of the consent form to each participant and I highlighted my contact information for the informant.

Confidentiality. In the research setting, confidentiality involves the management of private information. However, the understanding of confidentiality is culturally based. What is considered private in one culture and social context is different from other cultures. For example, in Iranian culture, people are not comfortable to be interviewed in front of their families and also they are not comfortable to talk about their personal life, especially sex related issues. If we interview participants in situations where they don't feel comfortable, we will not receive rich information. Thus as a researcher, I had to consider this issue very carefully during interviews and data analysis.

Overall, confidentiality means protecting personal identity. I did not reveal to others who had participated or what they said. All data and contact information were kept in a locked filing cabinet. Code sheets and data forms were kept in separate cabinets. For assuring anonymity, a letter code was assigned to each informant, e.g. ABY 1 for interview with participants #1, ABY 2 for interview with participant #2, etc. The confidential code list looked like this: informant real name #1=ABY 1 and was used throughout the dissertation. During and after the study, I checked all written materials from the start to ensure that participants were not recognizable. I removed real names and replaced them with a descriptor; for example, "husband" would replace the name.

I explained to each participant that excerpts of small portions of her interview would be used in writing the findings and in future publications and that any quotes used from the interview would not have any identifying information. If data from this study is used for a secondary analysis later on, the subsequent study will undergo another ethics review to ensure the proper use of the data. I will keep data (electronic based) and consent forms for a minimum of five years as required by the University of Alberta Health Research Ethics Board and will destroy them afterwards. All data were kept securely locked in a filing cabinet in my home office. I gave audio files to the transcriptionist and received transcripts in person.

Ethical risks in this study. Conducting qualitative research is considered to be low risk, but it is not entirely without risk for causing emotional harm (Morse, 2007). Bar-On (1996) believes that in qualitative studies “we hold the meaning of people’s lives in our hands” (p. 20). According to Hammersley and Atkinson (1993) taking part in research can lead to anxiety in, and exploitation of, participants and that publication of research findings may damage the reputation of participants or members of their social group. In the following section, I discuss two potential harms for my participants that I monitored and addressed throughout the study.

Anxiety and stress. My aim was to achieve an in-depth understanding of living with diabetes as an immigrant woman from Iran. This included an exploration of the reasons and context for my participants' beliefs and actions. My probing questions had the potential to create anxiety or distress in participants especially if their personal biography and experience were in some way traumatic to recall and discuss.

If a participant became distressed, I offered to halt the interview, comfort and make sure the participant was fine. I asked the participant if she would like to continue the interview or not. Some participants became distressed because they did not know what to do in regard to their diabetes. This was difficult for me to hear, as I am an experienced diabetes nurse educator, and it was difficult to hear about health care interactions that were ineffective in helping support the participant’s efforts to live well with diabetes. However, my role was not to provide diabetes education or counseling. When this occurred (with 4 women in this study), I referred the participant back to their diabetes care providers, clinic or physician.

Balancing my role as a researcher. While I was doing this study, I was in the researcher role and sometimes I felt a conflict between my role as researcher and my role as a nurse. Throughout the interviews, I was aware of the boundaries between my role as a researcher and a nurse. For example, with one participant I became concerned about her lack of a meal plan from her family physician. Following the interview, I contacted her to recommend that she return to her physician to ask for a referral to a dietitian or to the diabetes clinic for nutritional assessment and development of a meal plan. In a follow-up check in, I discovered that the physician had referred her to dietitian but she had not followed up because she was worried about paying for the consultation. I asked her to go to a diabetes clinic and register for a free consultation with the diabetes educator and dietitian.

Exploitation. The importance of power relationships and the potential for research to exploit as well as exclude women have been mentioned in the literature (Oakley, 1981). Power imbalance is more dominant when the researcher is a health professional. Holloway and Wheeler (1999) state that "the participant may feel pressured to participate in research because of a sense of duty, or because they depend on the good will of their care-givers" (p.232). I tried to minimize the possibilities for exploitation by explaining to participants that this study had no relationship to their diabetes care and that their participation did not have to be communicated in any way to their health professionals. I emphasized that they were free to choose or reject the invitation to participate in the research. I also clarified my role as a student researcher. I tried to reduce the power imbalance between the participants and myself by considering reciprocity and a sense of mutuality. I felt I succeeded because one of my participants mentioned:

> "It is nice having somebody to talk to other than your family. Because sometimes I feel I can talk to other people where I can't talk to my family" (ABY 15).

There was another aspect of power that was of concern when I started the study. Persian and Iranian social and political history means that some Iranian Canadian people may be distrustful of authority and may be reluctant to disclose negative experiences, perceptions, beliefs or feelings. Adding to this was the reality that some of my participants were in Canada on short-term visas, often because their children were attending school and they may have worried that their visas were at risk if they disclosed any problems with their diabetes. One participant told me she hid her diabetes because she was afraid her employer would fire her. Even though I explicitly presented myself as a doctoral student from the University of Alberta, and specifically said I was not employed as a nurse, my participant recruitment began slowly. I believe that as my early participants were able to share their experiences of being in my study with others, and as I became a known presence in my two recruitment centres, snowball sampling became more effective.

Reflection on the Researcher as Research Instrument

In this qualitative study as in most others, the researcher was the instrument through which the data were created and results produced. I believe, in qualitative studies, we as researchers interact with other people and having influence on each other is unavoidable, so “value-free interpretive research is impossible” (Denzin, 1989, p.23). Who I am has influenced my results, although I have taken rigorous steps to ensure that my assumptions and beliefs have not overwhelmed my ability to understand my participants’ experiences and to inductively analyse my data. Patton (2002) states that there are four ways in which a researcher might influence the data of a qualitative study: researcher presence - the reactions of the participants to the researcher’s presence; value imposition - influence of values of the researcher; professional incompetence or a lack of sufficient training or preparation; instrument change-in a qualitative study, changes in the researcher over the course of the project. In the following paragraph I explain my role in the study and the strategies I have used to be reflective and observant of the interaction between my position as a qualitative researcher and diabetes nurse and my participants and data.

Based on what Morse (1991) stated, “essentially skillful interviewing is characterized by the extent to which the investigator can establish rapport in qualitative research,” being part of my participant’s culture was beneficial, but also created some challenges for me. I tried to spend a period of time to establish rapport and trust with the women who took part in my study and to interact with them. When I was doing recruitment, I frequently attended the social and religious programs held by the centers. I had to be transparent about political issues. Usually Iranian people who live in Canada do not trust others to talk about their concerns or experiences in a particular situation. They do not like somebody writing about them. They hesitate to disclose their ideas to the authorities here, or in Iran, as they believe that this may cause difficulties for them in the future. Some of my participants were not able to go back to Iran because of political reasons and some of them were applying for Canadian. They were very cautious about what they said. For these reasons, I had to work very hard to reassure them about confidentiality and this resulted in increasing participant recruitment.

Before starting the interview with my participant, I tried to provide a relaxed environment by offering a cup of tea and a short chat before starting the interview. I let my participants talk without interruption. I used encouraging but non-directive prompts and encouraging words, and open-ended questions to facilitate the free expression of their ideas. My follow -up questions were based on reflections of what they had said. In order to minimize misunderstandings, I often asked for clarification or elaboration. Writing field notes and memos immediately after each interview also helped me to record all the verbal and non-verbal information that contributed to my interpretation and analysis.

As a novice qualitative researcher, I worked closely with my co-supervisors. My study continually evolved as I completed each interview and analysed the interview data, and I was able, in discussion with my co-supervisors, to consider how to alter my interview guide in order to probe more deeply in some areas, verify my emerging ideas in other areas, and to elicit the best descriptions from my participants. We met at least twice a month and we often discussed how my ‘taken-for-granted’ beliefs and assumptions fit into, or restricted my understanding of the data. For example, discussing how pervasive belief in the “evil eye” is in the Iranian Canadian community helped me consider how it combined with other religious beliefs, such as predestination, and how it contributes to regarding diabetes as a “ball and chain” that can, or cannot be ameliorated. I needed to reflect on how Iranian/Persian social customs, such as the role of women in society, might be related to beliefs about women’s intrinsic frailty and to stigma associated with chronic illness so as to produce a sense of futility and helplessness in the context of diabetes. Discussing these “background understandings” helped to strengthen my analysis and to bring credibility to my interpretations.

The third impact was my position within in Iranian community in Canada and being a novice researcher in exploring both cultures. In this study, I was studying my own culture and I was familiar with my own cultural values and beliefs, having lived in Iran for almost 30 years. As I have lived in Canada for almost 10 years, I was also familiar with the issues of moving to a new country. This experience allowed me to see aspects of both Iranian and Canadian cultures influencing women’s experiences of having diabetes perhaps more than other researchers who do not have this background.

Chapter Summary

My research journey in exploring and understanding the experiences of Iranian Canadian women living with diabetes was shaped by the characteristics of focused ethnography as a qualitative research method. My specific interest was in how the culture and religious context influenced my participants' experiences and patterns of behavior. Cultural and religious commitments shape their expectations and social roles as women, mothers, spouses and members of their social groups. My research strategies were designed to find the best people available to articulate their experiences, and my analysis aimed at discovering an emic and etic perspective of this experience. I was honored to be able to enter this aspect of my participants' lives and I maintained awareness at all times, of this privilege and responsibility. In exploring their experiences, I learned more about my own culture and values as a Iranian Canadian woman and as a nurse educator. My social and professional backgrounds allowed me a unique position to articulate these often hidden lives.

CHAPTER 4 - RESULTS

The narratives my study participants shared with me were their life stories in which having diabetes represented a major journey. While I focused on the voyage of learning to live with diabetes, there were also major threads from other parts of their life experiences. These included stories about how their immigration experiences influenced the way they and their families adapted to life in Canada. Another major thread was how their diabetes had altered the way in which they constructed their social identities within their religious and cultural communities. It is important to emphasize that my participants used the terms religion, faith and spirituality interchangeably, although generally they are different. My participants, each in their own way, had experienced tremendous transitional journeys that resulted in a greater or lesser ability to re-formulate their self-understanding and identity. Further, each individual transition was influenced by religious beliefs, socio-cultural and family factors. For example, for those participants who spoke English, transition was smoother and easier than it was for other participants.

> *I was a party person. I loved to have a party at home and join my friends in the parties. We have lots of religious and cultural ceremonies here in Vancouver through the year. I participated in every single ceremony before. Since I have diabetes I prefer not to go or even organize a party at home. I am not feeling good at the ceremony. I can't eat whatever I ate before.....I feel more isolated.....I am different now (ABY 1; aged 38).*
>
> من عاشق مهمانی رفتن و مهمانی دادن بودم و همیشه از در کنار دوستان بودن لذت میبردم. ما تعداد
> زیادی جشن های مذهبی و فرهنگی داریم قبلا در تمام مهمانی ها شرکت میکردم ولی الان ترجیح میدهم
> در خانه بمانم احساس خوبی ندارم هر چیزی که دوست داشتم را نمیتوانم بخورم...و احساس تنهایی
> بیشتری میکنم ...احساس تفاوت بین خودم و بقیه دارم

As ABY 1's quote above reveals, diabetes forced a transformation on a number of levels including personal, relational and social. I have conceptualized the common journey of learning to live with diabetes on a path or road that passes through a variety of vistas (Figure 4.1).

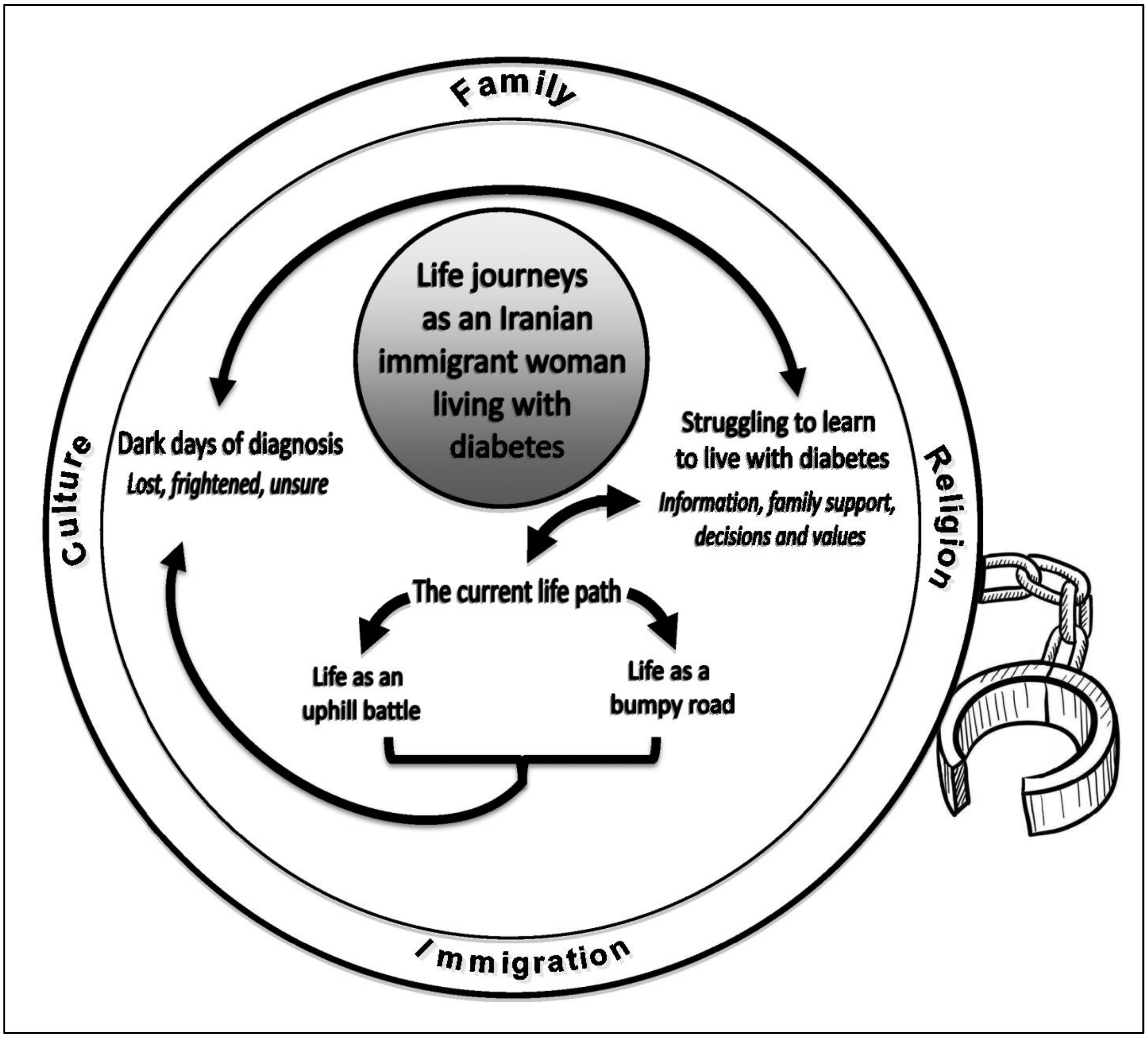

Figure 4.1 Life journey as an Iranian immigrant woman living with diabetes

At the beginning, starting with diagnosis, their paths enter a dark and terrifying place, as they face the challenge of diabetes for the first time. Following this, they embark on a path I have called ‘struggling to live with diabetes,’ in which they incrementally seek ways to integrate diabetes into their lives and cope with the obstacles it presents daily. Finally they find their way. For some, their life road is bumpy and for others, it is an uphill battle. A core theme throughout the study was diabetes as a “*ball and chain”* which described how it affected their lives. While I had two participants who perceived that they are living relatively well with diabetes, the vast majority continue to struggle with its impact on their immediate lives and anticipated future.

The women in this study went through different phases in learning to live with diabetes. In the following section I will describe their journey from diagnosis to the present. Although I will present these phases of their diabetes journey in a linear form, in reality these paths were not linear. Participants crossed from one road to the other, often in conjunction with challenges in other areas of their lives. Sometimes an event or experience would form a “short cut” that would lead them back to an earlier phase or move them from a fairly straight path onto a bumpy and difficult path.

Phase 1: Dark Days of Diagnosis

Entering into the world of diabetes started with “Dark Days” of diagnosis. The dark days of diagnosis represents the point in which participants’ current life path was interrupted and drastically rerouted to their diabetes path. Diabetes represented an unexpected disruption in their bodies and identities.

Pictorially, I imagine that the path of dark days of diagnosis is a rocky, unstable and twisted road, overshadowed by dense and threatening vegetation (Figure 4.2). The participants were shocked and bewildered by the diagnosis and experienced it both physically and emotionally. Some felt physically paralyzed while others experienced anger. For many participants, there was considerable resistance to stepping on this path and active efforts to deny and resist the diagnosis. All needed to find a reason for this disruption to their lives and many blamed themselves, their lifestyle, or believed it was a judgment from God. This new road was terrifying because everything that they held as familiar was gone and their confidence in their bodies and identities was fundamentally shaken. They did not know where this path would take them.

Figure 4.2 Life path in dark days

> *I remember those dark days clearly…It was very bad…I had lots of tensions (ABY 1; aged 38)*
>
> من آن روزهای سخت و تاریک را به خوبی یاد میاورم... خیلی روزهای بدی بود زندگی من پر از تنش شده بود

The initial reaction of women to the diagnosis of diabetes was surprise, horror and shock. In the following section I will describe the women's experience of the early days of diagnosis including the shock of diagnosis, physical complaints after diagnosis, resistance and seeking confirmation, disbelief and emotional reactions such as anger and fear.

Shock and horror of diagnosis. The initial diagnosis was described as a dramatic and significant life experience for women in this study. Nearly all the participants expressed their first reaction as a complete shock, and being in tears when they were told they had diabetes. These feelings were most common among the participants who had a family history of diabetes or had friends with diabetes. Most never expected it and did not want to believe it. The feeling of shock worsened when they thought of the possibility of an earlier death because of the complications of diabetes:

> *In the earlier days, it was very hard. I thought my death will arrive soon because of diabetes…I heard a lot of bad things about diabetes and its complications…I just gave up… (ABY 9; aged 48)*
>
> در ابتدا من روزهای بسیار سختی داشتم فکر میکردم به زودی خواهم مرد ... من چیزهای بسیار بدی
> درباره دیابت شنیده بودم و همه ش فکر کردن به مشکلات دیابت آزارم میداد ... من دیگر نمیتوانستم کاری
> بکنم

Some women expressed their shock with feelings of anger, fear and questioning; as one participant said, "*I was very angry with everybody with no reason*" (ABY 6; aged 49). The participants faced immediate fears about long-term complications, immediate bodily failure due to low blood sugar, fear of taking medications (in particular insulin), and fear of dependency on their family or friends:

> *Personally I am really scared of diabetes. Especially, I am scared of complications…I know about diabetes complications, especially eye problems and blindness… I am also scared of very low or high blood sugar …I am always scared of fainting (ABY 4; aged 43)*
>
> شخصا از دیابت وحشت دارم بخصوص از مشکلات همراه ان میترسم...من مشکلات همراه ان را میشناسم به
> ویژه مشکلات چشمی و نابینایی ...من همچنین از افت شدید قند خون میترسم ...از غش کردن همیشه وحشت
> دارم...

Fear of dependency on medications, such as Insulin, was common among the participants. Often the fear was a based on a combination of reasons such as not understanding the nature of diabetes or that the medications might have a negative effect on their body:

> *I do not like to take any medication…If I start taking oral medication I have to take it for my entire life…taking medication for controlling blood sugar causes more stress….my body gets dependent on it…I do not like to be dependent on any medication…as much as I can I will refuse to take oral medication for controlling my blood sugar…. (ABY 10; aged 46)*
>
> من اصلا دوست ندارم دارو مصرف کنم .. اگر من دارو مصرف کنم باید تا آخر عمر مصرف کنم...
> مصرف دارو برای کنترل قند خون سبب اضطراب بیشتر میشود... بدنم به آن وابسته میشود... من
> دوست ندارم بدنم به چیزی وابسته شود.. تا آنجا که بتوانم سعی میکنم داروهای خوراکی برای قند خونم
> مصرف نکنم

Looking for the reasons for getting diabetes. In the dark days, many of the participants were looking for the reason why that they got diabetes, including blaming themselves for developing diabetes or supernatural causes.

Blaming themselves. Blaming either their diet or excessive emotional pressure in their past was common. Shame was also a frequent experience. These feelings were shared among women with low educational levels, particularly in women with less than grade six education. They reflected on their past behavior and found fault with their lifestyles including poor weight control and eating habits:

> *I still do not know why I got diabetes …I know my grandparent had diabetes…I think my bad eating habits in the past for example eating a lot of sweets also caused my diabetes…every time when I think about the past I remember how much I ate sweets and fried foods…I believe I put too much pressure on my body and I finally got diabetes (ABY 7; aged 59)*

من نمی‌دانم چگونه دیابت گرفتم ...من می‌دانم پدربزرگم دیابت داشت ...من فکر می‌کنم عادت غذایی بد من در گذشته برای مثال خوردن زیاد شیرینی و غذاهای سرخ شده. با اینکه از فشار زیادی به بدنم آوردم و سرانجام دیابت گرفتم

As they reflected, some participants could recall other people expressing concern about their nutritional habits:

I think it was my fault, I ate too much sweet in the past and I did not listen to anybody not to eat too much sweet and white rice (ABY 2; aged 61)
همش تقصیر خودم بود من بیش از حد مواد شیرین می‌خوردم من به علایم داخل بدن توجه نمی‌کردم و به توصیه های دیگران برای نخوردن زیاد شیرینی و برنج توجه نمی‌کردم

A few participants had been oblivious to the consequence of their food choices:

I never paid attention to what I ate and amount of food I ate…I never thought about diabetes. Now I reached to a point of my life that being sorry for what I did in the past is not useful, maybe it is a lesson for young people…(ABY 15; aged 62)
من هرگز در گذشته به چیزهایی که می‌خوردم و مقداری که می‌خوردم توجه نداشتم ...من هرگز به دیابت فکر نمی‌کردم , الان در نقطه‌ای در زندگی رسیده‌ام که افسوس به گذشته فایده‌ای ندارد , شاید برای جوانان مفید باشد

Some women blamed themselves and believed that emotional factors, such as anger, stress, anxiety, and sadness (being home sick) were the cause of diabetes. The women who found out about their diabetes when they moved to Canada mentioned that immigration caused many concerns and stress for them which led to their getting diabetes, especially when they did not have any family tendency for diabetes:

I could not believe I had diabetes….I thought diabetes is only for very old people and we did not have any family member with diabetes…when we moved to Canada we had many issues and stress for whole family and I believe my diabetes is because of the stress and anxiety…. (ABY 8; aged 57)

> باورم نمی‌شد دیابت دارم.. فکر می‌کردم دیابت مال افراد بزرگ سال است هیچ سابقه خانوادگی دیابت نداشتم...اما وقتی به کلاس آمدیم همگی دچار اضطراب و تنش بودیم و فکر می‌کنم که من دچار دیابت شدم به دلیل همین اضطراب ها بود

Some believed that when they thought about their illness their situation seemed to worsen:

> *These thoughts (think about why I got diabetes) caused more stress and higher blood sugar for me... (ABY 2; aged 61)*
>
> فکر کردن به اینکه چرا در گذشته مواظب وزن خودم نبودم سبب استرس زیادی در من شد و قند خونم بالاتر رفت

Some women described feeling judged and blamed by others because of over eating and being inactive:

> *I found a lot of people like to judge and ask the reason I have diabetes…they start to convince me I have diabetes because I have a sedentary life and so on… (ABY 13; aged 42)*
>
> من متوجه شدم تعداد زیادی از مردم دور من دوست دارند درباره دیابت من و علت وجود ان جستجو و قضاوت کنند. شروع می‌کنند و به من می‌گویند دیابت من به سبب زندگی بی‌تحرک من است و چیزهای شبیه این

In their search for meaning, participants looked for a supernatural cause to explain why they developed the condition.

Supernatural explanations. Some women believed "*this is a test from God*" (ABY 7). Some women believed that God wants only good for humankind and there is always great wisdom behind illness or any trouble in their lives. Women who believed in a supernatural explanation for their illness were highly religious or grew up in a family with strong belief in supernatural causes. Most of these women had a low educational level. For some women diabetes presented them with the opportunity to develop a closer relationship with God:

> *We have to accept all the conditions, one day good, another day bad, one day ugly, another day blissful, one day healthy, another day sick-this is all from God. (ABY 2; aged 61, second round of interview)*
>
> ما باید همه شرایط را قبول کنیم یک روز خوب یک روز بد, یک روز خوبی یک روز بدی,یک روز
> بیماری یک روز سلامتی

Others believed it was God's punishment *for their sins* (ABY 3). Some participants engaged in attempts to negotiate with God through prayer. They struggled to understand why God would inflict such a terrible condition on them. One woman said:

> *At the beginning, I had very hard time. I complained to God about my disease and asked God why should I have diabetes? I attributed my illness to the will of God and sometimes I asked myself is my disease a punishment for sins of my past life or a test from God. I had lots of struggles (ABY 1; aged 39)*
>
> من اوقات سختی داشتم و عصبانیت داشتم من به خدا شکایت می‌کردم که چرا من دیابت گرفتم گاهی
> فکر می‌کردم شاید من در گذشته کاری انجام دادم و الان یک تنبیه از طرف خداوند است یا یک امتحان
> است من با این افکار مدت‌ها دست و پنجه نرم می‌کردم

In the early days of diabetes some women believed the *evil eye* caused the condition. The evil eye is a supernatural belief that a person can harm another with his/her psychic evil eye, causing illness or other bad luck for that person. Despite the differences in the cultures that hold the evil eye belief, the concept of the evil eye is one of the strongest symbolic images in the world (Ross, 2010). The concept of the evil eye and its significance vary widely among different cultures, primarily in West Asia and many Mediterranean cultures (Rivka, 1994). In Iranian culture, people say "ماشاءالله" "may God protect you" or recite two verses of Quran to ward off the effects of the evil eye:

وإن یکاد الّذین کفَروا لیُزلقونَک بأبصارِهم لمّا سَمِعوا الذّکرَ ویقولونَ إنّه لمَجنونٌ * و مَا هوَ إلاّ ذکرٌ
للعالَمین.(verses 51 and 52 of Chapter Al-Qalam)

> "*And indeed, those who disbelieve would almost make you slip with their eyes when they hear the message, and they say, "Indeed, he is mad." But it is not except a reminder to the worlds."*

Almost all the women acknowledged that the evil eye could cause harm in a different way, such as affecting their success or wealth, rather than specifically causing diabetes.

> *When you have everything –successful kids-husband-education and those things …you know, I believe success is a reason for "Evil Eye"…I believe in the Evil Eye- this is part of my belief...I believe it (ABY 6; aged 49)*
>
> *وقتی همه چیز در زندگی داشته باشی بچه های موفق همسر تحصیلات بالا و چیزهای دیگر کشم*
> *مکن علت سبب دید . من عقیده دارم موافق بودن سبب چشم زخم میشود ...من به چشم زخم عقیده دارم*
> *..بخشی از معتقدات من است ...من باور دارم*

According to Islamic beliefs, the Prophet Mohammad (pbuh) said that the evil eye is a reality; however, Muslims must be confident that nothing can harm them except by the Will of Allah.

Some of my participants believed that diabetes was the starting point for ongoing bad luck, such as divorce. Slaughtering lambs is not a shari'a-approved (Islamic laws) treatment for the evil eye and it is not mentioned in the Quran, but the Hadith (a report of the sayings or actions of Mohammad or his companions) teaches that it was practiced during the time of Prophet Muhammad (pbuh) at the birth of a child, and thus is an accepted practice that is continued to the present time:

> *I know all of my bad luck happened because of the evil eye…I sacrificed a lamb many times to avoid further bad luck… (ABY 7; aged 59)*
>
> *من میدانم همه بدشانسی ها به خاطر چشم زخم است ...من گوسفند قربانی کردم چندین بار در سال تا از اقبال بد*
> *جلوگیری شود*

On the other hand, some women in this study did not perceive a relationship between their diabetes and the evil eye:

> *I believe in the evil eye-[it] can destroy happiness, but I do not think it can cause diabetes; diabetes happens in my body gradually and has natural reasons… (ABY 13; aged 42)*
>
> معتقد با چشم زدن دارم ولی فکر نمیکنم ارتباطی بین بیماری دیابت و چشم زدن باشد

Overall, all of my participants stated the existence of the evil eye with some variation related to its causing illness or not, with women who practice Islam everyday more strongly believing in the evil eye.

The physical shock of diagnosis. The period of time in the dark days of diagnosis also included a somatic response to the shock of diagnosis. In other words, they experienced a range of strong physical reactions that could last for an extended period of time. The initial typical physical response to hearing the diagnosis of diabetes was feeling dizzy and light headed, accompanied by nausea and severe headache:

> *I never forget those moments after diagnosis, I felt lightness in my head like somebody with very low blood pressure and it causes more problem and concern for me (ABY 1; aged 38)*
>
> من هرگز ان روزهای ابتدای تشخیص دیابت ازیادم نمیرود سرم را نمیتوانستم بلند کنم مثل کسی که فشار
> خون پایین دارد

Other participants found it hard to be motivated about anything. The women were overwhelmed by the diagnosis and seemed to lose interest in their surroundings:

> *I could not move, I could not do anything…I preferred to stay on my bed most of the time… (ABY 13; aged 42)*
>
> من نمیتوانستم حرکت کنم, نمیتوانستم کاری کنم. من ترجیح میدادم بیشتر زمان خود را درتخت خواب
> بگذرانم

Continued stress and anxiety could be manifested as tension, headaches or physical pain which compounded their anxiety, as ABY 15 explained:

> *I found out I have diabetes few years after my husband …I had severe headache like somebody held my head…my physician believed it is a nervous headache then I had to see another specialist for my headache (ABY 15; aged 62)*
>
> چند سال بعد از ابتلا همسرم به دیابت من بحال شدم ...سر درد های شدید داشتم مثل اینکه کسی سرم را
> فشار میداد پزشکم معتقد بود که سر درد, سر درد عصبی است بعد متخصص دیگری را هم برای
> سر دردم دیدم

My participants understood that their physical reactions were related to their emotional reactions to the shock of the diagnosis of diabetes:

> *I remember the time I realized I have type II diabetes, I felt something in my throat and when I cried I felt more relief…this feeling was getting worse every time when I went to see the physician…it took many months to get relief from this symptom…(ABY 12; aged 52)*
>
> زمان تشخیص دیابت یادم هست فکر میکردم بغضی در گلویم هست وقتی گریه میکردم احساس راحتی
> بهتری میکردم .. این احساس من بدتر میشد وقتی برای ویزیت دکتر میرفتم .. چند ماه طول کشید که از
> این احساس راحت شدم

Overall, women did not feel good mentally and physically after their diagnosis with diabetes, and this sense of distress could take months to resolve.

Resistance and seeking confirmation. The majority of my participants reported that their initial reaction to their diagnosis of diabetes was to resist and reject the diagnosis. After hearing the news, some women did not believe the physician and requested further diagnostic blood work. Seeking additional blood work for confirmation was common experience among all women. Others sought a consultation with another physician. This resistance and search for an alternative treatment could last up to a year before they accepted that they did have diabetes and needed to take steps to manage it. Resistance was common in younger women. ABY 1 whose diabetes started with pregnancy (gestational diabetes) six years ago and type II diabetes after that, said:

> *I could not believe it and denied my illness for many weeks but they told me about the importance of having normal glucose during pregnancy for fetus and for myself… I asked my husband to make an appointment to see a private Endocrinologist. When we saw the specialist, he told us something worse, he said I do not need to wait for controlling my blood sugar with diet and exercise; I need to take Insulin (ABY 1; aged 38)*
>
> تا هفته ها بعد از تشخیص دیابت باورم نمی‌شد و انکار می‌کردم ولی آن ها راجع به اهمیت کنترل قند خون
> در دوران بارداری برای جنین...من از همسرم خواستم برای دیدن کارشناس غدد وقت بگیرد وقتی من
> ویزیت شدیم چیز بدتری شنیدم می‌گفت نیازی نیست منتظر باشم با ورزش و تغذیه قند خونم را کنترل کنم من نیاز به
> تزریق انسولین دارم

Part of the anxiety in the dark days for these women appeared to be related to the health care system in Canada. While all the participants praised the treatment and care they received from the health care system, some of them expressed perceived inadequacy in the content and quality of their consultations with family physicians:

> *At the beginning I was quite confused and surprised when we realized I have follow-up by General Practitioner…I do not believe they have enough knowledge for diabetes… (ABY 11; aged 63)*
>
> در ابتدا من کاملا متعجب بودم که باید برای درمان دیابت توسط پزشک خانواده درمان شوم ...من
> فکر نمی‌کنم آن ها دارای دانش کافی برای مراقبت از افراد دیابتی باشند

It was clear that the women who had diabetes while they lived in Iran had very different expectations. For example, when they were in Iran, they always saw an Endocrinologist. In comparison, here in Canada the services for people with diabetes are mostly provided by family physicians. Some did not trust what the family physicians advised them to do and they tried to go back to Iran to see an Endocrinologist to get further information and confirmation of the diagnosis:

> *I go to Iran twice a year and I check my diabetes with Endocrinologist and dietitian…I think they understand me better and I can discuss my situation and everyday challenges with them easily…(ABY 10; aged 46)*
>
> من سالی دوبار به ایران میروم و وضعیت قند خون خود را با متخصص غدد و تغذیه کنترل میکنم ...من فکر میکنم آنها بهتر من را درک میکنند و من میتوانم مشکلات خودم را با آنها راحتتر در میان بگذارم

Even at the time of diagnosis some preferred to go to Iran and discuss their blood work results with Endocrinologist in Iran before initiating any diabetes self-care actions:

> *I had a blood test; the result showed I had diabetes. I insisted that there was a possibility of wrong results. I told them I was very nervous for a long time and the blood sugar may go up because of that. I decided to go to Iran and see Endocrinologist before starting any medication (ABY 7; aged 59)*
>
> موقتی جواب آزمایش را گرفتم اصرار زیادی کردم که جواب این آزمایش قطعی نیست چون من برای یک مدت طولانی خیلی استرس داشتم و عصبی بودم تصور میکردم به خاطر این قند خونم بالا رفته است بنابراین تصمیم گرفتم برای دیدن متخصص غدد به ایران بروم

Resistance to treatment, a desire for a second confirmation, and distrust of family physicians in Canada is reflected in the following quote:

> *I was disappointed and it was hard for me to accept it…I went to Iran and saw Endocrinologist. The doctor believed I have to go on diet to control my blood sugar…It was very hard for me to accept this huge change in my body. (ABY 9; aged 48)*
>
> من خیلی جا خوردم برای من خیلی سخت است که قبول کنم ...من به ایران رفتم و کارشناس غدد را دیدم . پزشک معتقد بود من باید رژیم غذایی .برای من خیلی سخت بود که تغییر را در بدن خودم ببینم

Those women who had developed diabetes before they immigrated were very happy with the health care system in Canada, in part because they did not need to pay for every visit to the doctor. Some received financial support from the clinic for purchasing test strips for a glucometer:

> *When I was in US, I had to pay for every visit, when I was in Iran it was also the same …the good thing here we do not need to pay for every test or visit (Laughed)… furthermore if you have low income some test material will be paid by government…(ABY 7; aged 59)*
>
> وقتی من در آمریکا بودیم باید برای هر ویزیت پول پرداخت می‌کردیم وقتی ایران بودیم هم همین بود
> ...خوبیش اینجا این است که برای هر آزمایش خون و ویزیت پول پرداخت نمی‌کنید. بعلاوه اگر در
> آمد کمی داشته باشی دولت مقداری از وسایل لازم را پوشش می‌دهد

Over all, my participants’ experiences in the dark days of diagnosis focused on their illness and it dominated their lives. As long as they concentrated on their new health problem and the burden of their disease, they continued to feel lost, frightened and helpless. When the women realized the reality of their new situation, they moved toward accepting the need for medications and adjusted diet. Once they found a path out of the dark days of diagnosis, they found the path toward the next phase of their journey called “struggling to live with diabetes.” Although the length of time they spent lost in the dark days was varied, it was not uncommon that starts on the path of struggling to learn how to live with the diagnosis could take up to a year. In the following section, I go through the details of this stage of the life for women with diabetes.

Phase 2: Struggling to Live with Diabetes

The road women journeyed in struggling to live with diabetes was characterized by challenge and difficulty in learning and understanding the nature and implications of diabetes for their lives, identities, relationships, and well-being. This path was extremely challenging and rough. There seemed to be enormous obstacles each day. Sometimes the path narrowed as my participants experienced a sense of food deprivation and social isolation. Acute and chronic complications of diabetes caused emotional and mental challenges which intensified their struggles to find a way to live with diabetes.

For many of my participants, it was difficult to learn and understand what they needed to know about diabetes, and it was even more difficult to learn how to accommodate or adapt their daily routines. The signposts towards diabetes self-management seemed to contradict the direction, values and norms of daily life, whether it was culturally, socially or religion-based values and behaviors. Religious beliefs were an important resource and guide for many women. Support from family and friends, was an important resource, although it was evident that sometimes family support, or expectations were counterproductive:

> *I have to struggle with my illness all the time…diabetes reminds me everyday problem, limitation. I feel overwhelm most of the time… my family and close friends feel sorry for me… (ABY 1; aged 38)*
>
> من باید برای همیشه با دیابت در حال جدال باشم. دیابت برای من مشکلات هر روزه و محدودیت را یاد
> آوری می کند , من بیشتر اوقات احساس بی طاقتی می کنم ...خانواده و دوستان نزدیک من احساس ترحم به
> من دارند

Overall, when my participants stepped forward to start to grapple with the complexities of living with diabetes, the common elements were evident. In the following sections, I will describe these main categories.

Seeking information related to live with diabetes. The primary source of information about living with diabetes for the participants was the family physician. Only four women in my study were referred to a diabetes clinic and followed by a diabetes educator, dietician and physician. Some of my participants found the information was not sufficient, especially in the area of meal planning. This was mostly the case with women who had a low educational level and less ability to speak English. They then sought information from their home country (Iran) by travelling there or asking somebody from Iran to send educational booklets:

> *I do not know English so every time when I go to Iran, I asked my doctor to give me a sample of meal plan and she referred me to a dietitian in Iran and she gave me some advice for everyday meal plan based on what I usually eat…(ABY 10; aged 49)*
>
> من زبان انگلیسی خیلی نمی‌دانم من هر وقت می‌روم ایران از دکترم می خواهم برای من یک برنامه غذایی
> بنویسد و من را به یک کارشناس تغذیه فرستاد و او یک سری برنامه های غذایی بر اساس آنچه من هر روز
> می‌خوردم به ما داده است

Even for some of my participants who had meal plans, it was not very useful for them as Canadian foods dominated. The foods recommended in the Canadian food guide did not match with their cultural based foods, such as oatmeal for breakfast and so on:

> *The family physician gave me some booklets with some food map [she was addressing the Canadian food guide] although it has lots of picture still it is not very useful for me …pictures with very small font …I put it on my fridge for sometimes but it is not help me a lot …I am still eating based on word of mouth and what everyone recommends especially those with diabetes…as I said before my mother also lives with us and she always has some recommendations for me every day…[laughed]… (ABY 12; aged 52)*
>
> پزشکم یک کتابچه آموزشی به من داد و چندین تصویر آموزشی (منظور ایشان هرم مواد غذایی کانادا
> بود (اگر چه تصویر زیادی دارد ولی خیلی کاربردی نبود. تصویر با قلم خیلی ریز ...من یک
> مدت آن را روی یخچال چسباندم ولی خیلی مفید نبود ...من هنوز بر اساس آنچه از دیگران شنیدم و
> هر کس توصیه ای برای من دارد به ویژه افرادی از اطراف من که دیابت داشتند ... همان طور که قبلا گفتم
> مادرم با ما زندگی می‌کنه و ایشان هم توصیه های خودش را برای من داره

On the other hand, some of my participants found their family physician supportive and helpful. These women could communicate with their physician easily:

> *I always go to the walk-in clinic and check my blood works with my family physician …I do not have any problem with it… (ABY 9; aged 48)*
>
> من همیشه به درمانگاه نزدیک خانه می‌روم و آزمایش خونم را با پزشک چک می‌کنم ...من دچار مشکلی
> نشدم

In the following section, I will outline the main challenges in adapting to diabetes food regimen they encountered. These challenges included incorporating Iranian preferences into the meal plan, using herbal remedies, and cross-cultural language difficulties.

Food challenges. The most common struggle after developing diabetes for my participants was related to culturally inappropriate meal plans provided by Canadian dieticians. For example, one of my participants experienced difficulties determining acceptable foods as well as portion size, for example exchanging the right size of toast for traditional bread (Sangak) (This bread is heavier and thicker than typical Canadian bread), or white rice to brown rice:

> *I love to eat white rice, the rice we eat traditionally in Iran - but my diet advises brown rice. My family and I do not like it. I usually mix it with white rice. But I have to prepare white rice for my kids and my husband. I have one meal plan for myself and one for the rest of my family. This causes more cost for us. Some part of my meal plan has some food like oatmeal. We do not usually eat oatmeal and of course my family and I do not like the taste of oatmeal at all. I have some difficulty with the exchange list. We do not usually eat toast for breakfast. We have our own traditional bread, like Sangak or Barbary…I do not know how much of our bread I can eat for my meal…same problem with Persian stews (ABY 1; aged 38)*

> من عاشق برنج سفید هستم من در ایران بیشتر برنج سفید می خوریم - ولی کارشناس تغذیه برای من
> برنج قهوه ای توصیه کرده است . من و خانواده برنج قهوه ای دوست نداریم . من معمولا آن را با برنج
> سفید مخلوط میکنم . ولی برای بچه ها و همسرم برنج سفید درست میکنم . من یک برنامه غذایی برای
> خودم دارم و یکی برای خانواده درست میکنم . این کار هزینه زیادی برای ما دارد. یکی از مواردی که
> دربرنامه م کارشناس تغذیه گذاشته حلیم جو است معمولا ما نمی خوریم و من و افراد خانواده طعم ان را
> دوست ندارند . من در برنامه غذایی ولیست تعویض مشکل دارم برای مثال برای من نان تست نوشته
> است ولی ما صبحانه نان تست مصرف نداریم فقط نان بربری و سنگک داریم ... من نمیدانم چه مقدار از
> این نان ها میتوانم مصرف کنم ... همین مشکل با خورشت های ایرانی

It appeared that the nutrition counseling did not fit their Iranian cultural norms about food choices and food preparation. For women with families, food preference could be a significant challenge. In Iranian culture, usually it is the woman (wife or mother) who instills lifelong habits in her family. The wife/mother prepares dinner for the entire family based on family preferences, in particular, the children's preference. Often, my participants faced themselves preparing two meals - one for the family and one for themselves:

> *For my everyday meal, I have to prepare steamed vegetable for myself with no salt and fat and for my family something different…my family do not like what I eat…I have lots of responsibility at home and diabetes causes trouble to do my job perfectly. I have to spend a lot of time for myself and my diabetes (preparing specific meal and follow-up my eyes problem and visiting many specialists)… (ABY 7; aged 59)*
>
> برای هر وعده غذایی من باید سبزیجات بخارپز بدون روغن و نمک و غذای دیگری برای افراد خانواده
> ...آنها دوست ندارند غذایی که من میخورم ...مسئولیت های زیادی در خانه دارم و داشتن دیابت مانع انجام
> کارهایم است. من باید وقت زیادی برای کنترل دیابت بگذارم (تهیه غذای خودم، دنبال مشکل چشم و
> ویزیت های پزشکی)

Sweets are more likely to be consumed with tea in the afternoon than as a dessert following a meal (Figure 4.3). People from different parts of Iran have different traditional sweets that they are accustomed to eating and serving as a standard custom at every social gathering. Having sweets is a habit begun in childhood, so for many, it is extremely difficult to stop eating Persian style sweets:

> *I love eating sweets …I am powerless against sweets …it was very hard for me to not eat sweets, we had a high quality Persian bakery close to our house and it was our hobby to go –sit and eat sweets and tea…we are from a part of Iran called "The Home of Sweets" and we ate sweets since we were kids ….it was hard for me to switch from our traditional sweets to sweets such as raisin or dried fig… (ABY 11; aged 63)*
>
> من عاشق شیرینی خوردن هستم... و هیچ قدرتی در برابر آن ندارم...برای من خیلی سخت است
> شیرینی نخورم ما قنادی های زیادی نزدیک خانه داریم که به خوبی شیرینی درست میکنند و تمام سرگرمی
> من این بود که میرفتیم در قنادی ها و مینشستیم و چای و شیرینی میخوردیم... همچنین من از شهر
> یزد آمده ام که یکی از مراکز شیرینی پزی در ایران است برای من خیلی سخت است که خوردن شیرینی را
> با انجیر خشک و کشمش جایگزین کنم

Figure 4.3 Persian style cookies for Persian New Year.

My participants experienced challenges when they went out for meals in Persian restaurants. They really liked to eat their traditional foods, but most of these foods contain a lot of fat and portion sizes are large. They did not know how much or what they could eat at Persian restaurants:

> *We always went to the one of the Persian restaurants in North Vancouver –at least once a week; it reminds us being in Iran. Since I have diabetes I do not go to the restaurant very often. I think my family is very disappointed but they do not say anything to me. Being in Persian restaurants was full of fun for the entire family but we do not go very often recently because of me, I know they really like to go but they do not go… (ABY 10; aged 46)*
>
> ما همیشه در گذشته به رستوران های ایرانی در ونکوور زیاد میرفتیم حداقل هفته ای یکبار رفتن به این
> رستوران ها یاد ایران را برای ما میکرد ولی از وقتی من مبتلا به دیابت شدم نمیتوانم بروم خانواده من
> کمی سرخورده شدند و ناراحت هستند دلشان میخواهند بروند ولی به خاطر من نمیروند

Inadequate knowledge about foods exchanges in restaurants causes additional struggles for some women such as ABY 10 quoted above. They tended to avoid these situations. This often had negative ramifications for the family as a whole because meal times, especially in restaurants, are important social rituals. Diabetes formed a wedge between my participants and their families. When my participants could not go to a restaurant with friends, they felt more isolated and different from others:

> *I usually refuse to go to the restaurant with my friends, especially a Persian restaurant – even though I love to go-you know the meal served in our restaurant is not very good for diabetic people…(laughed)…when I refuse to go to the restaurant I feel weird…(ABY 6; aged 49-second round of interview)*
>
> من معمولا از رفتن به رستوران طفره میروم با وجود اینکه خیلی دلم میخواهد برم به رستوران های
> ایرانی شما میدانید غذاهای رستوران های ایرانی برای دیابتی ها خوب نیست ... (خنده)... احساس خیلی
> غریبی دارم وقتی درخواست رفتن به رستوران را رد میکنم

Refusing traditional foods because of having diabetes was difficult for some of my participants. Although those foods contain more red meat and fat, they still like to eat them once in a while:

> *Different types of Kebab have a special place in our traditional foods, I love to eat a variety of Kebab-especially Kobydah [laughed] but the nutritionist advised me not to eat fatty foods and lamb but it is very hard for me to avoid the foods I love to eat and I ate those foods my entire life (ABY 13; aged 42)*
>
> شما حتما میدانید کباب ها جای خاصی در غذاهای سنتی خود داریم . من خیلی دوست دارم که انواع کباب
> ها را بخورم به ویژه کباب کوبیده (خنده) اما کارشناس تغذیه توصیه کرده از این غذا ها و گوشت
> گوسفند صرف نکنم. ولی خیلی سخت است برای من که نخورم این جور غذا ها که تمام عمرم خوردم و
> عاشق خوردن ان ها هستم

The issue for some women who lived in North or West Vancouver was being close to many Persian restaurants and every time they passed through the most famous street for the Iranian community, Lonsdale Street, it was surrounded with good smelling Persian foods:

> *Every day when I pass [Lonsdale] street I smell the wonderful Kebab and Persian sweets along the street…it is irresistible not to eat but to come home and eat steamed vegetable …I am not sure how much can I eat of those foods - if yes, how much can I eat?…(ABY 12; aged 52)*
>
> هر روز وقتی من از این خیابان رد می‌شوم بوی خوب کباب و شیرینی‌های ایرانی می‌دهد .. تقریبا
> غیر ممکن است که از این غذاها نخورد و دوباره غذای بخارپز خورد ...من مطمئن نیستم چقدر و
> چه زمانی می‌توانم این کار را ادامه دهم

Some women believed food limitations could cause psychological problems. Dietary changes came to be seen more as a punishment and a restriction. Some of my participants could effectively deal with it by limiting their portions, but not restricting the range of their foods:

> *Food deprivation, especially [from] our traditional foods and sweets, does not work for me, I grew up eating these foods …by being so picky what should I eat and what I should not to control my blood sugar, I traumatize myself…I believe thinking about diabetes all the time is not good for me and diabetes can ruin my life. Then I stop thinking about restrict meal plan. I am eating whatever I like to eat in a small portion…although my blood sugar is not in a normal range, but I am living well for now (ABY 14, aged 59)*
>
> محدودیت غذایی به درد من نمی‌خورد به ویژه غذاها و شیرینی‌های سنتی من. با خوردن این غذاها بزرگ
> شدم. با دقت بیش از حد که چه چیزهایی بخورم و چه چیزهایی نخورم به خودم آسیب روانی می‌رسانم ...من معتقد هستم
> فکر کردن درباره دیابت همواره سبب نابودی زندگی من می‌شود بنابراین تصمیم گرفتم درباره آن فکر
> نکنم . هر چیزی که دوست دارم می‌خورم ولی در مقدار کم. اگر چه قند خون خیلی کنترل شده ندارم
> ولی خوب زندگی می‌کنم

After all, the majority of my participants had lived and grown up in Iran for more than 30 years. It was very hard to set aside culturally learned behaviors, including eating habits. The following quotes indicate the importance of incorporating traditional foods in their everyday meal plan and the lack of culturally specific knowledge in health care professionals in Canada:

> *I was born and raised in north of Iran and you may know our main dish is white rice. We had rice even for breakfast …I always prepare our traditional dish and I always buy our stuff from Persian supermarket…then I asked my doctor to give me a sample of a meal*

plan and she referred me to a dietitian but she did not ask me "what do I like" and she wrote something for me that I could not follow it...it is not exactly a match with the ingredients I have at home…believe me or not, I tried to have a restricted diet … I could not continue it…it was very hard for me …I was feeling hungry all the time even when I had salad before a meal…I think it is impossible to change what you were eating since you were a kid…it is too late for me to change my diet…I am trying to teach my son to change his lifestyle and try to eat less sweet and white rice…but for me it is not possible for me to not eat white rice…when I went to Iran to see specialist, I also saw dietician…it was amazing, she put everything from our traditional foods in my meal plan such as dates, Sangak bread, …(ABY 10; aged 46)

من در شمال ایران بدنیا آمدم غذا های اصلی ما برنج سفید است برای من سخت است ... من همه وسایل
مورد نیاز را از سوپر مارکت های ایرانی می خرم. یک کارشناس تغذیه به من یک برنامه غذا داد ولی هیچ
کدام از غذاهایی که ما مصرف میکنیم در آن نیست از من نپرسید غذاهای معمول من چیست تقریبا هیچ
کدام برای من عملی نیست ... من همیشه با این برنامه احساس گرسنگی میکردم. حتی با سالاد به نظر
من غذاهایی که از کودکی می خوردید سخت است عوض کنید ... ولی سعی می کنم برنامه غذایی پسرم را
به فرزندم یاد دهم وقتی رفتم ایران وقت یک کارشناس تغذیه متخصص گرفتم خیلی جالب بود همه غذایی
که ما به طور سنتی مصرف می کردیم در این برنامه بود مثل نان سنگک هم در آن بود
حتی خرما

In summary, difficulty in preparing foods and not receiving culturally based meal plans were the main struggles for my participants.

Herbal remedies as a diabetes treatment. Herbal and traditional medicine has always played a significant role in Iranian culture and dates back more than 3000 years. The majority of women in this study had used an herbal remedy of some kind. The role of traditional/alternative remedy was an integral part of my participants' beliefs about type II diabetes management. Almost all women received advice from family or friends about using herbal remedies before starting their prescription medication:

> *When my family realized I have diabetes almost everybody advised me to use some herbal remedy…I use some herbal tea almost every night…to help me to control my blood sugar (ABY 7; aged 59)*
>
> وقتی اعضای خانواده ام متوجه شدند من دیابت دارم هر کسی یک پیشنهادی برای من داشت و داروهای گیاهی
> خاصی را به من معرفی میکرد.. . من هر شب داروهای گیاهی میخورم... و به کنترل قند خونم کمک
> زیادی میکند

The most common herbal remedy was cinnamon tea for reducing high blood sugar levels. Bitter melon was another popular traditional remedy treatment for type II diabetes. It was a widely shared belief that these would be effective in controlling type II diabetes. Some women used cinnamon tea and drank it three times a day. For some, cinnamon tea was the only remedy for controlling blood glucose they used in addition to their diet:

> *When I was in Iran a nutritionist advised me about [drinking] cinnamon tea for controlling my blood glucose now I am using strong cinnamon tea…right now the physician suggested I use oral medications but I prefer to use herbal remedies besides my diet and exercise (ABY 8; aged 57)*
>
> وقتی من در ایران بودم کارشناس تغذیه به من گفت چای خیلی کمک کننده است و الان من چای دارچین
> غلیظ استفاده میکنم ...در حال حاضر دکتر به من پیشنهاد کرده است دارو مصرف کنم ولی الان تحت
> رژیم غذایی و ورزش هستم و ترجیح میدهم داروهای گیاهی را مصرف کنم

Using herbal remedies was common among women who culturally used it within their families. Some participants substituted herbal remedies such as bitter melon for their regular medication (oral hypoglycemic medications) for periods of time. This group of participants encountered severe complications such as severe low blood sugar or uncontrolled blood sugar after which they then decided to discontinue herbal remedies as a substitute for their prescribed medicine:

> *Some of my friends recommended me to eat bitter melon and they told me it is a magic vegetable for lowering blood sugar …I stopped using my oral medications for controlling blood sugar and used bitter melon every day, a few days later I felt lightness in my head*

> *for few days and my blood glucose was up and down during the day then I decided to not to use it for a while and use my medications as usual (ABY 6; aged 49)*
>
> تعدادی از دوستانم به من توصیه کردند که فلفل بخورم و گفتند اثر جادویی در پایین آوردن قند
> خون دارد در بین سبزیجات ...من داروهای خودم را قطع کردم و از این فلفل ها مصرف کردم چند روز
> بعد احساس سبکی در سرم می کردم تا اینکه قند خونم بالا و پایین می رفت بنابراین تصمیم گرفتم دوباره
> داروهای خودم را مصرف کنم مثل قبل

Some of them believed that using these traditional remedies would eventually wean them off prescribed medicines. One participant stated that she received a recommendation from one of her colleagues that Ginseng was a very strong medication for lowering blood sugar:

> *Because I discontinued my medication, it did not help me a lot and my blood sugar was still high (ABY 4; aged 43).*
>
> بخاطر اینکه داروهام را قطع کرده بودم مصرف داروهای خوراکی کمی به من کمک کرد و قند خونم هنوز
> بالا بود

On the other hand, some women still used herbal remedies to complement prescribed medicines:

> *My husband and I drink herbal tea every night…it helps us to feel more relaxed and keeps my early morning blood glucose in normal range…but I had never thought about discontinuing my medication…I think self-treatment is very dangerous for me and my husband based on our age…(ABY 15; aged 62)*
>
> من و همسرم شب ها چای های داروی می نوشیم و این کار هر شب به کنترل اعصاب کمک می کند و
> همچنین قند خون صبحگاهی ما را کنترل می کند ...من هرگز به قطع سر خود داروهای فکر نمی کنم ...من
> تصور می کنم در سن من و همسرم خیلی خطرناک است خود درمانی

The women in my study perceived that their health care professionals in Canada did not have any idea or knowledge about these herbal medicines. Health professionals merely told the women not to use the herbal remedies as a treatment. On the other hand, family and friends, even those who lived in Iran, recommended several herbal remedies, as ABY 8 explained:

> *I told my physician about using some herbal remedies while I was using my oral medications. He told me it is better not use it and he had no idea about herbal remedies in diabetes…it is frustrating that physicians only believe in chemicals and have no knowledge in other complementary treatments….In Iran it is very easy to find a remedy suitable for you … we have so many stores in Iran that only sell herbal remedies but here there is no such store here, everything is in a jar or box… (ABY 8; aged 57)*
>
> من به پزشکم گفتم درباره مصرف داروهای گیاهی در حین مصرف داروهای اصلی به من گفت بهتر
> است استفاده نکنید او هیچ تصوری از مصرف داروهای گیاهی نداشت.. برای من ناراحت کننده
> است که پزشکان فقط داروهای شیمیایی را قبول دارند و هیچ اطلاعی برای درمانهای تکمیلی ندارند
> ...در ایران شما میتوانی به عطاری بروید و دارو مناسب را مصرف کنید. شما تا دلت بخواهد ایران
> پر از عطاری است ولی اینجا هیچ مغازه ای نیست همه چیز داخل جعبه و شیشه است

The efficaciousness of traditional/herbal remedies mentioned by the participants reflects the cultural belief among most Iranian Canadian women in this study that traditional medicines are as effective as oral hypoglycemic supplements to achieve glucose control. Unfortunately, it did not work; all were forced to employ prescribed medication.

Physical activity challenges. All of my participants acknowledged physical activity as a part of diabetes-self-management, but the majority of them did not have pay enough attention to it. Some women mentioned physical problems, such as osteoarthritis, that made physical activity difficult:

> *I have knee osteoarthritis I cannot walk without walker I cannot exercise…sometimes I go for a short walk with walker… (ABY 15; aged 62)*
>
> من آرتروز زانو دارم بدون واکر نمیتوانم راه بروم نمیتوانم ورزش کنم ..گاهی اوقات کمی پیاده روی کوتاه میکنم

Many participants pointed to the difficulties of incorporating physical activities, such as walking and swimming, into what they regarded as extremely busy lives.

> *I am very busy with my everyday life…I cannot find time to exercise… (ABY 4; 43)*
>
> من خیلی سرم شلوغ است با بچه ها ...وقتی برای ورزش کردن ندارم

Struggling with language. A major barrier to seeking information for the majority of women was their lack of proficiency with English which made communicating with English-speaking health care professionals frustrating:

> *I feel I am in a cage…feeling isolated-…I am here because my kids are studying here…I cannot speak English…I cannot communicate with others in particular my physician (ABY 7; aged 59)*
>
> من احساس می‌کنم داخل قفس هستم... احساس تنهایی می‌کنم ... من آمده‌ام کانادا چون بچه هایم اینجا آمدند
> درس بخوانند... من نمی‌توانم انگلیسی صحبت کنم و این خیلی سخت است ...چون نمی‌توانم با آنها ارتباط
> برقرار کنم

Lack of English language skills causes greater dependency on family for some of my participants:

> *I have my family support here in Canada but I do not want to make them unhappy and put them in trouble….they spend a lot of time bringing me to the doctor because I can't speak English…(ABY 10; aged 46)*
>
> شما هیچ وقت نمی‌دانید درون دیگران چه می‌گذرد , من تحت حمایت خانواده‌ام در کانادا هستم ولی من
> نمی‌خواهم آنها را ناراحت کنم و سبب دردسر آنها شوم ..آنها مقدار زیادی برای من وقت می‌گذارند و با
> من به دکتر می‌رویم به دلیل اینکه من نمی‌توانم انگلیسی صحبت کنم

Even when they knew some English but were not fluent, the main struggle was misunderstanding what they were hearing from their health care professionals:

> *It is very hard to understand about diabetes in a different language. I am sure I missed a lot of education but my son helped me a lot to learn about diabetes. I also believe only group class is not enough for diabetes. Every time, when I see the family doctor he does not have enough patience to answer my questions…it may because I am not fluent in English and we do not understand each other well (ABY 14; aged 52)*
>
> برای من خیلی سخت است که متوجه شوم همه چیز درباره دیابت به زبان دیگری . من مطمئن هستم من
> مقدار زیادی از آموزش ها را متوجه نشدم ولی پسرم کمک زیادی برای یادگیری درباره دیابت به من کرد.
> من فکر می‌کنم کلاس های گروهی برای آموزش کافی نیست . هر وقت من می‌روم پیش پزشکم را می‌بینم احساس

> یکی همیشه برای جواب سوالات من نیاز دارد .. نمیتوانم به خاطر اینکه من انگلیسی
> خوب صحبت کنیم و همدیگر را درک کنیم

The issues related to language barriers were multiple. As can be seen by ABY 14's quote above, the women had to rely on their families as translators. The language barriers, however, represented a significant hurdle to the social interaction norms in Iranian culture. A key part of the communication challenges for my participants was the lack of confidentiality. They always needed a translator and they could not reveal all their problems because they did not want the translator to know about their personal problems. They preferred to keep quiet about those problems until they had a chance to go to Iran and discuss their personal issues with their physician in private. For instance, one participant said:

> *When I had genital problem, I could not tell my problem to the doctor because I do not know English and I have to go with one of my kids and I am very uncomfortable to talk about it in front of my kids (ABY 7; aged 59).*
>
> وقتی مشکلات زنان دارم نمیتوانم مشکل خود مطرح کنم چون انگلیسی بلد نیستم باید همراه یکی
> از بچه ها بروم و دوست ندارم جلوی بچه ها راجع به این مشکلات صحبت کنم

Women, who had accompanied their children, were struggling in Canada, relying on their children to translate their personal concerns violated boundaries between children and mothers:

> *I am very dependent on my kids and even my son in law …I cannot discuss my daily problems with my physician personally… I cannot discuss my private issues related to diabetes with my physician… (ABY 10; aged 46)*
>
> من خیلی به بچه هایم وابسته هستم و همچنین به دامادم وابسته هستم... من نمیتوانم مشکلاتی که هر روز
> دارم با پزشکم مطرح کنم...من نمیتوانم درباره مسائل شخصی خود با پزشکم صحبت کنم

Seeking information about diabetes was not limited to the information provided by health care professionals. Their family and friends also helped them to find information from the Internet (Farsi version). They also asked their family members in Iran to send them booklets from the diabetes clinics in Iran. Some families also helped the women to find recipes from different cooking magazines. One participant in particular was very successful in working with her family to find information and to adapt the entire extended family's diet. In the following quote by ABY 2, she explains how, as the families' cook, the rest of the family has adapted to new ways of eating:

> *My daughter-in-law now is very happy with our everyday meal. She believes she feels more comfortable with her recent diet. At the beginning it was very hard to adapt the entire family with a new and healthy meal plan. Sometimes I search for new and kids friendly recipes. Now we eat more green vegetable than before. My grandchildren love me and it is very funny, sometimes they borrow a cookbook from their library. We also learned to grill more than frying. In the past when we had guest I was in trouble. I had to prepare traditional foods and lots of sweet and cakes. Now I prepare healthy food and healthy desserts (ABY 2; aged 61)*
>
> عروس من از برنامه جدید من برای غذا خیلی خوشحال است او تصور میکند وضع جسمانی او بهتر
> است بعضی اوقات من خودم دنبال دستورات جدید غذا میگردم که بچه ها هم دوست داشته باشند در ابتدا
> خیلی سخت بود. نوه های من خیلی با مزه هستند آنها بعضی وقت ها برای من کتابهای آشپزی قرض
> میگیرند ما الان بیشتر گریل میکنیم بجای سرخ کردن قبلا وقتی مهمان داشتیم غذا ها شیرینی های
> مختلف درست میکردم الان گاه فقط غذا ها شیرینی های سالمتر درست میکنم

Few participants were able to find a physician fluent in Farsi. If they could find a physician who spoke Farsi, their communication blocks were eliminated:

> *I prefer to see the physician by myself…my physician referred me to specialist because my blood sugar was out of control for a while and I asked her to send me to Farsi speaking doctor and finally I have a doctor who speaks Farsi and it is much easier for me. Even his secretary speaks Farsi too. Every time when I meet a problem I can call them and ask my question and I am not bothering my family anymore (ABY 11; aged 63)*
>
> من ترجیح میدهم که خودم برای ویزیت دکتر بروم. پزشک من را به خاطر قند خون نامتعادل برای
> مدت طولانی به متخصص ارجاع داده و من از ایشان درخواست کردم که من را به پزشکی ارجاع دهد
> که فارسی صحبت کند این کار را برای من آسان کرده است منشی ایشان هم فارسی زبان بود بنابراین

هروقت به مشکلی برخورد میکردم میتوانم خودم زنگ بزنم و سوالات خودم را بپرسم و دیگر به
دیگران زحمت نمیدهم

Although ABY 2’s experience was more positive than other typical experiences among my participants, the role of family and friends in learning to live with diabetes was an important resource.

Support from family. Among Iranian culture, family is the most important social institution. Family provided extremely important resources for my participants by either helping them to progress through their diabetes journey or, paradoxically, by delaying their emergence from the dark days. All of my participants expressed feelings of depression and stress in being isolated from extended family back home as they attempted to adapt to a new life in a new country with a chronic illness. They explained that family and family support were very significant at the time of diagnosis and in their struggle to learn to live with diabetes.

It was clear there were three typical profiles of support. First, family for these women could provide the right amount of support that encouraged them as they struggled to learn what worked best and helped them feel reassured and accepted among the family. Some families, wanting to help, in fact provided too much support which was interpreted as monitoring, control or surveillance, and which served to undermine the women’s own sense of control and autonomy. Excessive support appeared to stem from paternalistic or pitying attitudes of their family. The women were regarded as needing guidance or compensation, which worked to undermine their sense of confidence and autonomy. More than half of my participants experienced paternalistic attitudes and actions from their family, such as policing whatever they ate or drank. A few women felt that they received no support at all and were alone and isolated in their struggles to learn to live with diabetes. This was often accompanied by families’ demands that the traditional status quo around food be maintained.

Overall, the three levels of support were about: a) recognizing the woman's individual needs in diabetes, b) giving the woman space and opportunity to be autonomous as well as physical and mental support to learn about diabetes and what she needs to do, c) being willing, as a spouse and/or family member to change their norms, expectations and values. In the following sections I will describe each group in detail.

Receiving the right amount of support. Some of my participants experienced adequate, appropriate and constructive support. For example, some women mentioned that after being diagnosed with diabetes, their family decided to change their lifestyle and meal plan based on the woman's needs. This positive attitude also included encouraging my participants to learn more about diabetes and helping them to find new information or new recipes. This small group of women mentioned that their families encouraged discussing their concerns and fears about diabetes with family members. Support from family helped them to cope, and provided reassurance and constructive action to help them learn and adapt to diabetes. The families were involved in every day diabetes self-care management activities:

> *Actually, we have never been closer, like we are now; my husband is more supportive in comparison to when we were in Iran… (ABY 1; aged 38)*
>
> همسر من از وقتی من دیابت گرفتم در همه جنبه ها از من حمایت میکند ما از قبل بیشتر به هم نزدیک
> شدیم حتی بیشتر از ان زمانیکه ما در ایران بودیم

When the entire family changed their meal plan, it was easier for the women to follow the diabetic diet and to be more organized in planning meals. Consequently, they had fewer struggles with their new life situation:

> *My husband always told me, If you follow your meal plan and your physician orders, it will not hurt you…They reassure me they will help me on this road and they will do whatever they need to do…They also told me we all help you to keep your blood glucose*

> *in normal range. My daughter always sends me a useful links to learn more about diabetes and new inventions…. (ABY 3; aged 45)*
>
> همسرم همیشه با من میگوید مرتب برنامه غذایی و دستورات پزشک را رعایت کنم دیابت را میتوان با
> من آسیبی بزند... همسرم و فرزندم همیشه به ما اطمینان میدهند که پشت سر من هستند... آنها با من
> میگویند ما همگی با هم کمک میکنیم تا قند خونت در حد طبیعی بماند دخترم بعضی وقتها لینک های جدید
> میفرستد تا من با دست آورد های جدید پزشکی در زمینه دیابت آشنا شوم

Some of my participants whose partners were still in Iran also mentioned the importance of family support while they travel to Iran:

> *When I am in Iran my husband is very supportive and he is with me wherever I want to go for checking my diabetes …my husband appreciates my effort to be with our kids overseas (ABY 10;aged 46)*
>
> وقتی من در ایران هستم همسرم خیلی از من حمایت میکند معمولا همراه من برای ویزیت متخصص میرود او
> همیشه سپاسگزار زحماتی که من برای بچه ها میکشم هست

Some women were proud of having a supportive family while they were struggling with diabetes:

> *Without these individuals (husband, her two girls, her mother and her son in law) in my life I could not go further…my husband believes my illness is the entire family's illness and we can work together… I remembered my son in law brought me an article in Vancouver Sun about new research in diabetes…I always appreciated him… (ABY 9; aged 48)*
>
> بدون اعضای خانواده ام من نمیتوانستم این راه را ادامه دهم همسرم معتقد است دیابت فقط بیماری من
> نیست بلکه مشکل همه اعضای خانواده است و با هم کار میکنیم منتهی یادم هست یک روز دامادم یک
> مقاله ای برای من از مجله آورده بود من خیلی ممنون او هستم که به فکر من است

The key support was the positive attitude the family/spouse encouraged. Some women found their husbands very supportive in this stage by changing their meal plan and accompanying them on every single visit. As well, some women found their husbands were very thoughtful in their personal relationship. A beautiful example of family support is noted below:

> *When I was in Iran, I had many close family members and best friends and they were good sources of support for me in every aspect of my life. I received energy from them and I really enjoyed being with them and my husband knew it. Since we moved to Canada my husband is more supportive. Although he is very busy with his job, but at least I feel his support and I admire it… (ABY 1; aged 38)*
>
> وقتی من در ایران بودم خانواده ام اطراف من بودند و شامل حمایت آنها بودم من همیشه از کنار آنها
> بودن لذت میبردم و از آنها انرژی میگرفتم وقتی ما به کانادا مهاجرت کردیم همسرم بیشتر از من حمایت
> میکند اگر چه همسرم خیلی مشغول است ولی همیشه حمایت ان را حس میکنم و سپاسگزارم

Another woman described how her husband was willing to be actively involved in meal planning and cooking:

> *My husband also has diabetes…he knows I loved jam and he helped me to prepare fresh jam without sugar …he always help me to prepare meals …he always helps me …I can't live and manage my diabetes without him…(ABY 15; aged 62)*
>
> همسرم مثل من دیابت دارد. ایشان میداند که من مربا خیلی دوست دارم و کمک من میکند تا مربا های
> بدون قند و تازه درست کنم. ایشان همچنان کمک میکنند همه جا ... من بدون وجود ایشان نمیتوانم زندگی کنم
> و بیماری خود را کنترل کنم

When the entire family was cohesive in developing new, positive attitudes and values regarding healthy eating, then living with diabetes was so much easier. Just as ABY 2 noted earlier, when the extended family all accepted the need to modify their diet, were actively involved in finding new foods and recipes, and did not resist the elimination of sugar and fat, or when other participants reporting that some of the family members who lived with them already had type II diabetes, then change and maintenance of new norms of behavior was much easier. My participants felt accepted, supported and encouraged in their efforts to choose beneficial strategies to live with diabetes. Unfortunately, only 3 women fit this profile. Most of my participants felt they received too much support or a dearth of support from their families.

Receiving too much support. Too much support was described as feeling monitored and criticized by the family. Oppressive kinds of support were described by some of my participants. They felt family members tried to be supportive by “spying” on participants and rechecking everything. One woman expressed that she felt as if:

> *Everybody is watching what I am eating…” (ABY 8; aged57)*
>
> همه به انچیزهایی که من میخورم نگاه میکنند

Family members would consistently remind the participants of participants’ obligations for everyday self-care activities. Usually the family responses were pitying and paternalistic for my participants in this group. Cultural norms and values around expected roles of sick people often resulted in attempting to control, monitor or constrict the participants’ lifestyle behaviors and choices. This undermined their confidence or ability to be autonomous. More than half of my participants experienced paternalistic attitude. It seemed the family members changed their social role from being a daughter, son or husband to being a caregiver or a supervisor. These women often felt too scared to disclose their concerns and attempted to look “normal” in front of their family because they did not want to worry them.

This excessive surveillance ignored the women’s sense of freedom and autonomy and had a contrary effect. It caused more difficulties in their struggle to learn to live with diabetes:

> *My daughter is acting like a “police” and her action really bothers me. When I am with her I am under pressure and sometimes I cheat and eat whatever I love to eat when they are not around. [She laughed] (ABY 14; aged 59)*
>
> دخترم مثل پلیس رفتار میکند رفتار ان من را اذیت میکند وقتی میروم خانه دخترم تحت فشار
> هستم وقتی آنها اطراف من نیستند من هر چیزی که دلم میخواهد میخورم

A typical comment from this group of women was that their families consistently provided unwelcome instruction, not helpful advice, about what to eat:

> *Mother, if you buy ice cream for children [the grand] do not eat it ...it raises your blood sugar again, OK? (ABY 14; aged 59)*
>
> اگر برای بچه ها بستنی خریدی خودت نخوری قند خونت دوباره میره بالا

Over time, this surveillance caused feelings of resentment about being monitored and constantly criticized. The women became frightened of complaining about daily diabetes challenges. They felt dependent on others and would try to pretend to be normal in front of others and trying to hide their diabetes symptoms:

> *I know they are very worry for me. Their worriedness makes me uncomfortable. I have to pretend I am OK all the time even when I am not feeling good. I just do not want to disappoint them… (ABY 3; aged 54)*
>
> من میدانم که همگی نگران برای من نگران هستند ولی نگرانی های آنان سبب ناراحت بودن من میشود من باید
> جلوی آنان تظاهر کنم که حالم خوب است در حالیکه حالم خوب نباشد من نمیخواهم آنها را ناراحت کنم

Overall, for this profile of family support, maintaining a sense of normalcy was important as a strategy to minimize unwanted surveillance. It seemed family were not spying because they did not care or love their mom/wife, but because they have such a high level of anxiety and fear that if she did not adequately care for herself, she would suffer complications. This level of anxiety eroded their confidence in her level of motivation, knowledge and ability to maintain self-care activities.

These participants struggled with finding a balance between obtaining a constructive support and causing worry for their family. They were unable to negotiate personal boundaries, autonomy and privacy and seemed to resent the dependent “sick role” imposed on them. One of the unfortunate consequences of the over monitoring was withdrawal behaviors. The women understood that their families only want the best, and often were very reluctant to disclose their struggles or concerns to the family/spouse who were trying to help. They attempted to “look normal” in front of them:

> *My family wants the best for me I do not want to disturb them…I am trying to look normal in front of them… (ABY 10; aged 49)*
>
> من میدانم خانواده‌ام برای من بهترین را میخواهند من نمیخواهم آن ها را آزرده خاطر کنم ...من سعی میکنم
> جلوی آن ها از مشکلات بیماریم صحبت نکنم

Insufficient support from family. A few of my participants felt very alone, either because their families and husbands were not in Canada or they had family here but perceived no support from them due to divorce. ABY 13, struggled because she lives in Canada with her son who is at school:

> *I am here to be with my son. He is studying here ….I had so many friends and family member in Iran and also my husband is living in Iran… I think I was happier when I was Iran… (ABY 13; aged 42)*
>
> من در این جا همراه پسرم هستم که دارد درس میخواند ...من در تهران دوستان واقوام زیادی داشتم
> همسرم هم آن جا است ...من قبلا خوش حال تر از الان بودم

ABY 6 was socially isolated through divorce and estrangement from her children:

> *I grew up in a large family in Iran with 10 brothers and sisters but since I came to Canada I lost my entire family members gradually after I divorced and I argue with my children (they are adult now) all the time and now they live separately on Campus… I am alone most of days… (ABY 6; aged 49)*
>
> من در یک خانواده بزرگ با ۱۰ خواهر و برادر زندگی میکردم از زمانی که به کانادا آمدم به تدریج تنها
> شدم از همسرم جدا شدم و به خاطر دعوای همیشگی با بچه‌هایم که الان بزرگ شده‌اند از آن ها جدا زندگی
> میکنم و آن ها در نزدیکی دانشگاه می‌نشینند ...من بیشتر وقت روز تنها هستم

The typical profile of no support however, was when a woman felt alone and unsupported even when she had a social network around her. Her family and friends ignore her diabetes and demand the traditional status quo in food and eating patterns. It seemed that for these women, those who surrounded her and for whom she was responsible in terms of food preparation or meal planning were not willing to alter their own habits in order to accommodate her special dietary needs. In this support profile, the women believed their families did not accept them as a person with a chronic illness which required special care and consideration. Their families resented any change in their “normal routines”:

> *For my family, I cook white rice and different types of stew. Sometimes they ask me to prepare some fried chicken and fries. (Laughed) My kids, and of course my husband, asked me to bake cakes and dessert for them very often. I tried to make cakes and desserts with artificial sugar, but the flavor was not very good and, of course, my kids did not like it. The only thing we share on the table is salad (ABY 1; aged 38)*
>
> من برای افراد خانواده پلو و خورشت درست میکنم بعضی مواقع به من میگویند برای ما مرغ سوخاری
> با سیب زمینی سرخ کرده درست کنم بچه ها و همسرم از من میخواهند کیک و شیرینی و دسر درست
> کنم. سعی میکنم با شکر رژیمی درست کنم اما مزه ان خوب نیست بچه ها و همسرم دوست
> ندارند تنها چیز مشترک در سر میز غذا سالاد است

Minimal or no support from the family caused greater struggles for the women in this profile group. Some women emphasized that their partners, in particular, did not understand their changed situation:

> *It was very hard for my husband to accept my new condition…my husband was not supportive of all effort I made to control my blood sugar…as soon as I met a problem with diabetes, he started blaming me for what I was doing for controlling my blood sugar (ABY 14; aged 58)*
>
> برای همسرم خیلی سخت بود که شرایط جدید من را قبول کند من تمام کارهایی که برای کنترل قند
> خونم انجام میدهم بدون حمایت او است ... به محض اینکه مشکلی در رابطه با قند خونم بر خورد
> میکردم همسرم سریعا من را سرزنش میکرد به خاطر کارهایی که من برای کنترل قند خون انجام میدهم

For some women, this lack of support could cause mental stress:

> *Since I came to Canada and having diabetes I am feeling helpless without any family, especially my close family support…I have only my husband here to support me and it is not enough, he is very busy with his job and sometimes he is out of town for days (ABY 4; aged 43)*

> از وقتی من وارد کانادا شدم احساس تنهایی خیلی زیادی میکنم هیچ حمایتی از طرف خانواده ام نمیشوم...
> تنها نوع حمایت من اینجا همسرم است ولی کافی نیست به دلیل اینکه ایشان خیلی کارشان زیاد است و
> بعضی وقت چند روز خانه نیست و سفر خارج از شهر دارد

Some women felt isolated and unheard. They believed their families or husband blamed them for their diabetes or for difficulties in their self-care activities:

> *I am trying to solve my problems and challenges with diabetes by myself…my husband is not a good listener to my problems …every time when I complain about my problems he starts to blame me. Then I prefer not to tell him about my every day challenges… (ABY 12; aged 52)*
>
> من سعی میکنم مشکلاتم را خودم به تنهایی حل کنم ... همسرم شنونده خوبی برای مشکلات من نیست
> ...هر وقت من درباره یکی از مشکلاتم صحبت میکنم ایشان من را سرزنش میکند و من ترجیح میدهم
> درباره مسایلی که با ان برخورد میکنم با ایشان چیزی مطرح نکنم

If lack of support undermined appropriate self-care, complications arose. Unsuccessful blood glucose control increased anxiety, dependency and loss in different aspects such as self-esteem, social- recreational activities, and in sexual relationships:

> *Our personal relationship changed over time and my desire changed and I am sure it is because of diabetes … he is tired of having a 'sick wife (ABY 7; aged 59)*
>
> رابطه خصوصی ما کم رنگ شده است من هیچ میلی ندارم و مطمئنم به خاطر دیابت است
> ...همسرم از داشتن همسر بیمار خسته شده است

Having a chronic illness, such as diabetes, with an unclear future caused a negative cycle of grief and sense of burden which intensified perceptions that diabetes was the root of many of their life challenges:

> *Diabetes was a starting point for all my bad luck. I divorced almost 2 years after having diabetes…my husband caused tension in our marriage. He was intolerant and he did not understand me very well…when I was struggling with diabetes… (ABY 6; aged 49)*

> گفتن بیماری دیابتش روع شکلات من بود من دو سال بعد از گفتن دیابت از همسرم جدا شدم...
> همسر سابقم سبب تنش در روابط زناشویی من شده بود. موقتی مشغول ست و پیچ اهن رمکردن با
> مشکلات دیابت بودم... او حال من را درک نمیکرد

Interestingly, very few participants referred to support from friends in learning to live with diabetes. It appeared that my participants' struggles to learn to live with diabetes following diagnosis occurred primarily within the narrow confines of their immediate and extended families. In the following quote, it is evident that disclosure of diabetes would only be made to close friends and that immigration had severed many important connections that had not been replaced in Canada:

> *I came to Canada almost three years ago I have my close family here …when I was in Iran I had so many friends and they knew my diabetes, they were very supportive …when we were gathering they knew I had diabetes and they gave the foods earlier to prevent hypoglycemia…I really missed their support ...no friend here (ABY 7; aged 59)*
>
> من ۳ سال پیش آمدم کانادا من دوستان زیادی داشتم وقتی من در تهران بودم من دوستان زیادی در
> تهران داشتم و همه میدانستند من دیابت داشتم و خیلی من حمایت میکنند وقتی ما در هم جمع میشدیم
> گاهی وقت برای من زودتر غذا میاوردند تا قند خون من پایین نیاید ...من خیلی وجود انها حس میکنم

Overall, what my participants said above reveals the importance of the right amount of family involvement when women were struggling to live with diabetes. The results also indicated no support or too much support created significant challenges with learning to live with diabetes. It was clear that during every stage of living with a chronic illness, support from family and friend was crucial.

Influences of religious and cultural expectations. Religious and cultural backgrounds were perceived to be a significant resource to support their struggle to learn to live with diabetes in different ways. For some women in this study, having a chronic illness such as diabetes created an inner struggle about their religious beliefs. Some of them experienced uncertainty about themselves, God and their relationship with God. For example some women believed having an illness was a test from God and they turned to their religious beliefs more than before. They undertook the spiritual practices of reciting the Quran, meditation or daily prayer (Doaa). For these women, expressions of their beliefs offered solace and considerable comfort during times when they were struggling with their new situation and accepting it as part of their lives, as this participant described:

> *Since I have diabetes, I pay more attention to my relationship with God…I do not think there is cure for my illness, but I always ask God for a cure or to help me so life is getting easier for me…I feel more relaxed while I am praying…it helps me to have hope and continue my life with its difficulties… (ABY 4; aged 43)*
>
> از زمانیکه من مبتلا به دیابت شدم توجه من به رابطه ام با خدا بیشتر شده است ... من فکر نمیکنم که
> شفایی برای من باشد اما از خدا طلب شفا میکنم یا تقاضای کمک میکنم تا زندگی برایم راحتتر شود
> وقتی نماز میخوانم احساس سبکی میکنم .. نماز به من کمک میکند که امید خودم را حفظ کنم و با
> مشکلات زندگی با دیابت زندگی کنم

As some women became more active in their religious beliefs, they found that prayer was a complementary strategy to cope with diabetes. Prayer and believe in God gave most of the participants' emotional and spiritual strength to cope with managing diabetes and helped them to move forward in their lives. ABY 8 reflected that:

> *Prayer makes my soul stronger … (ABY 8; aged 57)*
>
> نماز خواندن سبب تقویت روح من شده است

These women were thankful to God because of the other blessings in their lives. Three women strongly believed that there was a larger purpose and meaning behind the illness and they looked for ways to find gratitude for their lives. These women believed that diabetes was not the dominant feature of their realities:

> *I am counting my blessing (Nemat) in my life and it encourages me to continue my life… (ABY 9; aged 48)*

> من نعمت هایی که خدا به من داده همیشه مرا وادار کرده به من کمک میکنند بتوانم زندگی کنم

Connecting with religious leaders (Imam) helped them to recognize that they were not alone in the challenges they faced. Trust in God helped them to keep going through the difficult times of learning to live with diabetes. These women's reliance on God was expressed through prayer and asking God for help:

> *I always ask God to help me in this road…this part of Quran help me to keep going: [And certainly, we shall test you with something of fear, hunger, loss of wealth, lives and fruits, but give glad tidings to the client ones], I am reading the Quran whenever other thoughts come to my mind…every time when I am exhausted of everyday challenges with diabetes I start Doaa…(ABY 11;aged 63) [Doaa is the Arabic word* دعاء *it means to ask God for something, not as in prayers, in general when we raise our hands to God and ask for something that is Doaa]*
>
> من همیشه از خداوند میخواهم که به من کمک کند در این راه این آیه از قران که میفرماید همانا شما را با
> فقر بیماری گرسنگی ترس و از دست دادن اموال و نفس امتحان میکنیم و مژده بده به کسانی که صبر
> میکنند … هروقت افکار آزار دهنده به سراغم آمد قران میخوانم …هروقت مشکلات روزانه در رابطه با
> دیابت اذیت ام میکنند دعا میکنم

Overall, most of my participants strongly believed that prayer and faith were helpful and that religious belief was an integral part of successfully smoothing out their everyday challenges to live with diabetes.

There were two dominant views about the role of religion and God in living with diabetes. Some sought medical treatment regularly and hoped for a cure from God. Other women did not continue their follow up for their medical treatment and relied only on God for intervention through prayer and reciting the Quran for a short period of time. Eventually, those who had avoided medical treatment found their health deteriorated. This motivated them to become active in learning about their diabetes:

> *When my physician confirmed I have diabetes and she recommended I use medication…I refused to use it and I was waiting and hoping for cure by intense prayer and Doaa but my physical situation was getting worse …later I realized Prophet Mohammad asked us to seek treatment while having hope for cure and ask God for help… (ABY 7; aged 59)*
>
> وقتی پزشک من دیابت را در من قطعی کرد به من پیشنهاد کرد قرص مصرف کنم ...در ابتدا از خوردن
> آن خودداری کردم و توکل کردم به خدا با دعا و توسل ولی شرایط بدتر شد بعد متوجه شدم که
> پیامبر خدا فرمایند دنبال درمان بیماری خود باشید در حالی که هم زمان به خدا توکل می کنید

Some women acknowledge that their spiritual beliefs supported their emotional and psychological well-being and this would support their physical activities. They sought God’s help for patience through prayer. These women, through their narratives, noted that religion was an integral part of their lives and that their basic health care practices were based on their knowledge of the teachings of the Quran and the Hadith. This, in turn, affected their health care management. They recited two verses of Quran in the interviews in Arabic (which is the original language of Quran). These verses refer to patience in the context of problems and illnesses:

> یا أَیُّهَا الَّذِینَ آمَنُواْ اسْتَعِینُواْ بِالصَّبْرِ وَالصَّلاَةِ إِنَّ اللّهَ مَعَ الصَّابِرِینَ؛
>
> *And we will surely test you with something of fear and hunger and a loss of wealth and lives and fruits, but give good tidings to the patient (Quran 2:155)*
>
> And
>
> و لنبلونكم بشیء من الخوف والجوع، ونقص من الأموال و الأنفس والثمرات
>
> *O you, who have believed, seek help through patience and prayer. Indeed, Allah is with the patient (Quran 2: 153)*

These religious beliefs, often reinforced within the family system, helped these women to move ahead in accepting the reality of being diabetic and learning to live with it. This perspective is summarized in the following quote:

> *Life, death, health and illness are under God’s control. I am trying to control my blood sugar but the rest is out of my control then I do not bother myself… I think it is*

> *impossible for people with diabetes to live in complete peace. My husband and I deal with many problems because of our diabetes but every time my mother reminds me to be patient because God has advised us to bear our problems patiently. Thanks, God (Alhamdulillah) I have my parents here… (ABY 5; aged 34)*
>
> مرگ و زندگی دست خداوند است من تلاش میکنم قند خونم را کنترل کنم ولی همه چیز دست خداوند
> است و من ... من فکر میکنم غیر ممکن است که افراد دیابتی در آرامش کامل زندگی کنند من و
> همسرم هر دو با مشکلات دیابت هر روز دست و پنجه نرم میکنیم ولی مادرم که با ما زندگی میکند به
> من میگوید که صبور باشید و خداوند ما را به صبر فرمان داده است من خدا را شکر که مادرم با ما است
> و قوت قلب است خودم را خیلی امن احساس میکنم

Most of the women in my study sought treatment when ill, as advised by Islamic rules, viewing the doctor as the mechanism for receiving help, with God providing the cure. My participants also expressed their religious beliefs in the following ways while they were struggling to live with diabetes.

Prayer keeps them at peace. Some women mentioned daily prayers maintained their sense of peace by controlling feelings of hopelessness when they struggled with diabetes and feared for their future:

> *I have to tell you my religious belief is the only thing that keeps me alive. Islam, for me, is a source of inspiration. Sometimes I am thinking by myself if I did not believe in Islam and the Quran, I may do something bad to my body. But DOAA (prayer), reciting the Quran helps me lot. I also talk to one of the religious' leaders and he helped me a lot to stay on track for my religion. During performing SALAT [Salat is the obligatory Muslim prayers, performed five times each day by Muslims. It is the second Pillar of Islam], I find relief from daily troubles of life, my disease, my anxiety, fear of future and all my pain from my life's difficulty…Since I was a kid I learned to attach to Quran. I feel peace when I am reciting Quran. It also enhances my faith. I always ask cure from GOD. My belief in GOD is the only source of hope. I hope something happens in medical science and they can find something to replace insulin! (ABY 1; aged 38)*

> *من به طور کلی اعتقادات مذهبی من تنها عاملی است که من را نگه داشته است اسلام برای من یک منبع*
> *انرژی است هرگاه وقت فکر می‌کنم که اطمینان را نداشتم با بدن خودم آسیب زدم بودم دعا کردن و*
> *خواندن قرآن و مشاوره با افراد مذهبی بسیار به من کمک کرده است وقتی نماز می‌خوانم از استرس و*
> *نگرانی راحت هستم من از بچگی خواندن قرآن را دوست داشتم به من آرامش می‌دهد از خدا می‌خواهم*
> *که من را شفا دهد و دل پزشکی آقای دکتر ... گفتند که بجای انسولین راه دیگری کشف شود*

Religious beliefs help in re-defining the meaning of life and hope. Redefining the meaning of life happened when each woman realized that she would be diabetic for the rest of her life. For some women, religion helped them to redirect their minds to the new life road they were now travelling because of their diabetes. According to Islam, they have to take care of their bodies with patience:

> *At the beginning I had hope this is not real diabetes and my blood sugar showed high accidentally. I was hoping and praying to not have diabetes but I remember my husband kept telling me: "ask God to keep the power to manage your diabetes." It helps me to be strong for fighting with diabetes (ABY 3; aged 61)*
>
> در ابتدای تشخیص بیماری من امیدوار بودم که بیماری‌ام مطمئن نباشد ولی قند خونم چیز دیگری نشان می‌داد
> من امیدوار بودم و دعا می‌کردم که دیابت نداشته باشم ولی همسرم به من می‌گفت دعا کن که خداوند به من
> کمک کند تا تحمل کنم این به من کمک کرد که در مقابل دیابت قوی‌تر باشم

Asking help from their Imam (religious leaders) and participating in religious meetings in their mosque changed their worldview about the position of illness in their lives. According to them, this worldview helps them to have fewer struggles with everyday challenges:

> *God helps me a lot in this road. Now I am stronger than before. I participate in the cultural and religious program more than before but my blood glucose does not go up and down a lot. I have learned what Islam teaches us about life in this world. Our existence here on earth is but a transient stop, on the way to our real life in the Hereafter. Now I understand this world is a place of trial and testing. Now I know I am responsible for my body. I am not allowed to hurt it. ... My weekly Quran lesson and two religious consultant sessions helped me a lot. I always enjoyed my spiritual counselling and participating in religious activities… (ABY 2, first round interview) …Now I*

> *acknowledge that I am more than my body and illness; life has meaning beyond my diabetes (ABY 2, second round of interview)*
>
> خدا به من در این راه خیلی کمک کرد . الان من قوی تر از قبل هستم . من الان بیشتر از قبل در مراسم های مذهبی و فرهنگی شرکت می کنم و قند خونم کمتر بالا و پایین می رود باید بگویم که اسلام چه چیزی به ما آموزش می دهد . ما در این جا در این دنیا به طور موقت هستیم و زندگی حقیقی در دنیای دیگر است . من مسئول بدن خود هستم و نباید به آن آسیب بزنم ...جلسات فرهنگی قرآن و دو مشاوره با کارشناس مذهبی کمک زیادی کرد. من همیشه از مشورت مذهبی و فعالیت های مذهبی لذت می بردم ...الان من ارزشم بیشتر از بدن است ؛ زندگی فقط دیابت نیست

A small subset of the participant group entirely resigned their health to God as healer and did not have a strong commitment to self-management. For example one of the participants perceived that developing diabetes was God’s will for her and there was little she could do to change her situation:

> *Diabetes is my pre-destiny (Naseeb)…I can’t do too much for it… (ABY 7; aged 59)*
>
> دیابت قسمت من بود... و هیچ کاری واقعا نمی توان برای ان انجام داد...

For the only participant who was not Muslim, having hope of a cure was very important also. She mentioned two parts of Avesta (Scripture). The translation is: “There is a remedy for everything but death, a hope for everything but wickedness, and everything will lapse except righteousness.” (SLS20.17, tr. West). Another verse was:

> When a person stands in the religion of the Yazads, the Yazads notice the pain endured by him in the world -- even the fact that he came to pain by foot and that he lives lawfully on the work of his hands; and they carry and keep for him in the Reckoning of the Spirits (Armageddon) the discomfort, hunger, thirst, worry, and disease which affect him. (Dk6.106, tr. Shaked) (Downloaded from Avesta.org)

Some religious obligations cause more struggles. There were times when diabetes interfered with religious obligations. Following some Islamic rituals and customs caused some difficulties, especially after immigrating to Canada. One challenge was maintaining a healthy active lifestyle, such as swimming. In Iran, according to Islamic beliefs, women must swim separately from men. In Canada, this is not the custom:

> *I am not working outside the house. When I was in Iran I had more activity I was working and I did my favorite sport swimming almost three times a week. Here because of our religious belief I cannot use swimming pool here and really bothers me. Now the only option is walking. I try to go for walking 2-3 times a week. I really missed swimming. It helped me to be calmer and relax (ABY 1; aged 38)*
>
> *من خانه دار هستم. من ورزش مورد علاقه ام در ایران شنا بود که زیاد هم شنا میرفتم و خودم می فهمیدم که خیلی به کنترل قند خونم کمک میکند. ولی از وقتی وارد کانادا شدیم به خاطر مسائل مذهبی و حجاب نمیتوانم شنا بروم و همین خیلی من را اذیت میکند. ولی مجبورم برای اینکه تحرک بیشتری داشته باشم هفته ای 2-3 بار پیاده روی 22 دقیقه ای کنم. شنا به من آرامش می داد ولی متاسفانه من نمیتوانم انجام دهم.*

Fasting was another religious obligation that was difficult for my participants. Fasting without complications was one of the main concerns for some women during Ramadan. Ramadan is the ninth month of the Islamic lunar calendar. Every day during this month, Muslims around the world spend the daylight hours in a complete fast; Muslims do not eat or drink anything until sunset. Fasting is very important for Muslims. Fasting for my participants provides them with a sense of normalcy and well-being. Those women who could not fast because of their diabetes, felt uncomfortable in front of others who were fasting. Even though in Islamic Law a sick person is exempt from fasting, some women still tried to establish a plan with their dietician to allow them to fast during Ramadan:

> *The first Ramadan I realized I had diabetes I did not fast because of blood sugar fluctuation. When I went to Iran I also saw an Endocrinologist and he believed diabetic people who take only oral medication or [control their diabetes with] diet could fast. After that with a written plan from my doctor, I started to Fast. Thank God, I could do it for years after having diabetes… (ABY 2; aged 61)*

> اولین رمضان که متوجه شدم دیابت دارم روزه نگرفتم به خاطر اینکه قند خونم خیلی بالا بود پزشکم
> میگفت وقتی افطار کمتر غذا بخورم میگفت کسانیکه داروهای خوراکی مصرف میکنند میتوانند روزه
> بگیرند بعد از موافقت پزشکم برنامه قطعی از کنترلم من روزه گرفتم و خدا را شکر من سالهاست روزه
> میگیرم

Other women, who did not fast after having diabetes, told me that God gave them permission to not fast, and God "*wants us to accept this permission.*" In other words, according to their religious beliefs, unless they took care of themselves, they would not be able to fulfill the social and religious obligations expected of them. They needed to attend to their diabetes needs without fear that this compromised their religious commitment:

> *Having diabetes takes a lot of time and energy, we need to learn about diabetes and take care of our body. [If we don't] then we cannot find time to teach our kids Islam perfectly… although men work outside but women have more responsibilities than men. I have to think [about] many things. Sometimes I forget myself. I am worried for my kids, their school, their grades, and, and. If mother has an illness, the situation is getting worse… (ABY 1; aged 38)*

> داشتن دیابت مقدار زیادی انرژی از من میگیرد باید چیزهای زیادی یاد بگیرم و مواظب بدنم باشم
> وگرنه وقت پیدا نمیکنم که به بچه ها در دیار غربت مسائل اسلامی را آموزش دهم ... اگر چه مردان
> کارهای بیرون خانه را انجام میدهند ولی مسئولیت زنان بیشتر است من باید به خیلی چیزها فکر کنم و
> خودم را گاهی وقت فراموش میکنم من نگران فرزندانم هستم نگران درس شان نمرات و خیلی چیز
> های دیگر اگر مادری که خانه مریض باشد شرایط بدتر میشود

For participants who were experiencing significant challenges in living with diabetes, the fore-fronting of diabetes in their lives often meant that they could not observe all their religious rituals as they might have done before they developed diabetes. For these participants, all their available energy was directed toward their children and adapting to their new life situation:

> *Raising kids based on our Islamic regulation is very hard in a different country with a different religion and I need to spend time and energy to do it….with diabetes your brain*

> *does not have enough space to think about other life issues, this is an issue while I am struggling with my personal issues related to diabetes (ABY 9; aged 48)*
>
> بزرگ کردن بچه ها در کشور خارجی با تفاوت های فرهنگی مشکل است نیاز به انرژی و وقت زیادی دارد
> .با وجود دیابت مغزم جای خالی برای فکر کردن به مسائل دیگر زندگی ندارد این یکی از مهمترین
> مشکلاتی است که من با آن دست و پنجه نرم میکنم

Overall, these women's religious and cultural backgrounds had an important influence on their struggle to live with diabetes. Some of my participants believed prayers helped them to be more accepting and at peace with their disease. On the other hand, some of them believed some religious obligations created more struggles. Now, I will describe how my participants worked to preserve their cultural customs in the context of diabetes. The most important aspect of this are challenges with culturally based meals inherent in community feasts.

Culturally based meal and feast challenges. In Iranian culture, food is an integral part of social, religious and cultural gatherings. A couple of my participants did successfully manage these social situations, but the majority of women viewed diabetes as a significant limitation to participating in cultural and religious feasts. Usually, Iranian feasts, which are celebrated more than 20 times a year, contain formal dishes and sweets such as Persian style Baklava or Luxury rice with lots of sweet candied orange and lemon peel and sweet nuts. Social gatherings are the key way to connect and feel part of the social community.

The Iranian community in Vancouver is a tight community and everyone is usually involved in preparing the foods. It was hard for my participants to not to eat the food they helped to prepare. In the feasts, my participants tried every food and they did not want to appear different to others (Figure 4.4). ABY 1 in the quote below reflects on the paradoxical joy and support she experienced within their community events and the sense of deprivation and isolation:

I try to participate in these programs with my family. When I am in these programs I feel more relaxed. There are lots of friends around us and we chat with each other. The only negative thing [laughed] of course for me is the refreshments and dinners. I really like to go to these programs. When I was in Iran I always participated in these programs in the mosque near to our house. Actually I was part of their committee. I always helped them prepare sweets and dinners. [Laughed] I am a very good baker. Sometimes here the organizers ask me to help them with the cooking and baking. I usually accept their invitation but honestly it is very hard for me. Imagine I help to bake a lot of sweets, but I am not allowed to eat. I always loved sweets. I cannot remember any meal without dessert in the past…This is the reason I do not participate in these programs, of course I love to go. It is very hard for me. I tell myself I wish I did not have diabetes (ABY 1; aged 38)

من سعی میکنم که در این برنامه ها شرکت کنم وقتی در این برنامه ها شرکت میکنم احساس آرامش
بیشتری میکنم من با صحبت با آن ها لذت میبرم تنها چیز منفی غذا ها شیرینی ها است من وقتی در
ایران بودم همیشه با مسجد همکاری میکردم بعضی وقت برگزارکنندگان از من میخواهند در تهیه غذا
شرکت کنم ولی تصور کنید مقدار زیادی شیرینی درست کنید و نتوانید از این بخورید من عاشق شیرینی
خوردن را دوست داشتم من غذا را بدون دسر تصور نمیکردم الان کمتر شرکت میکنم و این یک درد
سر داشتن دیابت است کاشکی من دیابت نداشتم من همیشه آرزو میکردم دیابت نداشتم

Figure 4.4 Variety of Persian style food in a feast

The major challenge was gap between what they eat a diabetic and what the organizers served and expected guests to consume. The women found they were often unsuccessful in controlling their portion sizes. The portion size the dietitian recommended was smaller than the portion size they were offered at the feasts. For example in their meal plan it was recommended that they eat only eight tablespoons of rice but at a feast everyone is offered a big plate, full of white rice and big portions of meat:

> *I love to go to Iranian feasts but they usually serve a lot of food for every person and it was very hard to refuse to eat all foods they give it to you…usually a lot of rice and big piece of lamb…(ABY 13, aged 42)*
>
> من دوست دارم به مهمانی های ایرانی ها بروم که پر از غذا های ایرانی هاست ولی خیلی سخت است که
> جلوی خودم را بگیرم ...معمولا یک عالمه برنج وگوشت

They also talked about how difficult it was to substitute brown rice and whole wheat bread for white rice and white bread which are staples of the traditional Iranian diet. The majority of my participants did not like to substitute white rice with brown rice. In social events, they always serve traditional foods prepared in the traditional way. For example, putting a lot of butter on the rice:

> *In my diet plan, it is recommended to eat brown rice but we do not like it and I am still eating white rice, Basmati, or Gylan rice … (ABY 3; aged 54)*
>
> دربرنامه غذایی من توصیه شده است که برنج قهوه ای مصرف کنم ولی من دوست ندارم و هنوز برنج
> سفید یا بسمتی یا گیلان مصرف میکنم

ABY 12’s experience was typical of the participants in my study. As she reflects below, the social environment encourages people to fully indulge in the delicacies prepared for them, making it very difficult to remember the dietary principles in healthy diabetic eating. Usually encouragement from the host at every party to eat made my participants feel disrespectful if they declined to taste everything. ABY 12 admits she really does want to try everything, but even when she does not want to eat, her friends exert considerable pressure. When the women did not reveal their diabetes, they had no readily available excuse to refuse food and as a result, they then experienced high blood sugars:

> *As you may know Iranian people prepare variety of foods and sweets for their guests…even for simple party we see different types of our traditional foods on the table and that time I break my promise for having simple foods and I try everything on the table (ABY 12; aged 52)*
>
> شما ممکن است بدانید ایرانی‌ها در مهمانی انواع مختلف خوراکی‌ها برای مهمانان. حتی برای یک
> مهمانی ساده ما در روی میز انواع غذاهای سنتی است و در این مواقع من قول خودم را برای خوردن
> غذاهای ساده می‌شکنم و از همه چیز امتحان می‌کنم

The women believed participating in cultural and religious feasts was one of the best ways to introduce their culture to their children while they lived abroad. It was a constant struggle to follow their diabetic diet at these social events:

> *My older daughter is nine years old now and it is not easy to learn our Islamic practices in a different country, it is fun but it takes a lot of time and energy and I am already struggling with my illness. Participating in our feasts is very good and useful for them, not for me because of my restricted diet …I do not usually participate in our cultural feasts because everybody offers us something all the time in the parties, if I want to try, it is going be too much at the party (ABY 4; aged 43)*
>
> دختر من ۹ ساله است و خیلی سخت است که آموزش های دینی را به آنها آموزش داد مقدار زیادی
> انرژی و وقت می‌گیرد و شرکت در این مراسم ها خیلی مفید است.. برای آنها ولی برای من سخت است
> با این برنامه غذایی محدود همیشه غذاهای مختلف تعارف می‌کنند اگر بخواهی از همه چیز امتحان کنی
> قند خون خیلی بالا می‌رود و معمولا این برنامه ها تا دیر وقت طول می‌کشد و این برای من خیلی سخت
> است

Fear of offending family or friends (friends in particular) was a common theme among the women in this study. Declining to eat a Persian style cookie or other dessert was a social insult to their hosts. It was very challenging for the majority of women to avoid overeating when the prevailing social norm in cultural feasts is to eat large quantities of colorful and variety of foods.

In these feasts, they realized they were different. As a consequence, some women refrained from participating in parties, picnics, and other activities, because they felt unable to maintain their blood sugar level. Other women did not participate because they did not want others to know or see them monitoring their blood sugar. This, according to the women, led directly to a sense of stigmatization and isolation from their social group. It became a vicious circle where lack of social activities induced emotional distress, depression and further social isolation, which in turn could weaken their desire to maintain effective self-care for their diabetes. The following quote from ABY 3 reveals some of the struggles the women encountered in the cultural feasts:

> *The big problem is when my husband is in the town we have to go to many parties and based on our culture they prepare many colorful foods and of course desserts [Laugh]. The hard part is I want to try from everything especially new things. And again my blood glucose goes high. Sometimes I try to not eat from everything and having diet is a big excuse… when I have food restriction it causes psychological problems too such as being over sensitive, easily getting angry and so on (ABY 3; aged 54)*
>
> مشکل اینجاست وقتی همسرم اینجاست تعداد زیادی مهمانی میرویم با غذاهای رنگارنگ و
> دسرهای متنوع و مشکل اینجاست شما میخواهید از تمام غذاها امتحان کنید و بنابراین قند خون بالا
> میرود بعضی وقتها مجبورم نمیاورم و از همه غذاها امتحان نکنم با بهانه رژیم غذایی
> ...محدودیت غذایی سبب مشکلات روانی میشود مثل زود حساس شدن و بیش از حد معمول عصبانی
> شدن و چیزهای مشابه

Even entertaining guests in their homes – *Mehmooni* – could be challenging. Guests expected additional foods which include white rice and different kinds of stews at every meal as well as a variety of sweets including dried fruits, a variety of nuts (Pistachios in particular) and cream puffs. The extensive Persian community in Vancouver means that there is convenient access to all of the traditional foods in Persian bakeries and restaurants. Frequent social entertaining is a typical:

> *I have to invite my friends and family very often and I have to prepare different types of meals and desserts and sometimes I order some of them from the Persian restaurant in downtown…I can't prepare simple and steamed foods for them…usually after the party, my blood sugar is going to be very high…I try all the foods before putting on the table! [Laugh] (ABY 14; aged 59)*
>
> من هر از گاهی باید دوستان واقوام را دعوت کنم باید غذا ها ودسر های مختلف درست کنم بعضی
> وقت ها از رستوران ایرانی سفارش میدهم در دانتون ... من نمیتوانم غذاهای ساده وبخارپز تهیه کنم
> ...معمولا بعد از مهمانی ها من قند خونم بالا ست ... من قبل از گذاشتن هر چیزی سر میز خودم از همه
> چیزها تست میکنم

In summary, eating or not eating traditional foods, participating or not participating in cultural and religious feasts were significant struggles for my participants who lived here alone or with their close family. Being part of the large Iranian community was a fundamental source of social connection. A few women did manage but the more common experience was to ignore their diabetic needs and suffer subsequent high blood sugar or to avoid social gatherings entirely, which resulted in isolation.

Intersection of the immigration and diabetes journey. A sense of connection with Iran as the homeland was very significant for all participants. The majority of participants believed immigration to Canada promised them a better life but what they missed most was being in Iran and enjoying being with relatives, neighbors and all familiar things. Immigration to Canada also affected the journey with diabetes, including uncertainty about choosing to live in Canada or to go back to Iran; not trusting the family physician to manage their diabetes appropriately; feeling lonely and missing the extended family as a main source of support. All of my participants mentioned, in different words, that Iran is their real home (*Watan*) and being away and disconnected from Iran caused stress and exacerbated their struggles with diabetes. Feelings of stress and depression were most commonly expressed among the women who came here temporarily or on a visitor visa to stay with their children who are studying in Canada:

> *I am outside of my country for almost six years. I feel alone and I am always missing my extended family…this really bothers me …recently, I am struggling with depression too…and my blood sugar is not controlled well…I know I can't stay outside of my country more, eventually I have to come back to Iran… (ABY 7; aged 59)*
>
> من در خارج از کشور مدت ٦ سال است زندگی می کنم. من همیشه احساس دلتنگی برای خانواده ام در ایران می کنم... این مساله خیلی من را اذیت می کند... الان دچار افسردگی شدم... من نمیتوانم بیش از این خارج از کشور بمانم آخر سر به کشورم باز خواهم گشت.. با خاطر همین فکر قند خونم هم خیلی خوب کنترل نیست

A significant number of the participants identified being an immigrant and having to adapt to everyday life, dealing with the issues of living in Canada, was very stressful. This, along with feelings of loneliness, caused some women to feel sicker or experience more struggles. Usually, immigration brought new social roles and obligations. Diabetes plus immigration was a double burden for most of the women, especially those who had children. Some of them mentioned they really wanted to raise their children based on Iranian culture and Islam but the complexity of living with diabetes did not let them achieve this:

> *It is very hard to take care of your body and insulin issue and raise my children in different country based on what I like to teach them…ABY 4; aged 39)*
>
> خیلی سخت است که مواظب بدن خودم و مشکلات مربوط به انسولین هم زمان بزرگ کردن بچه ها در کشور دیگر براساس من دوست دارم بچه هایم یاد بگیرد ...

The reason for immigrating had different effects on the struggle to live with diabetes. Canada was considered as a "heaven" for some women, with better opportunities for employment as well as personal growth. It was seen to provide a better quality of life. These women were motivated to work hard to get to know and adapt to Canadian culture. They also found it easier to live with diabetes because they accepted Canada as their new and permanent home:

> *I am very happy with my job and enjoying my colleagues…we immigrated to Canada and we are planning to live here permanently (ABY 9; aged 48)*
>
> من از شغلم خیلی راضی هستم و از بودن با همکارانم لذت می برم ...ما برای همیشه به کانادا مهاجرت کردیم

Another group of women came to Canada with their adult children on a visitor's visa. Canada, for them, was a temporary place to live and they did not feel Canada was their real and permanent home. As noted earlier, many of these women could not speak English so they felt socially isolated. This social isolation could be lessened by participation and enjoyment of cultural activities but they perceived that having diabetes stopped them from participating in these events. Diabetes was directly or indirectly a cause of social isolation:

> *Since I came to Canada my diabetes is getting worse because I was very active in Iran but here I feel I am in cage …I can't speak English I can't go outside too much because I can't communicate with people and most of the time I stay home and I am gaining weight. This is not my real life here (ABY 8; aged 59)*
>
> از وقتی آمدم کانادا وضعیت دیابتم بدتر شده چون ایران خیلی فعال بودم ولی الان تصور کنم تو قفس هستم ...من نمی توانم انگلیسی صحبت کنم پس خیلی بیرون نمی روم چون خیلی با افراد دیگر نمی توانم ارتباط برقرار کنم بیشتر وقت در منزل هستم بنابراین دچار اضافه وزن شدم

In this second phase of the journey of struggling to live with diabetes there are three important categories that an important to understand the participants' experiences and how they attempt to recreate a sense of identity and meaning for their life.

Stigmatization. How Iranian culture portrays people with chronic illness is different from family to family, but there is a high probability of stigmatization for people with visible and invisible chronic illnesses such as diabetes. People who have diabetes in Iran may decide whether to disclose their illness or to conceal diabetes and its complications, pretending to be normal. In my study, some participants believed there was no stigma surrounding diabetes. This belief was common among older women. These women had no reservations about disclosing their diabetes and perceived that their friends and larger social group were receptive, able to accommodate their needs and respectful of their differences:

> *I don’t like to hide my diabetes. Instead, I like to let other people know about diabetes and learn how to take care of their bodies and prevent getting diabetes. I also want to let my friends know about my diabetes in case something happen to me can help me, for example very low blood sugar. I also have my bracelet from Canadian Diabetes Association and it is always with me (ABY 1; aged 61)*
>
> من دوست ندارم بیماری خود را پنهان کنم به جای ان دوست دارم دیگران هم درباره دیابت بدانند و
> چگونه از خودشان مواظبت کنند . من دوست دارم دوستانم بدانند که هر وقت مشکلی برایم پیش آید کمکم
> کنند مثلا قند خون خیلی پایین من همچنین دستبند انجمن دیابت کانادا را به همراه دارم

There were also a small number of women who believed there was no need to hide their diabetes because it provided them some opportunities to think more about their body and what they eat. It opened an avenue for them to a healthier lifestyle. One of the participants who adapted very well to having diabetes said:

> *Although diabetes is a serious disease, having diabetes provided me an opportunity to pay more attention to what I eat and having more organized physical activities…I never try to hide my illness…for me diabetes is a lifestyle disease and if we change our lifestyle, managing diabetes is getting easier. When people do not follow a healthy lifestyle, they will be at risk of having diabetes. On the other hand if you have diabetes changing lifestyle is an important key for managing diabetes, this is my understanding of having diabetes type II, we may need to do more than changing lifestyle, I don’t know…please excuse me for this explanation in front of you, I am sure you know better than me [laughed] (ABY 9; aged 48)*
>
> اگر چه دیابت یک بیماری خطرناک است ولی برای من فرصتی بود تا توجه بیشتری به آنچه می خورم و
> فعالیت بیشتر بدنی داشته باشم .به نظر من دیابت یک بیماری روش زندگی است وقتی ما روش زندگی
> را تغییر دهیم کنترل دیابت آسانتر است .ما وقتی یک زندگی اعتدال نداشته باشیم در خطر ابتلا به دیابت

هستم. اگر هم دیابتم شدیدتر بشه با تغییر روش زندگی راحت تر کنترل میکنم ان را. این تصور من از
دیابت است , ممکن است اما چیز بیشتری برای کنترل لازم داشته باشی که من نمیدانم بیشتر یک مبارزی
شامل توضیحی میدهم اما قطعا بیشتر از من یاد بدید

The majority of women, however, perceived considerable stigma related to having diabetes. They were usually not willing to talk about the illness. Stigmatization undermined the women's efforts to manage their diabetes in this study and contributed to more struggles:

> *I do not want to talk about my diabetes to anybody I do not like people's reaction when they realize I have diabetes… (ABY 4; aged 43)*
>
> *من دوست ندارم درباره دیابت خودم با دیگران صحبت کنم از واکنش مردم وقتی میفهمند من دیابت دارم*
> *را دوست ندارم*

Other people's reaction to diabetes was also the main challenge for ABY 1:

> *I decided to not talk about my illness… I am still struggling with diabetes-it is a lifelong problem. You may know in our culture when people know you have a chronic illness, they do not usually look at you as a normal person and they do not ask you same as others. They feel pity for me even my family and close family feel sorry for me. Then I usually prefer not to meet with them… when you did not adjust yourself to your disease and cannot accept your disease, then you do not want to reveal your illness. I do not like people know my disease. I think they felt pity for me and I hate this feeling (ABY 1; aged 39)*
>
> *من تصمیم گرفتم درباره بیماریم با دیگران صحبت نکنم... من فکر میکنم تا آخر عمر با این بیماری*
> *درگیر هستم شما ممکن است بدونید در فرهنگ ما وقتی یک نفر بیماری داشته باشه معمولا به*
> *صورت یک آدم معمولی به ان نگاه نمیکنند حالت ترحم به خوشان میگیرند و من دوست ندارم با این*
> *حال روبه رو شوم وقتی نتوانستی با بیماری خود رابطه برقرار کنی بیماری خود را نپذیری سعی*
> *میکنید ان را از دیگران مخفی کنید من دوست ندارم مردم درباره بیماری خودم بدانند دلشان برای من*
> *میسوزد و من از این حالت متنفرم*

The consequences of hiding their diabetes included not following the recommendations and prescriptions from health care professionals. Women who tried to conceal their diabetes ate and drank freely at the feasts so that they would not have to appear to be different from other people. Consequently, their blood glucose would go of control:

> *Every time when I go to the restaurant with my friends I eat whatever they eat and I tried to not eat during the day before going to the restaurant…usually few days after, my blood glucose is out of control…but it is always fun being with my friends…(ABY 14; aged 59)*
>
> هر وقت وقتی من با دوستانم رستوران میروم در طول روز هیچ چیزی نمیخورم قبل از رفتن به رستوران
> ...معمولا چند روز قند خونم بالا میماند...ولی بودن با دوستان نعمت است

Culturally, the women in my study were more willing to hide their chronic illness in Iran. Hiding diabetes caused the women in this study many problems. Some of the participants mentioned that they tried to hide the illness or live in secrecy because they had concerns about receiving negative responses from family members, colleagues at work and friends:

> *I do not want to deal with people's misconceptions about diabetes and I do not want to answer lots of questions about diabetes …I do not need people's sympathy. I prefer to stay home with my husband most of the time (ABY 15, aged 62)*
>
> من دوست ندارم با اشتباهات و خرافه های غلطی که مردم درباره دیابت میدانند و دوست ندارم کلی سوالات
> مردم را جواب دهم ...من احتیاجی به دلسوزی مردم ندارم . من ترجیح میدهم با همسرم در خانه بمانم

Some women also believed having diabetes was a personal concern and they were not willing to talk about it with others. The majority of the participants did not demonstrate any willingness to reveal their illness. They had many reasons for this decision. For example, they were afraid they might be fired by their employers:

> *It is impossible for me to be open to others about my weakness especially my colleagues and my manager. At the beginning I was thinking if they find out about my diabetes they would not willing to work with me. I usually check my blood glucose once during the day and I do it the time I go to washroom. I have a hope nothing happen to me such as low blood sugar when I am working. I love my job and do not want to lose it. I believe, when people hear somebody has diabetes they may faint all the time. I just do not like to tell people in my workplace. This is just my personal feeling (ABY 3; aged 54)*

بنظر برای من غیر ممکن است که درباره مشکلاتم با همکارانم و رییسم صحبت کنم. در ابتدا فکر
میکردم اگر آنها درباره بیماری من بدانند دوست ندارند با من همکاری کنند . من روزی یکبار قند خونم
را در محل کار چک میکنم. من این کار را در دستشویی انجام میدهم . من همیشه امیدوارم اتفاق
ناگواری برای من در رابطه با قند خونم نیفتاد. من کارم را دوست دارم و دوست ندارم ان را از دست دهم
. مردم در حالت عادی فکر میکنند افراد دیابتی غش میکنند. بنابراین احساس شخصی من این است که دوست
ندارم با بیماریم با دیگران صحبت کنم

Several other participants mentioned they do not like to reveal their chronic illness because they disliked when people ‘felt pity’ for them:

> *I believe we learned to hide any illness from others in Iran… when somebody has a chronic disease such as diabetes in Iran other people feel pity for us… (ABY 3; aged 54)*
>
> من یاد گرفتم که بیماری خود را مخفی کنم معمولا وقتی یک بیماری مزمن داشته باشی از دیگران مخفی
> میکنند چون حالت ترحم دیگران به خودشان میگیرد

Usually people in Iran do not want to reveal their illness to others, especially those they care about such as their husband, children and parents. Most of the time in Iran a mother keeps her chronic illness such as diabetes from her children or her parents in order to safeguard them from the anxiety her health status is perceived to create:

> *I do not like to talk about diabetes with my friends, as soon as somebody realize I have diabetes he/she express his/her feeling about diabetes and makes a comments and I do not like it (ABY 14; aged 59)*
>
> من دوست ندارم درباره بیماری خودم با دوستانم صحبت کنم به محض اینکه کسی متوجه میشود من
> دیابت دارم راجع به دیابت اظهار نظر میکنند و نظر میدهد و من اصلا دوست ندارم

Some women believed that people think of diabetes as a disease accompanied by blindness, kidney failure and amputation. These women stated that they prefer to keep diabetes as a personal secret:

> *There are no good stories about diabetes in public. Diabetes equals blindness for people and this perspective really bothers me and I prefer not discuss my diabetes (ABY 11, second round interview, aged 63)*

> در ذهن مردم دیابت مثل یک بیماری که همراه با نابینایی نارسایی کلیه و قطع پا است. این تصور از
> دیابت من را آزار می دهد و من ترجیح می دهم درباره دیابت صحبت نکنم

In summary, some women felt they were under strong social pressure to be “normal.” They wanted to carry out social expectations as a mother, wife or community member which created tension between their sense of self and social identity and influenced their ability to integrate diabetic needs into their social lives.

Identifying other milestones in their life. While my participants were struggling to live with diabetes, some women focused on other milestones in their lives as a strategy to avoid thinking too much about diabetes. This strategy was predominant in women who lived with their family in Canada or were employed here. They focused on the blessings and positive dimensions of their lives:

> *Having diabetes made me know my husband better. I am proud of my daughters. I am happy after many years effort to raise my children now they are good children for me and for my husband. I always try to do my best for my family, giving love to them. Doing all my duties without conditions and I am also trying to keep in touch with my friends. I am trying not to be stopped by having diabetes [Laugh] (ABY 3; aged 54)*
>
> داشتن دیابت اگر چه سخت است ولی فرصتی بود که همسرم را بیشتر بشناسم من به دخترهایم افتخار
> می کنم بعد از مدت ها زحمات خوشحالم که بچه ها را دارم من همه تلاشم را برای فرزندانم
> انجام می دهم سعی می کنم دیابت من را از زندگی متوقف نکند سعی می کنم همه کارهای مربوط به خودم
> را مستقل انجام دهم

Over time struggling with diabetes became exhausting and occasionally my participants wanted to “give up.” The thought that diabetes was a life-long condition was overwhelming. Most, however, used their faith and family as a source of strength:

> *Diabetes management is hard, it takes a lot of time and I should be patient to have blood glucose in normal range …but it needs life long effort. That is the reason sometimes I feel tired of controlling my life…I am doing it because of my family …because of my only*

> *granddaughter…I am counting my blessing in my life and it encourages me to continue my life (ABY 9; aged 48)*
>
> کنترل دیابت خیلی مشکل است مقدار زیادی انرژی از من میگیرد و برای کنترل قند خون باید انرژی
> زیادی بگذارم و صبور باشم. باید تمام امور را شکر کنم بعضی وقت احساس خستگی زیادی میکنم ...من
> همه اینها را به خاطر خانواده انجام میدهم به خاطر نوه هام... افتخارات زندگیم را میشمارم و این
> امید من را به زندگی زیاد میکند

Recreating life meaning with diabetes. After struggling with many issues, the women in my study tried to find new way of living with diabetes. Women in this stage of their diabetes life journey realized their former lifestyles were no longer functional and they tried to construct a new reality that incorporated their diabetes in a new lifestyle:

> *Although it is very hard for me to not to eat rice and sweet but I realized by eating this stuff my blood sugar is going very high and I am not feeling good after that …besides diabetes complications will appear soon, so I decided to modify my meal plan based of what my doctor told me…recently, I do not experience very high blood sugar (ABY 11; aged 63)*
>
> اگر چه برای من خیلی سخت است که برنج سفید نخورم ولی با خوردن ان قند خونم خیلی بالا میرود و
> احساس خوبی بعد از ان ندارم درد سرهای بعدی ان شروع میشود. بنابراین تصمیم گرفتم برنامه غذایی
> خودم را بر اساس آنچه دکتر به من گفته است تعدیل کنم... الان احساس بهتری دارم و قند خونم خیلی
> بالا نمیرود

Others felt they had “no choice” but to create a new life if they wanted to live:

> *I want to live to be with my granddaughter (live longer) I have to control my diabetes and I have to learn more about it to live longer (ABY 9; aged 48)*
>
> من میخواهم با نوه هام زندگی کنم باید یاد بگیرم که چگونه با دیابت زندگی کنم و بتوانم طولانی تر
> زندگی کنم

Some women felt exhausted, victimized or worthless (inadequate) after struggling for months or years to incorporate diabetes into their lives. A sense of being inadequate happened when they perceived they could not perform their expected roles as a mother, wife, colleague or friend. These women believed they have to live with stigma (being diabetic) for the rest of their lives. Their lives were dominated by thinking about diabetes and its complications all the time. These women no longer enjoyed the everyday moments in their lives. Diabetes was an endless source of sorrow for them and food was the main focus of struggle. These women described their lives as “abnormal.” Overall these feelings were dominant in women who were living in Canada temporarily or live alone, particularly without their partners. They believed they could not do whatever other people do and they felt different from others:

> *I feel I can’t have normal life while I have diabetes. I can’t do whatever other people do or eat; I am always doing the opposite. Lunch time earlier than others, I can’t wait if the meal is not ready…I have to go to the doctor many times a year, this is an abnormal life… my life changed in the wrong direction gradually (ABY 6; aged 49)*
>
> من احساس می‌کنم من نمی‌توانم زندگی نرمال داشته باشم . من نمی‌توانم هر کاری که همه مردم انجام
> می‌دهند یا می‌خورند انجام دهم باید زودتر از دیگران غذا بخورم اگر غذا آماده نبود نمی‌توانم صبر کنم.. .
> باید چندین بار در سال دکتر را ببینم و این غیر نرمال است ...زندگی من در جهت مخالف دیگران است

When complications, such as loss of vision appeared, participants felt even more isolated and restricted:

> *When my vision problem started I realized I couldn’t have a normal life anymore…I was feeling like it is the end of the world for me (ABY 7; aged 57)*
>
> وقتی مشکل بینایی من شروع شد متوجه شدم که دیگر زندگی نرمال نخواهم داشت ... در ان زمان فکر
> می‌کردم آخر دنیا است برای من

Some women did remain hopeful while they struggled to live with diabetes. They tried to follow their written meal plan and some of them believed the new meal plan changed their life paths to a better and healthier road:

> *I try to control my blood sugar and I have a hope not getting diabetes complications (ABY 5-second interview; aged 34)*
>
> من سعی می‌کنم قند خونم را کنترل کنم. من امیدوارم که عوارض دیابت را نگیرم

Overall, the second phase of life with diabetes was very important in how they continued to live with diabetes. There are many factors which accompanied my participants as they continued on this road such as: food challenges, issues with trying alternative remedies such as using herbal treatments, language differences, family support, culture and religion, and immigration. The final phase in these women's diabetes journey represents how they portrayed their current life with diabetes. In my analysis, there were two trajectories: "life as a bumpy road" and "life as an uphill battle." In the following section I describe each of these ways of understanding and valuing their lives as they are now with diabetes.

Phase 3: Life Roads

The life path for my participants, after going through the dark days of diagnosis and struggling to learn to live with diabetes, divided into two different paths. Some women, after struggling to learn to live with diabetes, began to improve their situation. They experienced diabetes as a paradox with both burden and opportunity. The life road for these women was a "bumpy road." The other group of participants experienced loss and endless uncertainty; these participants perceived life as an "uphill battle."

Life as a bumpy road. Early resistance and rejection of diabetes gradually faded into acceptance through many struggles and over a considerable period of time. When women described their lives with diabetes as a "bumpy road," they accepted diabetes as a fact and lived within their limitations. Life paths for these women sometimes included periods of time where their lives were easy to tread. When challenges appeared, the path becomes difficult to navigate. Sometimes hills and challenges are brief, sometimes longer, but eventually, the path would become flatter, easier and more comfortable. The following picture represents this metaphor as life as a bumpy road (Figure 4.5).

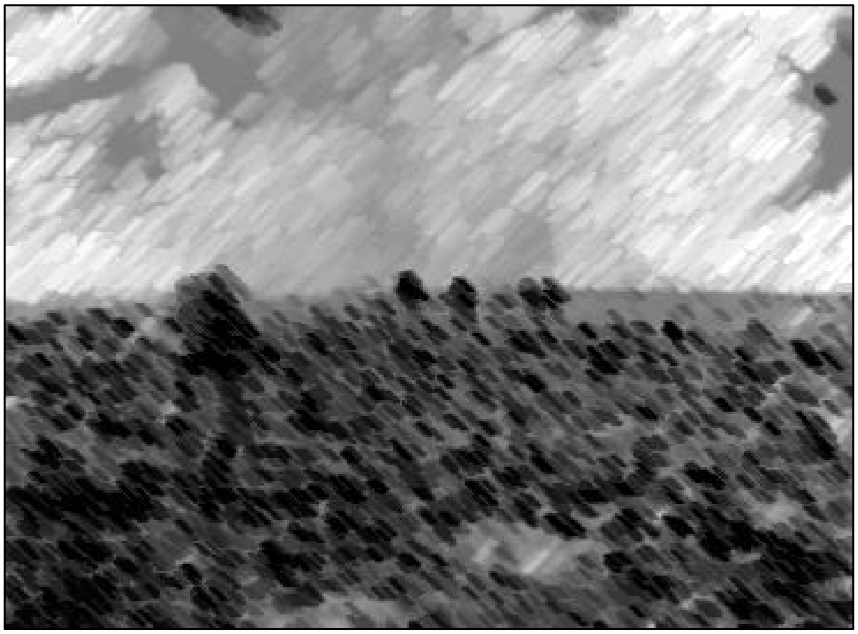

Figure 4.5 Life path with diabetes has always has some bumps.

Women in this life trajectory acknowledged that diabetes was challenging at times, but they lived with both joy and discouragement at the same time. These women were able to move forward by engaging in the process of diabetes self-management, such as the minimization of negative effects by focusing on blood sugar control. The ability to live with diabetes was dependent on each woman's personality, but overall happened in women with highly supportive family, higher education or who came to Canada to reside permanently. Having appropriate support from partners, family and friends helped them to stay on a relatively smooth life road. When women suddenly encountered an acute or chronic complication, the road did become bumpy. They refocused on their illness and started to struggle with it. A positive attitude and appropriate support throughout the crisis were key factors that kept them from being defeated by the bumps, and allowed them to continue life:

> *Diabetes is not very easy ...sometimes it is bumpy road... family support and receiving motivation from them and of course reward from my blood sugar is very helpful...I am counting my blessing in my life and it encourages me to continue my life...sometimes I*

> *feel disappointed because I can't control my blood sugar without any reason and it goes up and high blood sugar bothers me a lot or sometimes I have blurry vision, I do not want to lose my hope then I work hard to find out about the reason of high blood sugar. (ABY 9; aged 48)*
>
> داشتن دیابت آسان نیست..گاهی اوقات راه با دست انداز است... حمایت خانواده و دیدن جواب خوب قند
> خون شکل یک پاداش است من خوبی های که در زندگی دارم را می شمارم..گاهی وقت ها قند خونم تنظیم
> نیست و بدون هیچ دلیلی بالا است و سبب آزار من میشود و سبب تاری دید ولی این اتفاقات سبب از دست
> دادن امیدم به زندگی نمیشود من سعی میکنم علت آن را پیدا کنم

These women could focus more on the positive side of their illness by believing that they needed to acknowledge their disrupted lives and by recognizing that having diabetes was an opportunity for them to have a healthier lifestyle and get to know the people around them better. Women in this group believed having diabetes caused them to focus more on their body and healthy eating. When their families supported and participated in adopting healthier lifestyle choices, diabetes self-care was much easier and their life paths were smoother and easier:

> *It is obvious that having diabetes is very difficult but my meal plan for diabetes helps me to follow a healthy lifestyle and being serious about controlling my weight …this is not only useful for me but my entire family also enjoy it…(ABY 5; aged 34)*
>
> این روشن است که البته دیابت خیلی سخت است ولی برنامه غذایی من سبب شده یک روش خوبی
> برای زندگی خود ایجاد کنم و وزنم را کنترل کنم این برنامه غذایی نه تنها برای من مفید است تمام افراد
> خانواده هم از این برنامه غذایی استفاده میکنند

These women no longer needed to view themselves as a "*sick person*" because they had learned to focus on the other milestones of their lives. These women's stories reflect their struggle and resolution in this stage of the life journey. This group of participants did not sweep their feelings and problems with having diabetes "under the carpet." They planned to be more open in order to live in a different way, changing their self-expectations. Some women mentioned that by believing in God (Tavakol), the "*wind will not blow them away.*" This is a common metaphor among Iranian people that means being strong. Prayers would keep them safe:

> *Sometime I feel hopeless when new complication appear but I always thanks God because I am not dependent to others I can do all my everyday routine without help…I always ask God to help me… (ABY 7; aged 59)*
>
> گاهی وقت احساس ناامیدی میکنم وقتی دچار مشکل جدید میشوم ولی من همیشه الحمدلله میگویم خدا را
> شکر میکنم که روی پای خودم هستم و به دیگران وابسته نیستم کارهای روزانه خودم را به تنهایی
> انجام میدهم

These women put great care into looking after their bodies, trusted the diabetes treatment and continued to follow it. They learned a new way of living that offered a whole new range of opportunities and challenges. Change was part of their life with diabetes. Exploring and accepting their chronic condition made life easier for them. These women had achieved "peace" with their situation:

> *Although living with diabetes is hard, I accepted it as a part of my life- of course after a while- then I tried to live with it in peace …diabetes provided me and my family with the opportunity to follow a healthy lifestyle. For example, I pay more attention to our foods and consider physical activity every day. (ABY 9; aged 49)*
>
> گر چه زندگی با دیابت خیلی سخت است ولی بعد از مدت طولانی قبول کردم و سعی کردم با آن زندگی
> مسالمت آمیز زندگی کنم ...دیابت برای من و خانواده ام فرصتی بوجود که توجه بیشتری به آنچه میخوریم و
> به فعالیت بدنی خود داشته باشیم و فرصتی بوجود که سبک زندگی خود را عوض کنیم

Unfortunately, life as an uphill battle was the dominant trajectory that ten women seemed to reflect, viewing the role of diabetes in their lives as a continual uphill battle.

Life as an uphill battle. For the women in this life trajectory, diabetes was always the dominant concern in their life. Their paths were shadowed by a sky darkened by a ferocious thunderstorm. They believed they would never have a normal life, yet they did not have the energy to try and continue their life as before. Their fear of diabetes and its complications was so overwhelming that they felt helpless and hopeless (Figure 4.6).

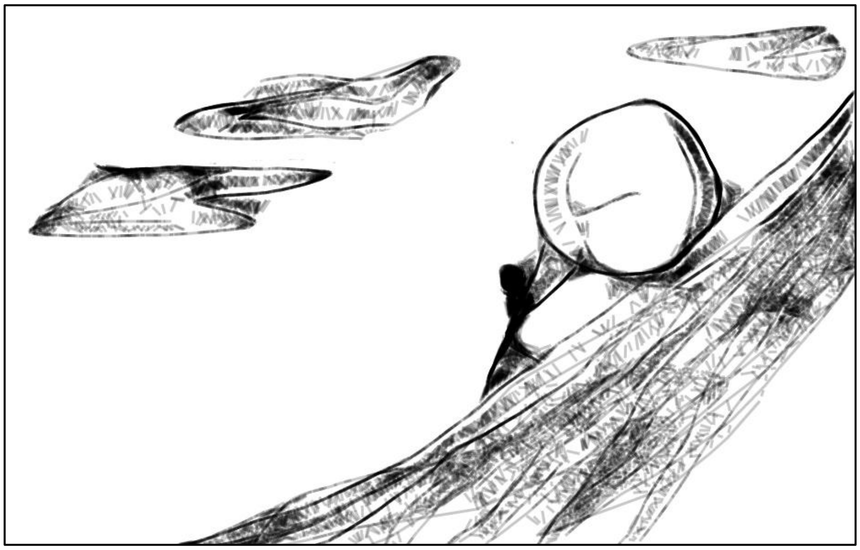

Figure 4.6 Life with diabetes looks like an uphill battle.

Women in this category were generally living in Canada temporarily on a visitor visa or are unemployed and living alone without family support. For some women, their house was like a battlefield between them and their family members. Arguments usually started from issues related to their diabetes meal plan, the frequent medical visits and reflected the resentment toward diabetes held by both women and her family:

> *My diabetes causes too much trouble in my life such as a restricted meal plan, unstable body ...after my divorce, I am still [finding it] challenging with my kids. The clash between me and my grown up kids usually starts when they question or blame me about what I am doing or eating... (ABY 6; aged 49)*
>
> دیابت سبب مشکلات زیادی در زندگی من شده است و همچنین محدودیت های فراوان مثل برنامه غذایی
> بدن غیر قابل پیش بینی حتی بعد از طلاق... هم من همچنان با بچه هایم برای برنامه غذایی خودم
> مشکلات دارم و مشاجره و دعوا ها از سوال کردن آنها از آنچه خوردم و کردم شروع می شود

The new obligations, strains and frustrations caused a lifelong battle for the majority of this group of women. They felt isolated within their family and were often overwhelmed by feelings of sadness, helplessness, hopelessness and abandonment. As well, they often had uncontrolled blood sugars. Women in this group found family and friends disrespectful and ignorant:

> *I was a mother in the house. I expected respectful behaviors from my children but it was reversed since I realized my diabetes and consequent complications. They were telling me what to do or to eat…I asked them to leave me alone …they are living somewhere else now. I am by myself…this situation is very scary sometimes especially when I feel hyper or hypoglycemia. (ABY 6; aged 49)*
>
> من مادر خانواده بودم و انتظار احترام از طرف فرزندانم داشتم ولی از وقتی دیابت گرفتم و مشکلات
> بعدی آغاز شد همه چیز برعکس شد آنها به من دستور میدادند چکار کنم یا چه بخورم من از آنها
> خواستم که من را به حال خودم تنها بگذارند... الان آنها با من زندگی نمیکنند..تنها بودن خیلی سخت
> است به خصوص وقتی که یکدفعه دچار افزایش یا کاهش قند خون شوم و تنها باشم

Women feared they would be blamed for developing diabetes complications and felt unable to participate in regular personal and social activities:

> *As soon as I experience a new problem in my body, my family, especially my mother – because she has diabetes too-started blaming me for what I am eating and questioning me about what did I do… (ABY 8; aged 57)*
>
> به محض اینکه مشکلی برای من در رابطه با دیابت افراد خانواده به ویژه مادرم چون خودش هم
> دیابت دارد شروع به پرسش کردن و سرزنش کردن من میکنند که من چه خوردم و چه کاری کردم

Feeling guilty all the time was very common because these women had not paid attention to what they ate in the past, before having diabetes, or because they didn't exercise today or they ate the wrong food last night. The self-blame was endless:

> *It is not possible to have a perfect life with long-term disease…right now I have problem with my vision in my left eye and I think it is my fault in the past …I did not take care of*

> *my body at the earlier days of diabetes and I did not pay enough attention to medical and diet advice now I have diabetes complications… (ABY 7; aged 59)*
>
> ممکن نیست که زندگی بی کاستی داشته باشی با وجود دیابت الان من مشکل چشم چپ خودم دارم و
> فکر می کنم تقصیر من بوده است من مواظب بدنم نبودم و به دستورات پزشکی و رژیم غذایی توجه
> نداشتم الان دچار آسیب های دیابت شدم

These women felt defeated and disempowered after a long period of struggling. The majority of the women in this group considered themselves to be depressed and some of them required anti-depressant medication. One of my participants said:

> *I feel [like there are] never-ending problems and it increases my level of suffering from diabetes. Diabetes is following me like a shadow… My brain always is full of calculation and worriedness about diabetes complications…I am scared of disability, being totally dependent on others, on my family… food restriction caused psychological problems such as being over sensitive, easily getting angry and so on…(ABY 3; aged 54)*
>
> مشکلات زندگی با دیابت پایان ندارد. فکر می کنم مشکلاتی ناشی از دیابت من را اذیت می کند دیابت مثل سایه
> دنبالم می کند... مغزم پر از محاسبات است و نگرانی از مشکلات دیابت...من واقعا از معلولیت
> می ترسم دوست ندارم به اعضای خانواده و دوستانم وابسته باشم...محدودیت غذایی سبب مشکلات روانی می شود
> من متوجه شدم که با راحتی عصبانی می شوم

When diabetes became a lot harder to handle, it became even harder for them to escape depression. Over time they experienced reduced interest in and obtained less pleasure from the things they used to enjoy:

> *I always enjoy preparing and eating a variety of foods but I do not have the same feeling now…most of my previous activities are meaning less now… (ABY 11; aged 63)*
>
> قبلاً از غذا درست کردن و غذا خوردن لذت می بردم...ولی تمام کارهای قبلی الان برایم بی معنی شده
> است

Anxiety and uncertainty about the future of their life with diabetes and a distrust of their bodies was common. They perceived that their spirit, mental health and relationships suffered because of diabetes:

> *My body now is a collection of many diseases…now my life is full of crisis, when one finished the other one started…. controlling blood sugar takes me a lot of time and energy. Every morning my day started with pain, I feel tired and exhausted all the time but I can’t sleep… (ABY 15; aged 62)*
>
> بدن من کلکسیون دردهای مختلف است... زندگی پر از بحران وقتی یکی تمام میشود دیگری شروع
> میشود... کنترل قند خون مقدار زیادی وقت از من میگیرد هر روز صبح روزمن با درد صبح من
> شروع میشود من احساس خستگی مفرط میکنم ولی خوابم نمیبرد

The women in this “life as an uphill battle” trajectory were disempowered by the overwhelming force and impact of their diabetes. They were unable to efficiently manage their diabetes and often forget its existence by failing to follow up with physician regularly or by ignoring their diabetic diet for long periods of time:

> *Living with diabetes is very hard; I always fail to keep my blood sugar normal… I am like a desperate person. I do not know what to do… I have to sleep with icepack in my socks to reduce the pain… (ABY 14; aged 59)*
>
> زندگی با دیابت خیلی سخت است من در نگه داشتن قند خونم همیشه شکست میخورم... من دچار
> درماندگی شدم نمیدانم چکار کنم... من از شدت درد شبها باید با کیسه یخ بخوابم

Overall, chronic illness was a dynamic experience for all my participants. Each woman had their own individual journey within three broader stages of dealing with the chronic illness. Their journeys are continuing and their experiences may change over time again.

The Symbolic Meaning of Diabetes

Making sense of life is important to everyone, not only people with diabetes. Meaning is what connects things and gives cohesion to our lives (Roussi & Avdi, 2008). Roos and Neimeyer (2007) make the point that chronic loss can hamper the reconstruction of meaning. It is important to understand the meaning of life with diabetes for women in this study. Understanding different aspects of the meaning of diabetes is very important for realizing the strategies for helping people with diabetes in self-management activities. Through this study, I realized that for an

Iranian woman with diabetes, factors such as culture, family, religion and immigration experiences are important components that facilitate the shift from wellness to illness and vice versa.

The participants had different perceptions of having diabetes. Attribution regarding the cause of diabetes for women in my study, such as being under too much stress, immigration, pre-destination and perceptions of their experience, such as: "*Why did this happen to me?" (ABY 1, aged 38), "Having diabetes means having trouble all the time…" ABY 13, 42)* have been associated with a negative meaning of life with diabetes:

> *I am really scared of having diabetes, for my future; diabetes for me means early death or being blind or so on… (ABY 7 aged 59)*
>
> من واقعا از دیابت میترسم برای من داشتن دیابت یعنی مرگ زودرس یا نابینا شدن است

On the other hand, some women revised their beliefs and goals about having and living with diabetes by changing the meaning for themselves of having a chronic illness. For example, they accepted their diabetes diagnosis and tried to change their lifestyle:

> *Diabetes provided me an opportunity to pay attention on my body better than before… (ABY aged 48)*
>
> دیابت برای من فرصتی پیش آورد که بیشتر به خودم توجه کنم

The women who were taking insulin believed diabetes severely restricted most aspects of their daily lives. They used many metaphors to express this sense of burden, social stigma and helplessness, such as feeling tethered to a ball and chain:

> *Diabetes is a huge limitation for my life. I have two young kids and every time when I inject insulin it reminds me of people who are addicted to injections…diabetes affected every aspect of my life…it caused too much work for me… having diabetes is like [having a] fence around me… I cannot enjoy being in the feasts and with other friends…people always feel pity for me, I am just tired of their feeling…I have to spend a lot of time and energy to prepare two separate meals for myself and my family… I feel hopeless about*

> *uncontrolled blood sugar and too much checking…diabetes is dominant in our life…my bad feeling about diabetes is increasing over time. (ABY 4; aged 43)*
>
> *دیابت یک محدودیت زیادی در زندگی ام گذاشته است من دو تا فرزند دارم هر زمان که انسولین تزریق*
> *می کنم حس یک آدم معتاد را دارم دیابت تمام جنبه های زندگی من را تحت تاثیر گذاشته است مثل یک*
> *حصار در من است و من از چیزی در مهمانی ها لذت نمی برم احساس می کنم مردم حالت ترحم دارند من*
> *از این احساس خسته شدم من باید خیلی وقت بگذارم دو جور غذا درست کنم من واقعا احساس ناامیدی*
> *از قند خون کنترل نشده دارم من احساس خستگی از کنترل کردم که قند خون دارم دیابت بزرگ*
> *ترین مسئله در زندگی ما است و این احساس به مرور زمان بیشتر می شود*

Perceiving diabetes as a burden that restricted many aspects of their lives was common for all of my participants. Regardless of whether they saw life as a bumpy road or an uphill battle, all the women defined living with diabetes as living with a ball and chain. As well, the majority of them perceived diabetes as a lifelong battle. In this section I will go through those symbolic meanings of diabetes from my participants' perspective.

Diabetes as a ball and chain. A ball and chain (غل و زنجیر) is an ancient form of fastening prisoners by clamping a cuff around the prisoner's ankle attached to a heavy ball with a chain. Having a ball and chain means that someone or something is severely restricting one's freedom of movement, and whatever movement is possible occurs with difficulty under this enormous weight. In Iranian culture, ball and chain means having limitations in any dimension of life and living with restricting conditions. The majority of the women in my study understood diabetes as a ball and chain controlling their lives (Figure 4.7):

> *I feel my hands and legs are tight with chains (handcuffs) for the rest of my life. I cannot do anything that I like before. I had no idea by having diabetes my life is shifting into troubles. I think diagnosis with diabetes means entering to a road that goes down to the early death or severe problems… (ABY 1; aged 38)*

من احساس می‌کنم دیابت مثل یک قفل و زنجیر به دست و پای من است من نمی‌توانم کارهایی که در گذشته
انجام می‌دادم انجام دهم من انتظار نداشتم دیابت بتواند اینقدر تنش در زندگی من بگذارد مبتلا شدن به
دیابت مثل وارد شدن به راهی است که پایانش مرگ زودرس و معلولیت می‌باشد

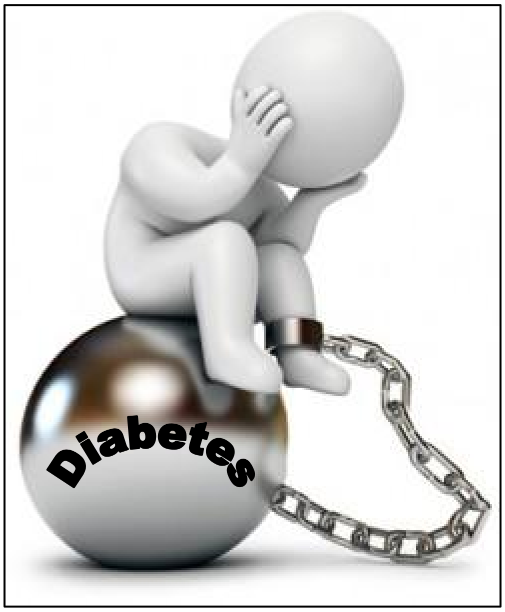

Figure 4.7 Ball and chain in people with diabetes. Reprinted with permission from http://www.123rf.com/portfolio/kharlamova

Even over time, there did not seem to be any strong sense of adaptation, mastery or accommodation of diabetes within their daily lives for the majority of my participants:

> *After eight years of having diabetes, I am still struggling with it especially my meal plan. I could not adapt myself to it. For me diabetes means separation from my husband and my grown up kids…I cannot get rid of it… (ABY 6; aged 49)*
>
> بعد از هشت سال داشتن دیابت من با مشکلات هنوز دست و پنجه نرم می‌کنم به ویژه غذاهای
> روزانه من نمی‌توانستم خودم را با این شرایط تطبیق دهم برای من دیابت یعنی جدایی ده جدایی از
> خانواده من هیچ راه خلاصی از آن ندارم

Ball and chain was a common expression of being involved with diabetes in the majority of my participants from the early stage of having diabetes until the current situation of their lives.

In the dark days of diagnosis, diabetes acted as a ball and chain because of emotional and physical responses to the illness, seeking confirmation and so on. All of my participants experienced a huge disconnection from their previous activities and pleasure. Overtime, while they were struggling to learn to live with diabetes, they perceived it as a ball and chain due to spending too much time on learning and carrying out self-management activities and this feeling continued to their current stage of life. For all of my participants, diabetes was perceived like a heavy burden that was always with them even when they were well-adjusted to their diabetes. For example, the occurrence of new complications interfered with everyday activities:

> *Although I try to do my best to live normally and keep my blood glucose in normal range but I know this is a chronic illness and it is always with me. When something new happens in my body such as a tingling or burning feeling, I cannot continue my everyday activity normally…of course it is a ball and chain in my life…sometimes it bothers me and sometimes not…(ABY 2, aged 61-second round of interview)*
>
> من سعی میکنم تمام تلاشم را بکنم تا قند خونم را در حالت طبیعی نگه دارم ولی میدانم که یک بیماری مزمن است و همیشه با من است. وقتی یک اتفاق برای من میافتد مثل وز وز کردن پاهایم دیگر کارهای روزانه را نمیتوانم انجام دهم .. البته یک قفل و زنجیر برای من است. بعضی اوقات من را اذیت میکند بعضی مواقع نه

Some of my participants experienced living with diabetes far beyond a ball and chain. They believed diabetes was a life battle too. In the following section I will describe it.

Diabetes as a life battle. Living with diabetes constituted a continual battle to move through life with such a heavy and restrictive burden:

> *I have to battle (JANG) with my everyday day challenges with diabetes.*
>
> من همیشه در حال جنگ با مشکلات هر روزه با دیابت دارم.

Carrying the ball and chain of diabetes influenced other roles in this battle of life. They felt hopeless and inadequate due to their inability to keep their blood sugar under control. They felt lonely and isolated due to restrictions of diabetes and expressed a sense of loss:

> *I feel I lost my health- having any long-term illness is like losing your- self that is equal to losing your health (ABY 15; aged 62)*
>
> من احساس می‌کنم سلامتی خودم را از دست داده‌ام داشتن یک بیماری برای مدت های طولانی سبب
> از دست دادن سلامتی و از دست دادن خود واقعی می‌شود

These women viewed diabetes as an intractably intrusive disease. They could not predict or control their blood glucose, or predict when they would need more oral medications or insulin for controlling blood sugar. They lost their natural sense and trust in their bodies:

> *I cannot trust my body anymore-fear of having very low blood sugar and very high blood sugar… (ABY 6; aged 49)*
>
> الان یک طوری شده است که من به بدن خودم هم اطمینان ندارم من از قند خیلی پایین و خیلی بالا
> می‌ترسم

This situation created unbridgeable divides between them, as who they once were, their current selves, and their families:

> *Diabetes reminds me [of] disability …not being the same person as before…having an unknown future …I can't do whatever I like to do for my son here and the rest of my kids in Iran…I can't enjoy making dinner and eating dinner…I can't eat whatever I love to eat…(ABY 7; aged 59)*
>
> دیابت برای من رفتن به سوی معلولیت است من متوجه شدم قبلی نیستم آینده من مشخص نیست من
> کارهایی که قبلا برای افراد خانواده‌ام در ایران انجام می‌دادم را نمی‌توانم انجام دهم الان دیگر از درست
> کردن غذا لذت نمی‌برم هر چیزی که دوست داشتم را نمی‌توانم بخورم

The future is uncertain and they felt helpless in the face of encroaching complications in spite of their best efforts:

> *It was very hard for despite the fact that I had a restricted diet and was taking my oral medication regularly, my blood glucose was above normal range and the physician started insulin for me…I do not know what I should do with my diabetes… (ABY 4; aged 43)*

برای من خیلی سخت است با وجود رژیم محدود و سر وقت مصرف کردن داروهای خوراکی باز هم
قند خونم بالا بود و پزشکان برای من انسولین شروع کردند ...من نمیدانم با دیابت خودم چکار کنم

Developing diabetes complications resulted in significant adjustments and struggle in the lives of my participants. It made some of them less mobile and they became more dependent on others. Some women with limited vision needed to concentrate harder on achieving tasks that were previously easy. Depending on what impact the complication had on their life; they grieved for the loss of full health. Almost all of the participants mentioned that diabetes consumed a vast amount of time and energy and many women did not participate in any other activities or special events, such as their children's graduation from university. For some of them, even many years after starting insulin, they were very uncomfortable in taking it. They especially complained about the reaction of people when they took insulin:

> *People react weird if they notice I am taking insulin…these reactions always bother me... (ABY 6; aged 49)*
>
> *رفتار مردم وقتی من انسولین میزنم عجیب است .. این رفتار من را اذیت میکند*

Some women believed life was becoming more complicated over time. They kept attributing diabetes to the likelihood of an early death. Sometimes, usual diabetes management routines suddenly interfered with other life priorities, such as doing shift work in a new job and putting the needs of young children first. When they felt diabetes interfered, it was easy for them to feel very angry and frustrated towards their diabetes. Sometimes, feelings of grief about the impact of diabetes were highlighted:

> *Diabetes is the dangerous event in my life …it is like a cancer …it does not show how dangerous it is at the beginning but over the time the complications show up and I can't do anything with it…it is slow movement to early death…it takes many years to realized how bad diabetes is…(ABY 12; aged 52)*

> *دیابت خطرناکترین اتفاق زندگی من بود ..مثل البته سرطان بود ...خطر ان در اول نبود ولی با مرور زمان مشکلات خود را نشان داده و من کاری نمی‌توانم انجام دهم .. یک حرکت آهسته به طرف مرگ است ...سال ها طول میکشد تا متوجه شوید چه قدر بد است*

For many, diabetes had not just changed their lifestyle; it had changed their personality and mood as well:

> *I am not the same person as before…I get angry very easy …intolerant, very sensitive…then my life is getting harder over the time…(ABY 10; aged 46)*
>
> *من همان قبلی نیستم... من خیلی راحت عصبانی میشوم. تحمل من کم است خیلی حساس شدم... زندگی من سختتر میشود به مرور زمان...*
>
> *Having diabetes caused too much trouble for me…it changed my body emotionally and physically…I was very calm person before and now I turn to a person with no tolerance and easily get angry. (ABY 13; aged 42)*
>
> *البته دیابت سبب دردسر های زیادی برای من شده است. تغییرات زیادی در جسم و روان من گذاشته است ...من فرد آرامی در گذشته بودم اما با مرور زمان با وجود دیابت به یک فردی که تحملم کم شده است و خیلی سریع عصبانی میشدم*

Overall these varied meanings changed over the course of their living with diabetes and were prevalent in the various phases they went through since being diagnosed with diabetes.

Chapter Summary

This qualitative study provided rich and meaningful information about Iranian Canadian women with type II diabetes who immigrated to Canada. My analysis led to a detailed and extensive understanding of how Iranian women who immigrated to Canada observed diabetes as a long-term illness, how they struggled through the early stage of diagnosis, and how they perceived it in their current situation. The stories these women shared with me revealed that their struggle to live with diabetes forced them to change every aspect of their lives and roles. Every life story was unique and acknowledged the importance of religion, culture and immigration experiences on diabetes self-management activities. Religious beliefs and activities ranging from fasting in Ramadan to participating in social events were integral to their coping with diabetes.

Women in my study went through different stages including (a) dark days of diagnosis - referring to shock and horror of diagnosis, (b) struggling to learn to live with diabetes, and finally, (c) finding their life path as a bumpy road or uphill battle. Going through these phases was not a straightforward process. As new and differing events occurred they would move back into earlier phases of their journey. Some were able to move forward again more quickly while others seemed to be stuck in this earlier phase as they had to take stock once again of the implications of these events on their life and how they needed to now re-define themselves. Different phases of their illness posed different challenges to the individuals but the majority of my participants perceived diabetes as a ball and chain through those phases. Moreover, diabetes for the majority my participants became an obstacle to a normal life. For a few of them, diabetes provided an opportunity for practicing a healthier lifestyle. Immigration added an extra layer of complexity and made it more difficult for them to access health care professionals and caused some degree of social isolation.

CHAPTER 5 - DISCUSSION

In this chapter, I present a summary of the study and its findings. I will discuss the wider outcomes of this research by drawing together the overall findings within the context of existing literature. I will assess the contribution of these findings to nursing knowledge and make suggestions for further research. I will end with the limitations and implications of the study. I have started my discussion according to the core concept of Meleis' transition theory (2010), as transition seemed to be the central idea underlying many of my participants' experiences and perceptions of diabetes.

The Journey of Living with Diabetes

In this focused ethnographic study, I examined the experiences and perceptions of Iranian women with diabetes who immigrated to Canada. The journey of living with diabetes for Iranian Canadian women implies stages and this is what I found in my study. There were two main interlinked journeys, their immigration journey and their diabetes journey. Immigration took them thousands of kilometers from their home country to a very different country geographically, physically, socially and culturally. Everything was different, from the language, to education and work systems, expectations and the health care system. All experienced some degree of culture shock, which brought them emotional and physical distress while they were settling into Canadian culture. The immigration journey also involved adapting and adopting some Canadian values and practices while preserving some of their own. Many sought the familiarity, cohesiveness, and support of the Iranian socio-cultural and religious community; this could present challenges as their diabetes meant they could not participate in the ways they previously could, or were traditionally expected.Although I learned about immigration journeys, I have focused on how it affected their diabetes journey.

Diabetes was a second journey, often one that was a complete surprise and that some women had difficulty in acknowledging. From the shock of their diabetes diagnosis, they travelled through “dark days of diagnosis” when the reality of diabetes threatened to shatter all of their expectations and hopes for the future. Some women had suspected the presence of diabetes for some time, based on their symptoms and family history. For others, it was an unexpected occurrence. For all, no matter their level of knowledge and familiarity, the medical diagnosis was a blow. Diabetes disrupted their lives. It fractured their understanding and confidence in their bodies, and de-stabilized their sense of identity. Universally recalled as a dark, stressful, frightening period of their lives; it was a traumatic time.

Over time, their paths reflected their struggle to live with their new situation, to find ways to integrate diabetes self-management into their lives, renegotiating roles and relationships within the family, with friends and their social communities. This path was difficult as they attempted to negotiate a largely unknown Canadian health care system in which the expectations and roles of health care providers and patients were very different, and which was further complicated by language and cultural differences. Later, as patterns of living with diabetes stabilized, they came to understand that while their lives were irreversibly changed, they had choices about which path to follow in living with chronic illness. In the last phase of their diabetes journey, the women gained a personalized knowledge and understanding of what living with diabetes meant for them. Very few described their current diabetes path as mainly smooth. Sometimes, they could care for their diabetes so that it could fade into the background and life was relatively easy. Other times, the diabetes life road became bumpy and unpredictable. When women encountered problems controlling their blood sugars, experienced new complications, or when other life goals took precedence, diabetes came to the foreground and dominated their daily life. These participants tried to control their blood sugar seriously and their families were ever-present in the process of diabetes management. They tried to learn more about the variety of meal plans. They also attempted to focus on the other parts of their life. They learned to live with their chronic illness by taking care of their bodies more efficiently, and learned as much as they could about controlling their blood glucose. Eventually their lives with diabetes would settle down and diabetes receded to the background in their daily lives.

The vast majority of my participants viewed life with diabetes as essentially difficult, unpredictable, consisting of endless uncertainty, and like an unending uphill battle. They struggled to adapt to the recommended diabetic lifestyle. These participants often tried to forget or ignore their diabetes. They believed that having diabetes meant weakness in their life and instead of attending to their bodies' needs, they tried to hide their condition. Hiding, however, tended to exacerbate their condition, which led to complications and thus they remained largely within the dark side of diabetes.

The phases of the diabetes journey were not linear. Participants crisscrossed from one path to another, often in conjunction with challenges in other areas of their lives. Sometimes an event or experience would form a "short cut" that would lead them back to an earlier phase or move them from a fairly straight path onto a bumpy and difficult path. Their cultural-religious backgrounds and immigration journeys strongly shaped how they experienced their diabetes journey, lifestyle behavior choices and relationships with others.

The two most important theoretical approaches that guided me through this study were (a) the idea of illness in the foreground/background based on the Paterson's (2001) shifting perspective model of chronic illness; and (b) the concept of transition as conceptualized in Meleis' (2010) transition theory. When I started my dissertation journey, I was more interested in the shifting perspectives model as a conceptual framework, but the research process and engagement with my participants' experiences led me to understand the totality of the diabetes and immigration journey as essentially a transition process. Although some of my participants did progress to a more or less balanced life, more described life as a bumpy road, therefore, the shifting perspective model remained useful to understand how these women continually shifted between diabetes in the foreground and diabetes in the background. On the other hand, many of my participants continually faced an uphill battle. This perception does not fit with the shifting perspective model. Transition theory seemed to be more applicable. This model can help us to understand there are many facilitators or inhibitors (transition conditions) such as religious and cultural beliefs, family and community support, and immigration challenges that affect how people gradually learn to live with diabetes. This study demonstrated the value of transition theory for providing an understanding of the nature, conditions, and processes of health-illness transition associated with diabetes as experienced by women in my study. In the following sections, I will discuss the study findings within the context of the existing literature based on transition theory.

Sequential Nature of Transition

Women in my study had undergone two major transitions, health/illness (having diabetes) and situational (immigration to Canada). Woven into my participants' stories were the interrelations and connections of multiple transitions. Health/illness transition in conjunction with situational transition created a multiple (complex) pattern that occurred over long periods for my participants. Figure 5.1 outlines the major concepts of the middle range theory of transition.

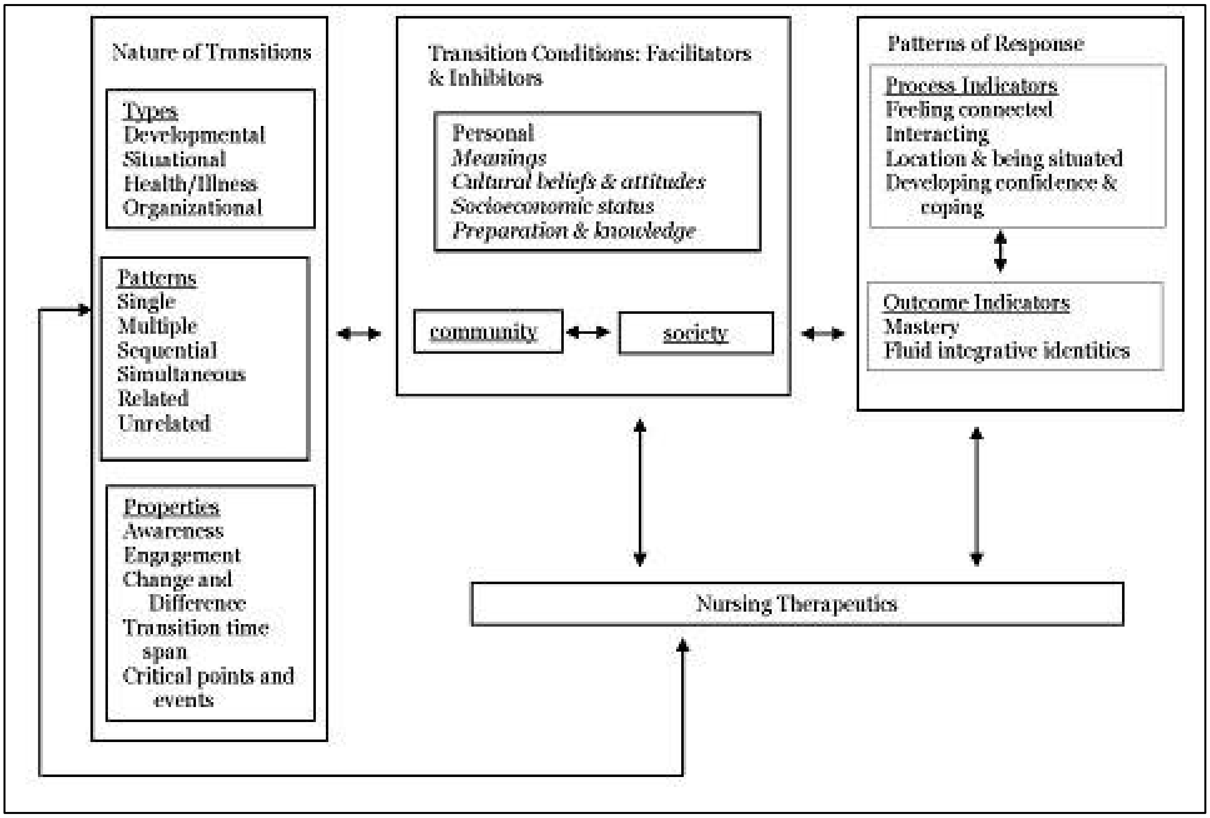

Figure 5.1 Transitions: A middle-range theory. Adapted from: Meleis, A.I., Sawyer, L.M., Im, E.O., Schumacher, K. and Messias, D.K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science, 23*(1), 17. Reprinted with permission.

Patterns of Transitions

Living with diabetes, like many other chronic illnesses, is a dynamic and complex process. Kralik (2002) believes living with chronic illness is considered complex because it generates changes in all aspects of the person's life; dynamic because it moves along time; and cyclical because it fluctuates and there are setbacks throughout the experience of living with it. In my study, it was clear that the majority of the women did not experience any effective progress in diabetes self-management for many years after diagnosis. Resistance and anger toward diabetes were the dominant attitudes and experience for my participants.

The notion of phases in learning to live with diabetes is not unique. My findings are congruent with several empirical reports that describe the complex trajectory of adjustment to live with chronic illness. Some studies in the literature indicate that people with diabetes go through sequential phases (Ambrosio et al., 2015; Lubkin & Larsen, 2013; Kneck, Klang, & Faqerberg, 2012; Jutterström, Isaksson, Sandström, & Hörnsten, 2012; Moser, Van der Bruggen, Spreeuwenberg, & Widdershoven, 2008; Kralik, Van Loon & Visentin, 2006). These phases generally start with shock at diagnosis, an extraordinary phase (Kralik et al., 2006) and then a phase in which people start to construct personal modes of illness and learn more about diabetes self-management. Finally, the last phase involves moving toward an “ordinary” state of being and incorporating their illness into their daily lives (Kralik et al.). The movement through these stages is not linear. Life for people with diabetes has a non-linear trajectory with cyclical processes that potentially recur throughout the course of life (Rayman & Ellison, 2004). Sometimes people regress in response to another change in their lives (Kralik et al., 2006; Jutterstorm et al., 2012). Kralik et al. (2006) also challenged the notion of linear trajectory in transition; in chronic illness, movement can be in many directions. Paterson et al. (2001) believed plateaus, peaks, and retreats characterize transformation (evolutionary activity that entailed responding to illness-related challenges). Retreat, in Paterson et al.’s research, does not mean regression or abandonment of the transformative journey; rather it is a fluctuation. They also indicated that having challenges in everyday life with diabetes was as an opportunity to learn and move forward.

Although my findings are similar to these studies, I also have a unique finding: the majority of participants in my study were "stuck" in the early phase of learning to live with diabetes for many years after diagnosis, or experienced recurrent returns to those early phases. Why women in my study reacted so individually, with the same cultural and religious background depended on many factors. These factors included her level of social support, level of education, cultural understanding of chronic illness, role alteration, religious interpretation, the meaning they associated with having illness, and lastly, the personality of the woman. When a woman in my study saw herself as a victim of the disease and felt unfairly treated by life, she experienced diabetes as a continuous struggle. When she also received less or no emotional support, the journey forward to a balanced life process was stagnated. She would be stuck in one stage for prolonged periods.

Properties of Transition

Transitions are complex and multi-dimensional, but they have several essential properties: awareness, engagement, change and difference, time span and critical points and events (Meleis et al., 2000). According to Meleis et al., these properties are interrelated parts of a complex process. The transition time span varied from a few months to years, with some women still not being fully situated or engaging in a diabetes management plan. Critical points and events leading to transitions, such as starting to take insulin and developing new complications, were evident in interview data. The most important properties of transition in my participants were what Meleis called "perceived changes and differences."

Perceived changes. Changes related to disruptions in relationships, routines, roles and responsibilities (Meleis et al. 2000). Based on my participants' experiences, they perceived diagnosis with diabetes and immigration to Canada as critical change events in their lives. The way the women in my study viewed changes related to the different transitions (health/illness and immigration) is the central concept of change in transition theory. The women viewed living with diabetes differently, such as "uphill battle" or "bumpy road." Changes in their roles, responsibilities and obligations in response to diabetes was quite challenging for the women in my study. Many researches (Atsednesh, 2014; Lawrence, 2012) address these changes. Lawrence mentioned people with chronic illness feel guilty about the demands it places on family and resent the change in roles and responsibilities caused by the limitations imposed by the illness. Forming meaningful relationships with family, friends and community members is essential to the women's management of transition (Rasmussen, O'Connell, Dunning, & Cox, 2007). Some women in my study perceived that self-management activities required a lot of time and energy; therefore, it hindered and changed their familial roles and responsibilities. This issue was also one of the main complaints in Swedish with type II in Hörnsten et al.'s study (2004). Constant, recurrent, and/or unpredictable episodes of hypo or hyperglycemia often caused feelings of loss of control for the women who were stuck in an earlier stage of their journey with diabetes (Rasmussen et al., 2007). Diabetes' chronic complications also caused people with diabetes more difficulty fulfilling their everyday roles and responsibilities within and outside the family structure (Rasmussen et al). Some of my participants felt inadequate to perform their roles and responsibilities as a mother, wife or community member. Diabetes put personal and social relationships in danger and led some women in my study to live in isolation. Macaden and Clarke (2015) also found that participants in their study felt inadequate for everyday roles and responsibilities. Women in their study were not able to exercise due to their roles and associated responsibilities as wife and mother and cultural expectations.

Personal relationship difficulties. When individuals with diabetes felt supported and engaged in meaningful relationships, they were capable of, and resourceful in, managing diabetes during transitions (Rasmussen et al., 2007). Some women in my study talked about frustration in their personal relationships. This was specifically relevant when describing tensions in relationships with current or previous partners. Tensions arose about partners' difficulties in accepting the illness, sexual intimacy, frustration with limited and structured diabetes meal plans. Many of the women experienced more than one of these difficulties. Some common challenges in roles and responsibilities are also mentioned in Murray, Kelley-Soderholm and Murray (2007), including tension in family relations, time management struggles, disrupted family activities, disconnection from social networks. Women in my study also believed when they moved to Canada they had more responsibility toward educating their children based on Islamic principles and their maternal language (Farsi). However, with diabetes they felt that they would not have enough time and energy to fulfill this important role. For many of my participants, it was a choice between paying attention to diabetes self-management and attending to their children's religious and cultural education. Changes in roles and responsibilities, feelings of vulnerability and loss of control in people with chronic illness are common themes in the diabetes research (Millen & Walker, 2000; Murray et al., 2007; Majeed-Ariss, Jackson, Knapp & Cheater, 2015). Chronic illness can affect many areas of family life, such as, daily routines and friendship relationships (Majeed-Ariss et al., 2015). Like some women in my study, if the family views diabetes as an obstacle in family relationships, the relationships may weaken and the negative effects of stress can accumulate and negatively affect diabetes self-management (Murray et al., 2007).

Social relationship difficulties. As my participants shared their life stories, it emerged that they were concerned about their involvement in the public domain. These concerns touched upon their sense of identity of living with diabetes and its impact on their work, participation in social activities, Islamic and cultural feasts, and stigmatization, especially when chronic complications appeared. Some women who worked carried constant fear of having a hypo- or hyperglycemic episode. As a result, they often avoided engaging in social activities with their colleagues. Some women said they did not want to engage in community events because of social norms that required them to participate in preparing and eating the variety of foods served and staying up for a long time. Suhl and Bonsignore (2006) among others has described this fear of having short-term complications (hypoglycemia) and social isolation.

Confronting differences. Confronting differences is another property of transitions. Feeling different with diabetes as well as differences in food, health care systems, and language are different aspects of perceived difference (Meleis et al. 2000). For my participants, the difference between health care systems in Iran and Canada was the major divergent experience. In Iran, people with diabetes directly interact with Endocrinologists, but in Canada, family physicians are in frontline contact for diabetes care. Many researches have addressed confronting differences, including cultural health practices, language, health care system and social support networks (Lassetter & Callister, 2008; Messias, 2002; Messias & Rubio, 2004). Meleis (2000) suggested perceived differences sometimes result in changing behaviors and indeed, the women in my study responded in a variety of ways according to their perceptions of these differences. Some did not accept the differences and did not change their behavior. According to Bergmark, Barr and Garcia (2010), Mexican immigrants are drawn for health care to where the language is familiar and they can have more time with physicians. In a study by Lee, Kearns and Friesen (2010), part of the difficulty in providing care to Koreans immigrants is that they continue to have the same expectations of health care as they had when in their home country. These differences had significant impact health-decision making processes. In summary, relationship alteration and perception of differences are unique in each person with diabetes and could affect a person on many levels.

Transition Conditions

The second dimension of transition is “transition conditions” that include the inhibitor and facilitator factors for transition processes. According to Schumacher & Meleis (1994), transition conditions are those circumstances that influence the way a person moves through a transition and that facilitate or hinder progress toward achieving a healthy condition. Meleis et al. (2000) believes in order to understand the experiences of our clients during transitions, it is essential to explore more about the personal and environmental conditions that facilitate or inhibit a smooth and healthy transition. According to this theory there are some conditions that facilitate or constrain the transition process exist at the personal, community or society levels. Considering a factor as a facilitator or inhibitor to diabetes self-management varies for each person. In the following section, I will discuss these conditions that emerged as significant for the women in my study and explore the extent to which my findings reflect transition conditions in extent literature.

Personal conditions. Personal conditions include meanings, cultural beliefs and attitudes, socioeconomic status, preparation, and knowledge (Meleis et al., 2000). The most important personal conditions in women in my study were meanings of health and illness, cultural beliefs and attitudes, and the role of Islamic beliefs.

Meaning. Perception and meaning of health and illness are influenced by, and in turn influence, the conditions under which a transition occurs (Meleis et al., 2000). Diabetes had different meanings for my participants. A number of participants described diabetes as a “ball and chain” that they will never escape. A number of other researches have also indicated that individuals with diabetes feel they are deprived of a normal life (Abdoli, Abazari & Mardanian, 2013). The results of a study on the public perception of diabetes in Kenya showed 51% of the community's population had negative views about diabetes (Kiberenge, Ndegwa, Njenga, & Muchemi, 2010). The presence of negative attitudes is evident in another study carried out on Appalachian population in United States. (Tessaro, Smith, & Rye, 2005). On the other hand, a study by Yamakawa and Makimoto (2008) indicates Japanese people with diabetes considered the disease a positive alteration and an opportunity to enjoy a new social network as well. When individuals hold a positive attitude toward their illness, self-efficacy can increase and they can make positive life changes to manage their diabetes (Tol, Alhani, Shojaezadeh, Sharifirad, & Moazam, 2015).

Self-efficacy was the main indicator in personal conditions in my participants. Perceived efficacy in particular, is a powerful construct that plays a major role in explaining how people think, feel and act (Bandura, 1997).

Self-efficacy. The role of self-efficacy has a strong influence on personal meaning of health and illness in individuals with chronic illness (Bandura, 1997). The sense of self-efficacy reflects the individual's belief in his/her own skills to plan and perform certain activities to attain particular aims (Keedy, Keffala, Altmaier, & Chen, 2014). Self-efficacy is a cognitive construct implicated in initiating and maintaining self-management activities and moving persons forward in their lives after diagnosis and it this was evident in the story of my participants (Bandura, 1997). Self-efficacy refers to a "person's subjective estimation that he or she is capable of engaging in a particular action in a particular situation" (Bandura, 1997, p. 201). Self-efficacy is linked to better health, higher achievement, and more social integration (Bandura, 1997) as well as adhering to healthy habits (Sacco et al., 2005). Self-efficacy theory also is able to explain why some of my participants were successful in diabetes self-care management behaviors and able to move forward in their lives. It provides a suitable framework for understanding and predicting commitment towards self-care behaviors and effectiveness of self-management behaviors such as diet, exercise and foot care (Al-Khawaldeh, Al-Hassan, & Froelicher, 2012; Knight, Dornan, & Bundy, 2006; G. Kim, Shim, Ford, & Baker, 2015; Maddigan et al., 2004; Sarkar, Fisher, & Schillinger, 2006). Once diabetes self-care management has begun, persons with high self-efficacy invest more effort than those with low self-efficacy (Bandura, 1997). There are many factors such as cultural gaps, immigration challenges and inadequate support from social groups (family, community or friends) that may also contribute to lower self-efficacy, such as seen in the experiences of my participants. My findings are similar to those in many studies (Ambrosio et al., 2015; Majeed-Ariss et al., 2015). Overall, we need to understand what a chronic illness means for each client. Partnership between people with diabetes and health care professionals across the illness trajectory, in accordance with the demands of each phase and unique needs of individuals, is crucial for increasing self-efficacy.

Religious, cultural beliefs and attitudes. Religious and cultural beliefs and attitudes were an important transition condition for the women in my study. Care and health situations differ as they were shaped by people’s cognitions, values, and practices among different cultural groups (Leininger, 1978). Thus, religion and culture play a pivotal role in how health and illness come to be understood (S.Shaw, Huebner, Armin, Orzech, & Vivian, 2009). As Lupton (1994) stated, “health and illness do not have a universal meaning as located within the biomedical model; instead, it is made meaningful within the logics of culture and religion” (p. 36). Several studies have illustrated how cultural and religious beliefs might affect the perception, interpretation, experience and self-management behaviors in people with chronic illness, especially among ethnic migrant groups (Abdulrahim & Ajrouch 2010; Boggatz et al., 2010; Carbone, Rosal, Torres, Goins, & Bermudez, 2007; Daniulaityle, 2004, Rosal et al., 2011; Thomas, 2003).

In the following sections, I will elaborate upon the effect of religion and culture on the transition process. Although there is a considerable overlap between religious and cultural concepts in Iranian belief systems, I will try to discuss these two aspects independently.

Religious conditions. In my study, Islam was practiced by almost all of my participants, with the exception of one, who was Zoroastrian. There were some participants who did not practice some aspects of Islam in their everyday lives. For example, they did not wear Hijab, practice daily prayers, or fast during Ramadan. The practicing Muslims in my sample perceived that Islamic beliefs and values influenced decision-making and self-management activities in different ways for my participants. Religious practices and spiritual experiences were respected by all of my participants.

My participants' quests for religious and spiritual belief and meaning were manifested in different ways through their diabetes journey. Each individual woman's unique journey was influenced by how she conceptualized and lived Islamic/religious roles and obligations, which were, in turn, influenced by each of the participants' social and cultural context. Religious practices have both positive and negative effects on health behaviors (Bai, Chiou, & Chang, 2009; Barnes et al., 2004; Lunsberg & Thrakul, 2013; Nam, Janson, Stotts, Chesla, & Kroon, 2012; Polzer & Miles 2007; Zwingmann et al., 2006). For some of my participants, Islamic beliefs were a source of hope and a motivator to continue life with diabetes. For others, these beliefs fostered more passive behavior in diabetes management. Religious and cultural beliefs and obligations may also affect the level of adjustment to diabetes self-management (Lu, Lum &

Chen, 2001; Wilkinson & Whitehead, 2009) and in my study were a significant influence on whether or not self-care activities were undertaken.

Islamic beliefs as a source of power and motivation. Religious beliefs has an important effect on the sense of self-fulfillment, happiness and self-esteem, finding meaning and strength to better cope with diabetes and facilitate self-management behaviors (Carbone et al., 2007; Hjelm & Mufunda, 2010; Lunsberg & Thrakul, 2013). This group of women in my study believed illness was either a test fromGod or their destiny. According to their Islamic beliefs, they were always responsible for taking care of their bodies in illness or wellness, and diabetes self-care management was meaningful for them. They believed that according to Islamic roles, being a patient does not mean not taking action. Based on many hadith (Traditions of Prophet Mohammad) Muslim people are encouraged to seek for a cure through both natural and spiritual means, as their effects are interrelated. One of these hadith indicates, "There is no disease that Allah has created except that He also has created its remedy" (Bukhari, p. 582). Lowenthal, Cinnirella, Evdoka, & Murphy (2001) argued that Muslims tend to believe – more than any other religious group – in the efficacy of religious coping mechanisms for illness. Muslim people with chronic illness in different studies, including mine, directly and indirectly pointed to this part of Quran:

> "…And on the Day when the Hour will be established, that Day shall all (men) be separated… for those who believe (in Allah) and did righteous good deeds such shall be honored and made to enjoy a luxurious life (forever) in a Garden of Delight (Paradise)." (Quran, 30, Verses, 14)

These women viewed their diabetes as God's will. Therefore they expressed acceptance of the illness and less self-blame, which consequently, lead to better self-care management outcomes. This group of women believed God commands them to pray, as everything was in

God's hand. However, they believed they should behave as if everything was in their own hands, for example, they assumed the capacity for self-management.

Other researchers have also indicated religious beliefs give people with chronic illness some hope to move forward. Belief in God in every aspect of illness is not exclusive in Muslim people with chronic illness. Belief in God's will (which implies a relationship with God) is evident in other cultures. A study by Polzer and Miles (2007) about African-Americans living with diabetes revealed the importance of God in everyday life for their participants. Dalal (2000) showed that patients in Indian hospitals consistently attributed their illness to karma and God's will. Belief in destiny or God's will and belief in the healing power of prayer is evident in many other studies (Murguía, Zea, Reisen, Peterson, 2000; Rippentrop, 2005; Wiech et al., 2008; D. Anderson & Christison-Lagay, 2008). Abdoli et al.'s study (2008) in Iran with people with diabetes also indicates that religious beliefs have a powerful influence on self-management behaviors and gives people the inner strength to take responsibility for their diabetes. Iranian people, in their study, indicated that their body was a "divine gift from God; therefore, they had an obligation to look after their body" (p. 449). Abdoli et al. (2008) concluded religious beliefs in Iranian people provided some facilitators to empowerment, such as believing diabetes was God's plan for them (God's will), their faith gave them the inner strength to accept their diabetes. In another attempt to describe beliefs about chronic illness, Hjelm et al. (2003) indicated that understanding cultural and religious attitudes is essential for understanding self-care practice and care seeking behavior in individuals living with chronic illnesses.

Moreover, religious beliefs can help individuals to construct a new view of their lives with a chronic illness (E.J.Taylor, 2002). For two women in my study, religious beliefs provided a crucial element for happiness and good emotional and mental health. Belief in Islam provided meaning for every bad or good event in their lives. Prayers and reciting the Quran as part of Islamic faith had an important effect on their mental and emotional well-being. The majority of my participants did experience this feeling after prayer and participating in religious programs, and it supported them to continue self-care management activities with new hope. The Quran also affirms, “Verily in the remembrance of Allah do hearts find tranquility” (Quran, 13, Verse, 28). These women felt that reciting the Quran had a good effect on their positive thinking and helped them to struggle with any side effects of having diabetes -by fostering a sense of being strong-and becoming more relaxed.

A number of studies have specifically examined how commonly religion is used as a coping mechanism in chronic illnesses (Baesler, 2012; Wachholtz & Sambamoorthi, 2011). Religion and prayer are common resources that exert beneficial effects on adjustment to chronic illness (Gall & Grant, 2005; Yeung & Chan, 2007). Studies by Dalal (2000) and Mok, Martison, & Wong (2004), also indicate that religious beliefs give people with chronic illness the strength to endure suffering and most Muslim clients found relief when they engaged in prayer and having a relationship with God. They found it uplifting and that it enhanced their ability to cope with and accept chronic illnesses. This group of my participants also believed they might see a healthy future, despite their chronic illness. These participants’ statements echo several components of empowerment that are also noted in the literature, such as active participation in diabetes self-management (Baumann & Dang, 2012; Gallant, Spitze, & Grove, 2010; Dalal, 2000). A study by Vonarx and Hypolite (2013) revealed religious beliefs allowed people to hope, to develop abilities and skills in their fight against cancer, and to actively participate in the resolution of the problem. They found spirituality and religion became useful for people with chronic illness to shape the meaning given to the illness.

Although religious beliefs and practices have largely been shown to facilitate healthier behaviors and more positive health outcomes (Abdoli et al., 2011; Wachholtz & Sambamoorthi, 2011; Zwingmann et al., 2006), one should also be attentive to the potential negative aspects of religious belief on diabetes self-care management activities. In my study, personal religious beliefs could be used to justify more passive self-management. It appeared that religious beliefs could lead to a sense of disempowerment for some of my participants.

Islamic beliefs grounds more passive behaviors. Certain religious beliefs or cultural customs may inhibit health care utilization and health care behaviors, leading to poor health outcomes. Sometimes beliefs lead people to feelings of abandonment and helplessness and encouraged them to passively accept their illness. The belief that diabetes was caused by supernatural sources, such as God's will or the evil eye (Vaughn, Jacquez, & Baker, 2009) is widely held among various cultures, primarily in West Asia, but also in Greek and Iranian cultures. Overall, the most common cause of illness identified by the women in my study was God's will. This group of women did not follow their physician's advice regularly. Qada' and Qadar (destiny and divinity) had strong positions in the values and beliefs for this group of women. Most of these women recited this part of Quran: "Nothing shall ever happen to us except what Allah has ordained for us" (Quran, 9, Verse 51).

They perceived diabetes as a test from God and it was under God's control. Therefore, they had limited control over it, so diabetes self-care management did not have much meaning for them. Some of my participants said, "If it's time for me to die, there's nothing I can do about it." They often paid little attention to their meal plan and did not attend follow up appointments. They were uncertain about their present and future. When complications appeared, they were more susceptible to passiveness, depression, despair, and feelings of powerlessness around controlling their blood glucose. Some researchers have shown that culturally, some people with chronic conditions often believe that once they feel better their diabetes or hypertension is cured and they can discontinue treatment (Baumann, Opio, Otim, Olson, & Ellison, 2010). Ow and Saparin (2014) discovered that depending on the degree and level of faith, Malaysian people with chronic illnesses may have to struggle and clarify the apparent polarity between human efforts and Qada' and Qadar in everyday events, especially difficult events.

This behavior is considered an inhibitor to participation in health promotion programs and health care utilization (Plante & Sherman, 2001; Powe & Finnie, 2003; Straughan & Seow, 2000) and the transition process. It is a manifestation of Fatalism in which all events are predetermined and beyond the person's control. (Powe & Finnie, 2003; Straughan & Seow; Sharf, Stellies & Gordon, 2005). The concept of fatalism is also related to the locus of control-LOC- and attribution style. It can be defined as "non-behavioral explanations of the cause and distribution of illness and death" (Davison, Frankel, & Smith, 1992, p. 680). In my study, women who endorsed fatalistic beliefs about their illness were less likely to follow health care professional recommendations. Diabetes fatalism is an important psychosocial construct to consider when designing interventions, and patients exhibiting this life outlook may benefit from targeted interventions (Walker et al., 2012).

Another subject related to Islamic beliefs was fasting during Ramadan. Although individuals with diabetes are exempt from fasting (Quran, 2, 183-185), many still wanted to fast which could cause problems with glycemic control. Muslim people believe that fasting is the best spiritual practice and the majority of my participants wanted to fast even when they were not in a suitable physical condition to do so. Some of my participants articulated they were uncomfortable during Ramadan because nobody ate except for them, or that they perceived others felt pity if they did not fast. They believed health care professionals needed to be aware of this religious obligation and direct them appropriately. Women with type II diabetes in Aghamohammadi-Kalkhoran, Valizadeh, Mohammadi, Ebrahimi and Karimollahi's study (2012), experienced sadness because of their inability to perform religious duties, such as fasting. From their participants' perspective, praying and fasting were the only things they could do to thank God. This was one of the clearest indicators of how religious belief systems coincide with social systems to reinforce expected norms and values in behaviors. Overall, people look at Islamic beliefs with different perceptions. Considering the complexity of spirituality and religious beliefs and attitudes is essential for high quality care.

Cultural conditions. Many studies have explored how culture influences diabetes self-management progress (Fleming, Carter, & Pettigrew, 2008). I discovered Iranian culture and Islamic beliefs in my participants were not homogenous, but diverse, and it was impossible to map specific beliefs and behaviors for all women in my study. In the following sections, I will discuss different aspects of cultural conditions in terms of how they influenced transition processes in my study.

Stigmatization and hiding the illness. Stigma is a universal phenomenon and has received substantial research attention in medical conditions such as obesity and diabetes (Schabert, Browne, Mosely, & Speight, 2013). When an individual is regarded as different from the norm within a specific social context, they may experience stigma (Major & O'Brien, 2005). Stigma is a negative social label that associates a person to a set of unwanted characteristics that other people use for individuals with a different physical, mental or social character (Jacoby, Snape, & Baker, 2005). It is a serious threat to their view of having chronic illness and social identity (Schabert et al., 2013). Stigmatization can also make people unwilling to open up about their condition, which can have a profound effect on their health and wellbeing (Quinn, 2012). According to the literature, a group of people with diabetes may choose to eat or drink some itmes that they know is harmful for them just to avoid being different from their peers. Some of my particiapnts also mentioned a smilar situation (Earnshaw & Quinn, 2012; Shiu, Kwan, & Wong 2003; Singh, Cinnirella, & Bradley, 2012). The treatment for diabetes, such as meal plans or medications, can also compound this sense of stigma (Nash, 2013). People who perceived stigma, described strong feelings of low self-worth, low self-esteem, self-blame, unwillingness to disclose conditions, emotional distress, suboptimal self-management and ultimately poorer physical health outcomes (Abdoli et al., 2012; Browne et al., 2015; Chatterjee & Biswas, 2013; Rasmussen et al., 2007; Schaber et al., 2013; Smart & Wegner, 2000; Teixeira & Budd, 2010; Wellard, Rennie, & King, 2008). The adverse effects of stigma for my participants that are reflected in other works included: delay or avoidance in seeking medical treatment, early treatment discontinuation, poor quality of care, and increased mental illness (Drury & Louis, 2002; Earnshaw & Quinn, 2012; Schabert et al., 2013).

Stigma is also relative and considering people as unusual or normal is different in every culture. Individuals also handle stigma differently. According to Goffman (1963), some people make special efforts to compensate for their stigma, such as drawing attention to another area of their body or life, or they use their stigma as an excuse for their lack of success. Sometimes people with chronic illness hide their illness to minimize the effect of stigmatization around other people. Hiding the illness can lead to further isolation, depression, and anxiety, ignoring symptoms, skipping medications (insulin in particular), failure to follow recommended treatment, acute complications such as diabetic coma, and eventually isolation (Abdoli et al., 2012; Corrigan, Druss & Perlick, 2014). Women in my study tried to hide their diabetes to avoid unnecessary attention from others in social gatherings. There are many studies diabetes-related stigma that provide similar examples of these reasons (Shiu, Kwan &Wong, 2003; Singh, Cinnirella & Bradley, 2012; Wellard, Rennie, & King, 2008). Hiding diabetes with the threat of being found out also has risks. Charmaz (1991) believes risks include being rejected and stigmatized, having difficulty handling the responses of others, and losing control. Unwillingness to disclose diabetes to others is potentially dangerous and caused some medical emergencies for some of the women in my study. An unwillingness to disclose also caused delaying their oral medications or insulin, eating under social pressure and not measuring their blood glucose levels. A study by Nam et al. (2013) revealed social stigma and hiding the illness among immigrant Korean-Americans with type II diabetes. Most of their participants were reluctant to disclose diabetes because of social stigma and said that they did not know much about diabetes and its complications. Hiding the illness equaled less self-care activity and social isolation in their participants. This is a concern, since research has consistently shown that social isolation is negatively related to impaired self-care management in people with diabetes.

The source of social stigma of type II diabetes arises from media, health care professionals, and family and friends (Browne, Ventura, Mosely, & Speight, 2013; Wingert, Johnson, & Melton, 2015). Helman (2007) points out that how a disease is perceived in society depends on its recognition as being something abnormal. The women in my study complained about the way media presents diabetes. They believed that media always connects diabetes to blindness and other negative complications. According to Abdoli et al. (2012), the Iranian population gets most of its information about diabetes and its complications and limitations through media, such as TV advertisements and daily articles in newspaper and that what the public knows about diabetes is negative and destructive. My study and similar research indicate that diabetes complications, such blindness, kidney failure, and amputation, can have an effect on how the public views those living with diabetes (Abdoli et al., 2012; Abdoli et al., 2013; Pujilestari, Ng, Hakimi, & Eriksson, 2014). The results of my study also illuminated how the perception of a restricted life, with greater focus on treatment and meal plans, caused some women to become hypersensitive to potential stigma, moving them towards social isolation. This was especially apparent in those who were taking insulin. My participants had different explanations and perceptions of diabetes, and their responses suggested the existence of a negative image of diabetes in Iranian culture. The results of my study highlighted: feelings of fear, the perceived need to enforce social norms, experiences of being judged and rejected, and the perception that they were mistaken as drug users. Many felt that others blamed them for causing their own condition. They experienced feelings of social stigma causing constant stress and sub-optimal self-management activities. According to Goffman (1963), hiding their diabetes or refusing to talk about it, can create constant stress because of worry about the risk of discovery and the embarrassment of being caught. This problem is also identified in many other studies with people with diabetes from different cultural backgrounds (Abdoli et al., 2012; Wingert, Johnson, & Melton, 2015). In particular, studies on Middle Eastern people, both men and women, showed that having diabetes is associated with stigma, shame and embarrassment (Khoury, 2001). Interestingly, people who do not have diabetes do not consider it a stigmatized condition, but people who have diabetes feel judged and constantly monitored (Schabert et al., 2013).

The stigma surrounding diabetes in some women in my study was a major barrier to seeking medical help, especially during the earlier stage of diagnosis. These women compared diabetes to cancer and avoided talking about it with strangers in social gatherings. They felt they were abnormal and tried to act “normal” and eat whatever they thought socially appropriate in social and cultural gatherings. They even concealed their glucometer and blood sugar logs in public places. Women in my study felt embarrassed and awkward when they needed to eat while nobody else was eating, particularly in Ramadan when the social norm is to fast. Some of them explained they had a sense of separateness because of their need to make different dietary choices than the rest of the family, and if they needed to perform self-care management activities in front of others, such as using a glucometer. They believed they did not have a “real life” by having diabetes. To these women, they merely had “an existence.” Some women believed their life would never move to wellness; their situation would only worsen, moving towards more complications or even early death. Although women in my study were surrounded by a large Persian community, the majority of them felt isolated. The findings of my study, along with other studies, highlight the role of cultural beliefs and norms in creating and promoting diabetes-related stigma (Aikins, 2006; Sato et al., 2003; Schabert et al., 2013). Iranian cultural and social values, expectations and norms, and some immigration issues, made the experience and fear of stigma worse for some women in my study for the following reasons:

(1) Many social and cultural feasts through the year meant they felt more distance from their friends.

(2) In Iranian culture, refusing food as a guest is considered impolite or rude. Thus, my participants tried to avoid participating in social events. They experienced difficulty in declining offers of sweets when they were guests in other people homes or at community events.

(3) In conjunction with immigration, they perceived restrictions in job opportunities and fear of losing their job.

> In my study, some women hide their illness from their employers because of fear of social stigma. They believed having diabetes meant having an unpredictable life and they would not be considered fit to hold any formal employment. These women did not want diabetes to affect employment opportunities. Although employers and others are not permitted to discriminate against people with diabetes, sometimes it occurs because of a lack of correct information about diabetes or assumptions made about diabetes (Canadian Diabetes Association, 2015). Unfortunately, perceived or experienced stigma is also evident in other research (Agerstrom & Rooth, 2011; Shiu, Kwan, &Wong, 2003).

Self-blame was another negative aspect of stigma and can also lead to guilt. A common experience for women in my study was self-blame and looking for the reason for having diabetes (individual factors or supernatural features). They commonly identified behavioral habits such as eating too many sweets in the past, being less active compared to their previous habit in Iran, obesity, family history of diabetes or having too much stress due to immigration as causal factors. Many researches have conceptualized self-blame as a coping mechanism (Klein, Turvey, & Pies, 2007; Voth & Sirois, 2009) or maladaptive behaviors to manage the chronic illness (Browne, Ventura, Mosely & Speight, 2015; Plaufcan, Wamboldt, & Holm, 2012; Singh, Cinnirella & Bradley, 2012). Considering self-blame as a maladaptive or as a positive coping mechanism is dependent on the individuals' perception of diabetes. Self-blame can be a positive coping mechanism when the individual puts in extra effort to assume control over the condition. On the other hand, when people with diabetes focus on things they could have done to prevent it, it is considered a maladaptive behavior (M.Clark, 2004). Overall, understanding the cause of the illness and developing an insight into the implications of the illness gives the illness meaning. A sense of meaning contributes to the process of coping and adapting to the transition process in the diabetes journey.

Labeling. According to Ogden and Parkes (2013, p.80), labeling someone as diabetic “positions diabetes as the defining factor of their life”. It also increased stigmatization (Schabert et al., 2013). The experience of stigma, dislike of being labeled and hiding or ignoring any visible or invisible disability, is common to many cultures. There is a relationship between the concept of stigma and the decision to disclose or hide diabetes based on individuals’ own understanding of diabetes. Women in my study expressed their frustration of being labeled as “diabetic.” Experiencing stigma and hatred at being labeled may be explained through the “labeling theory” by Goffman (1968). Goffman defined stigma as “the situation of the individual who is disqualified from full social acceptance and any attribute that is deeply discrediting” (p. 126). When a disease label is attached to a person, the very label itself has the power to “spoil the sufferer's identity” (Goffman, 1968, p. 126), both personally and socially. The social stigma that results from this labeling process can significantly change a person’s self-identity. Lack of confidence in self-care management skills, isolation and withdrawal from social life, restriction of activities and social roles can be explained with labeling theory. The power of labeling was quite significant for some of my participants. Once an individual had been diagnosed, they perceived themselves as a “diabetic patient” (مریض دیابتی) or “insulin patient” (انسولینی). They often felt stripped of their old identity and with a new one, stigmatization followed. The impact of labeling and its consequences for stigmatization can be represented as a negative feedback in everyday activities, which results in greater reduction of social participation. The harmful effects of labeling (negative attitudes toward diabetes; low self-esteem and social isolation), have been addressed in people with diabetes in many studies (e.g. Abdoli et al., 2012; Pujilestari, Ng, Hakimi & Eriksson, 2014).

As a result, stigma, self-blame, hiding or disclosing illness' symptoms are part of social and cultural understanding and it is essential to consider them in our care plan for people with chronic illness. Although the majority of research has focused on the negative effects of diabetes on social and personal identity, there are some studies that explored the existence of positive experiences of having diabetes (Choe, Padillla, Chae, & Kim, 2001; Koch, Kralik, & Taylor, 2000; Yamakawa & Makimoto, 2008). For this group of people, having diabetes is an opportunity to improve their relationship with family and friends, increase social networks and enjoy a healthy life. The positive or negative experience of having diabetes depends on the individuals' beliefs about health, personality characteristics, and cultural contexts (Yamakawa & Makimoto). My study highlights the mostly harmful role of stigma in diabetes self-care management process and quality of life, because most of my participants felt helpless in the face of diabetes within the context of their social and cultural norms. By exploring stigma in our clients, we can increase the outcomes of self-care management behaviors in our educational programs by developing more positive identities (Quinn, 2011), undermining the legitimacy of stigma (Abu Hassan et al., 2013), providing a supportive environment and making opportunities for the necessary discourse to facilitate implementation of lifestyle changes, while reducing stigma (Corrigan & Wassel & Rafacz, 2008). Encouraging empowerment among people living with chronic illnesses may help to reduce internalized stigma and improve their outcomes (Earnshaw & Quinn, 2012; Rüsch et al., 2005; Schabert et al., 2013). Therefore, our thoughtful interactions with our clients with diabetes can improve coping strategies, increase a sense of self-efficacy and through this, mitigate the effects of stigma (Abu Hassan et al., 2013). Health professionals need to address the understated distinction between taking personal responsibility for diabetes self-care and blaming themselves for causing diabetes, diabetes complications or uncontrolled blood sugar (Browne, Ventura, Mosely, & Speight, 2013).

Overall, a holistic understanding of diabetes related stigma, by focusing not only on the perceptions and experiences of stigma, but also on the causes of stigma, is essential to identify the potential strategies to support self-management. In my study, one of the significant sources of diabetes-related stigma originated in the social norms and expectations related to cultural and religious ceremonies and feasts.

Feasts and social functions. Food, especially traditional Persian foods, were an important part of socio-cultural life for my participants, and the associated cultural significance of food for Iranian people can make dietary changes difficult to sustain. Dietary restrictions often made the women in my study feel uncomfortable at social events, as they had to decide whether to accept offered foods that were not healthy choices. The traditional Iranian diet, like the diets of the many Asian cultures, is often characterized by high fat, carbohydrate content including white rice and sweets. Cultural and religious feasts are an essential feature in many religious and social groups, and participating in ceremonial feasts is a key component in maintaining ethnic identity (Scott, 2015; Tripp-Reimer, Choi, Kelley, & Enslein, 2001; Wellard, Rennie, & King, 2008). My participants reported feeling embarrassed when turning down offers of a variety of sweets in Iranian Feasts. Most of these events were accompanied by the provision of high calorie celebratory foods, which are prohibited on diabetes self-management plans. They also experienced feeling judged about their food choices by other people who were unaware of their diabetes and dietary needs in any private or public parties. Other researches have also reported perceived judgments of others about their food choices in social situations and the negative impact upon their self–management choices (Browne, Ventura, Mosely, & Speight, 2013; Wellard, Rennie & King, 2008). Some of my participants developed their own strategies to overcome food barriers in social situations, for example, they accepted very small portions of their favorite foods in Persian feasts.

Overall, feasts and social functions were significant barriers to diabetes self-management and transition processes. In my study, my participants did not have enough knowledge about food exchange lists or about how to adjust their medication in special situations. For example, they did not know how to increase insulin when they ate too much. By addressing these issues in diabetes education plans, we can help individuals with diabetes to participate in feasts and social activities with greater knowledge and confidence.

The role of family and social support. Close relationships and social support are universal needs of all people, regardless of culture (Ryan, La Guardia, Solky-Butzel, Chirkov, & Kim, 2005). There is clear evidence in research that individuals are able to achieve optimal psychological well-being when they have strong, supportive relationships with family and friends (Diener & Seligman, 2002; Gallant et al., 2007; Uchida, Kitayama, Mesquita, Reyes, & Morling, 2008). Given the strong role of the family and social group, it is particularly critical in diabetes self-management (Falvo, 2013; Rosland, Heisler, & Piette, 2012).

There are cross-cultural differences in perceived social support. It is clear that levels of subjective well-being differ significantly cross-culturally (Suhail & Chaudhry, 2004; Uchida et al., 2008). Cultural values and practices, and family ties may affect self-care and glycemic control in some cultures (Sukkarieh-Haraty & Howard, 2015). Sometimes high levels of family or social support can lead to better managed diabetes, although in other research, those with less family or social support tended to have more control over their diabetes (Sukkarieh-Haraty & Howard).

Family support and its relation with diabetes self-management is a common issue addressed in research (Chew, Khoo, & Chia, 2015; Gallant, 2003; Goetz et al., 2012; Herpertz et al., 2000; Pruitte & Epping-Jordan, 2008; Van Dam et al., 2005). Ethnicity, cultural context and religious beliefs play strong roles in family relations and the relationship between family and friends, and thus diabetes self-management (Becker & Newsom, 2005; Gallant et al., 2010; Wen, Sheperd, & Parchman, 2004). In many cultures including Iranian culture, the family plays an important role for all of its members (Brannan, Biswas-Diener, Mohr, Mortazavi, & Stein, 2013; Mortazavi, 2006). The value of the family is highly significant to health status in Iranian people because the family makes many decisions, including those around individual health care. Many researchers have suggested that support from family and friends can impact positively upon health outcomes, such as engaging in glucose monitoring, giving direct help with medications, healthier eating habits, increased physical activity, and offering understanding (Gallant et al., 2007; King et al., 2010; Tang, Brown, Funnell & Anderson, 2008).

Indeed, cross-cultural researchers posit that the differences in support-seeking and perceptions of support have been directly tied to culture (H.S. Kim, Sherman &Taylor, 2008; Mortenson, Lui, Burleson, & Lui, 2006). After people move to different country, close family and friends are often a part of their everyday life in the host country. Family members and social groups can have a positive and/or negative impact on the health of people with diabetes by facilitating, or interfering, with self-care activities. Support may contribute to, or buffer, the deleterious effects of stress on glycemic control (Mayberry & Osborn, 2012).

The range of family support for my participants was diverse, both positively and negatively. While some women received support, especially from their spouses and close family and friends, some participants reported feeling unsupported by their family and friends. My participants emphasized the importance of the family support rather than support from friends or their social group.

Some women in my study considered family an excellent resource for support in diabetes self-management which has also been identified in other research (Gallant et al., 2007; King et al., 2010; Tang et al., 2008). Supportive behaviors included: preparing one meal for the entire family, choosing or accepting healthy foods, accompanying the women to every single physician visit, and showing their support by being with them through every stage of transition. Family and friends exert positive influences in many ways by facilitating dietary adherence by cooking proper meals and by offering understanding, assisting with glucose monitoring and giving direct help with medications (Gallant et al., 2007; King et al., 2010; Tang et al., 2008).

Overall, when the families of my participants were involved in positive ways in decisions about diabetes self-management, the women felt valued and encouraged to disclose their everyday concerns and problems, and were more successful in diabetes self-care management.

On the opposite side, there are some negative effects for family relations (transition barriers) on adherence to diabetes self-management. This group of my participants did not always experience family involvement positively. In my study, women disliked a sense of pity, or that others felt sorry for them. Unsupportive behaviors from family, in particular caused my participants to feel helpless and powerless. Feeling unsupported can cause many emotions, including frustration, stigma and a sense of being a burden (Gallant et al., 2007). Qualitative researchers have found that when family members try to support people with diabetes, the person can feel criticized, nagged or guilty (Carter-Edwards, Skelly, Cagle, & Appel, 2004; Gallant et al., 2007; Trief et al., 2003). A mixed-methods study by Mayberry & Osborn (2012) on family members of people with diabetes indicated that some people with diabetes perceived non-supportive behaviors from family members, such as not being motivated to make lifestyle changes or support their own diabetes self-care behaviors.

It is crucial to mention that many negative influences that emerged from the results of my study reflect situations in which family members in particular, are intending to be supportive, but their actions pose an unintended hindrance to my participants. This may include for example, discouraging eating homemade jam for breakfast or traditional sweets for Persian New Year or offering unwanted advice were seen as not beneficial. There is evidence that supportive attempts by family members can actually lead to worse outcomes if they are poorly executed (Franks et al., 2006, Gallant et al., 2007). In summary, when individuals feel the family's attention to their blood glucose level was judgmental, disrespectful, and ignorant, they can experience this as an additional barrier to effective diabetes self-management. Some of my participants had their husbands'support at the beginning of the journey, but found that their partners and close family members withdrew support at later phases, especially when complications appeared or if multiple hospital appointments became necessary. Family, especially their grown-up children, subsequently neglected some of my participants. It is possible that there were other reasons for this rejection, but my participants mainly perceived this abandonment as a consequence of their diabetes. Without family support, these women found it even hard to deal with everyday challenges with diabetes.

Specific forms of unsupportive family behavior. The primary unsupportive behavior identified in my study was family resistance to changing eating habits especially adapting in any way to the new diet. My participants found it difficult when they, as the main person responsible for food preparation, had to continually prepare two very different meals. When family members resisted losing the culturally meaningful and familiar eating habits and preferences (from rice, high fat dishes and sweets to eating out and indulging in traditional social eating practices with family and friends or community celebrations), the women felt strong tension between their perceived traditional role expectations as a woman, mother and host, and their diabetic dietary practices. These women found it very difficult to adhere to their diabetic meal plans during meal preparation and social events. Women reported feeling significant pressure to continue to prepare traditional Iranian foods. This is referred to a food conflict. Unfortunately, food conflicts with established family norms are not uncommon across cultures (Chesla, Chun, & Kwan, 2009; Gallant, Spitze, & Prohaska, 2007; Zeng, Sun, Gary, Li, & Liu (2014). Family food conflict arises when there is disagreement about whether all family members should have the same food (Chesla et al., 2009; Gallant et al., 2007) and when family members do not cook the recommended foods and insist on following their traditional diet (Gallant et al., 2007). To conclude, family members can unintentionally hinder dietary management by not understanding the reality of living with a chronic illness, subverting dietary adherence by not accommodating dietary needs and offering “forbidden” foods.

Family role conflict was another negative aspect of support. A strong cultural value places the family first and this often translates into placing family needs over the participant’s self-care needs. As in many other cultures, taking care of children and household duties is also a part of everyday life for women. As I mentioned in a previous section, some women found it difficult to take care of their own needs by following self-management activities. Similarly, Korean people with diabetes in Nam, Song, Park, & Song’s study (2013) believed family members do not understand how hypoglycemia can affect the energy levels. There is a strong sense of pity, yet there is dietary support. Examples of inconsistent support include asking the diabetic person not to eat something one day, yet later saying, “Eat it just for today.” As a result, the person with diabetes would rather not talk about their condition with their family members and may try to manage their diabetes by themselves because the family members do not have enough knowledge and patience to help them. Conversely, Filipino-Americans with diabetes in Finucane and McMullen’s (2008) study described their families as a major source of emotional and financial support.

Some of the women I interviewed received too much unconstructive support from their family members. Many of them found the supportive behaviors overwhelming and irrelevant. Other researchers also found that not all support improves diabetes self-management behaviors (Neufeld, Harrison, Hughes, Stewart, 2007; Strom & Egede, 2012). Over-protective responses from family showed a negative effect on self-care management in some studies. A descriptive study by Oftedal (2014) with adults with type II diabetes revealed the majority of the participants experienced non-constructive emotional support such as negative attitudes and emotional reactions or intrusive informational support. Interestingly in both my study and literature, people with diabetes who receive too much support stated that they did not need this kind of support and response by trying to hide the symptoms of their diabetes (Oftedal, 2014; Veinot, Kim, & Meadowbrook, 2011).

Community gatherings throughout the year play a central role for Iranian people in general and Iranian immigrants in particular, providing spiritual comfort, social resources and supports. Some Iranian-immigrants describe community gatherings as being “among family.” There are many studies that indicate social support can help individuals with diabetes to improve self-management behaviors. (Gallant, 2003; Mayberry & Osborn, 2012; Misra & Lager, 2009; Van Dam et al., 2005; Wallace, Driessnack, Bohr, & Tripp-Reimer, 2015). However, there is a negative aspect to these social gatherings as well. Similar to some women in my study, Filipino-Americans expressed a strong desire not to offend their hosts in social gatherings with special dietary needs. Others' lack of understanding sometimes limits the helpfulness of their attempts at emotional support (Carter-Edwards et al. 2004), and lack of knowledge among community members is perceived as a barrier to self-care activities (Gallant et al., 2010). The high cultural value of family and being part of a large community does not necessarily equate with receiving a lot of support for my participants, but rather carries with it a strong expectation for providing support and actively engaging in their community's programs, for example, the need to actively engage in preparing food for the gatherings.

Ultimate social support is achieved by collective collaboration of the individual and his or her social network including family, friends and health care providers (Sukkarieh-Haraty & Howard, 2015). Unfortunately, the association between social support and diabetes control is inconsistent (Chew, Khoo & Chia, 2015). Social support, along with other psychosocial-cultural factors, such as acceptance of the disease and perceived ability in coping with lifestyle adaptation have also been shown to contribute to glycemic control (McDonald, Wykle, Misra, Suwonnaroop, & Burant, 2002). Overall, I have found that family members are frequently involved in the self-management activities with my participants, but that family members often express this support in ways perceived negatively by patients, and are seen to interfere in self-care for some women in my study. There is the variation in the literature about the relationship (positive or negative) between family support and self-care management behaviors, but we need to understand the dynamics of the relationship to accurately assess whether it is helping or hindering self-management, or design interventions that maximize its potential. It is clear from the evidence that too little or too much support may worsen diabetes outcomes (Van Dam et al., 2005). Effective family support, as perceived by the individuals with diabetes, ultimately improves diabetes management. Contrasting results related to family support could be related to different cultural-religious and social backgrounds of the participants and their families, different social network composition, culturally defined measures of support, family obligations and responsibilities (Chesla et al., 2009; Gallant et al., 2007; Sue & Sue, 2003).

Support from family, friends, community or health care professionals is an important factor in transitioning and adapting to living with a chronic condition in my study, as it is in other research (Wang, Morrel-Samuels, Hutchison, Bell, & Pestronk, 2004). The stories from my participants show inadequate knowledge and understanding about diabetes type II might be one of the reasons that some family/friends or community members were not perceived as supportive. Forming meaningful relationships with people in their social networks, including health professionals, is essential to the women's management of transitions (Rasmussen et al., 2007). My study illuminated that during transitions, the majority of women felt that it was important to involve family members in management, particularly in the early stage of diagnosis or when they encountered new diabetes complications. The results of my study indicate that there is an urgent need to explore how negative social support in the Iranian Canadian community can be mitigated and effective positive social support maximized.

Underlying mechanism between social support theory and self-management. Social cognitive theory helps to illuminate the underlying mechanisms by which social interactions may influence self-management behavior and lends a useful theoretical explanation for these findings. This theory also explains the effectiveness of the amount of support from social support networks (Gallant, 2003). Social support theory can also explain the different effects of family support and help us better understand how family support might influence self-care behaviors in diabetes (Web et al., 2004). Based on social cognitive theory, chronic illness self-management occurs in a context that includes formal health care providers, as well as informal social network members. All of these contextual factors have the potential to significantly influence self-management behavior, either directly or indirectly through self-efficacy (N. M. Clark, Gong, & Kaciroti, 2014; Gallant et al., 2007).

The timing and amount of support are also explained in this theory. When the kind of support and the timing of support given are congruent with the requirement of the situation and the needs of the person, the effect will be maximized. When there is a difference between the recipients and the providers perceptions of the type of support that should be given, then the recipients may be unhappy or unappreciative of the support and feel they did not receive what was needed; thus, they may not consider it as a helpful behavior (Bandura, 1997; Mulvihill, 2015; Shumaker & Brownell, 1984). In chronic illnesses such as diabetes, support provided must match the individual need for the most optimal outcome (Wen, Shepherd, & Parchman, 2004). Sometimes people with chronic illness experience stress or feel inadequate by receiving negative or non-reciprocal support because of either the amount of support (more than expected or less than expected) or timing (delivery of support in relation to when it is needed) (Fiori, Antonucci, & Cortina, 2006; Van Dam et al., 2005).

This theory is useful to explain different types of support from family and friends and different perceptions of this support in my study. For example, encouraging some participants to not eat sweets or rice may be a positive act, but some of my participants did not consider it such. Negative support could take the form of family or friends providing unusual support and causing more stress by violating the person’s privacy. Social support is not always positive. The recipients of the support sometimes perceive the support negatively (Gallant et al. 2007; Rosland, Heisler, & Piette, 2012). Greater attention to social support theory may also clarify which dimensions of support are particularly important for self-management and provide direction for the appropriate support for people with chronic illness (Gallant, 2003).

In summary, employing both social theory and social cognitive theory may contribute clinically to designing consultation services to teach this important issue (timing and amount of support) for clients and families. It is an important part of a diabetes educational plan and family based education. Health care professionals need to teach families how to be helpful in appropriate ways, and to emphasize the importance of both activity and the need for independence in diabetes self-management.

Immigration

Migration is a complex situational transition that interacts with other factors (Meleis et al., 2010) causing great stress for the women in my study. My participants had to deal with leaving their homelands and resettling in a new country either permanently or temporarily. According to Meleis (2010), transition is a combination of change and the individuals’ reaction to this change. My participants experienced many changes and challenges when they moved to Canada, whether or not they had already been diagnosed with diabetes. These included social and economic challenges, different modes of language, religious and cultural expression, diet, access to culturally appropriate physical activities, family and social networks, gender norms, relations and communication, as well as a very different health care system. These challenges were exacerbated when combined with learning to live with diabetes. Immigration also affected the health-illness transition in different ways when participants did not trust the Canadian health care system for treating their diabetes. Many factors contributed to poor glycemic management including a perceived gap between themselves and health care professionals in Canada, missing extended family, language barriers resulting in social isolation, anxiety and fear.

Immigration to a country with different cultural and religion backgrounds required a lot of work and consumed enormous energy for families, in particular women, including how to pass on Islamic teaching and Iranian customs to their children. Some women felt a sense of guilt toward their children due to spending more time on diabetes self-management activities than meeting their children’s needs.

These challenges are reflected in extent research with immigrants living with a chronic illness. Themes of isolation, language barriers, and difficulties accessing health care services abound across all cultures. For example, Chesla et al. (2013) found that immigrants, particularly Chinese immigrants, struggle with disease management when health care providers do not share their language. Increased levels of distress related to immigration challenges are a predictor for poor diabetes self-care management. According to Fisher, Hessler, & Polonsky (2012) and Fisher, Glasgow and Strycker (2010), diabetes distress is a clinically sensitive indicator and the key psychological factor that is closely related to self-care behaviors and HbA1C levels. Importantly, these researches showed the positive impact of culturally specific diabetes management programs (Chesla et al., 2013; Hjelm & Atwine, 2011). In the following sections, I will address the following themes: distrusting the diabetes care system, cultural gaps with health care professionals, language difficulties, changes and differences in dietary and physical activity in relation to the literature. These themes mostly acted as inhibitors to health-illness transitions for my participants.

Distrusting Canadian health care system. Distrusting the Canadian health care system in terms of diabetes self-management was one of the main challenges for the women in this study. The difference between the systems they were familiar with the new system created anxiety, confusion and mistrust. For example, they complained about the Canadian system in which the family physicians were front -line providers and expected to take care of all aspects of their diabetes management. In Iran, people with diabetes are treated and followed by a specialist, specifically, an Endocrinologist. Based on these preferences some women travelled to Iran and spent time and money to see their Endocrinologist in Iran at least once a year. They believed that general physicians do not have enough medical knowledge and technical competency to handle all aspects of their diabetes management. In the same vein, Mexican people with diabetes in Ransford, Carrillo & Rivera's study (2010) stated that they trusted doctors in Mexico more than they trusted doctors in the United States. Many said that Mexican doctors charge less, take more time with patients, and provide more holistic care, enabling them to provide more exact treatments. U.S. doctors were viewed as hurried, not listening well, and drawing quick conclusions about the patients' illnesses without considering their input. Several other studies had similar findings that immigrants with chronic illnesses expressed their distrust of the health care system of the host countries. Eckstein (2011) found that participants had minimal trust of the medical system and limited experience with Western concepts of disease. Although some researchers identify immigrants'complaints about the new health care system, there does not appear to be any evidence of such strong criticism towards the family physicians versus Endocrinologists in diabetes management as I found in my study.

Distrust is accompanied by high rates of self-treatment and failure to follow the family physician's advice in my study. Some women only saw their family physician to refill their medications. Distrusting the health care system of the host country caused insufficient adaptation to diabetes and enhanced the risk of severe complications as a result of poor metabolic control and mental health as found in other studies (Aroian, Wu, & Tran, 2005; Peek et al., 2013; Povlsen & Ringsberg, 2008). The danger of mistrust of the health care system is an important focus for researchers (Durant, Legedza, Marcantonio, Freeman, & Landon, 2011; Egede & Michel, 2006; Iten & Jacobs, 2014). Consistent with this literature, I found that a poor relationship between the women in my study and heath care professionals compromised the quality of care. Even for those women who were following their family physicians' recommendations, some negative feelings toward both treatment and physicians developed. This influenced their self-care management behaviors in areas such as rejecting or changing the dose of medications or turning to traditional remedies. My results, along with those of other studies, suggest that physician mistrust may potentially be reduced through physician training in interpersonal skills and cultural appropriate comunication. Physician support of patient information sharing can foster trust and reduce cultural gaps in understanding (Peek et al., 2013).

Cultural and religious gap with health care professionals. Cultural and religious gaps between health care providers and individuals with chronic illness can interfere with effective delivery of health services (Saha, Beach, & Cooper, 2008). When health care professionals with different cultural backgrounds do not pay attention to these issues, or other cultural and religious milestones, the gap can grow larger. It is also critical to assess each person with diabetes individually and not make cultural assumptions about an individual's cultural beliefs or health practices (Rankin, Stallings, & London, 2005). The greatest challenges occurred when health care professionals' health explanatory model differed from clients' health explanatory model. Illness explanatory models are broader beliefs about how the body works as well as the nature, cause, prevention, and response to an illness (Kleinman, 1978). Differences in explanatory models between patients and providers can contribute to ineffective communication and misunderstandings and may affect optimal management of diabetes (Weller et al., 2013). In other words, recognizing and accessing a patient's and family members' explanatory models will provide the practitioner with information about any cultural and idiosyncratic health beliefs and practices relevant to the individual's mental health presentation (Seah, Tilbury, Wright, Rooney, & Jayasuriya, 2002). The explanatory model opens up the communication pathways between the health care professional and their client by adapting their expert advice to the patient's own explanation, understanding and viewpoint. (Baumann & Dang, 2012). The explanatory model promotes questions for clinicians to ask in their everyday practice in a culturally sensitive manner, such as "what do you think about the cause of the illness? In culturally sensitive approaches, multiple areas should be considered, including language. The stories of my participants addressed many aspects of this gap including using traditional medicine, impractical meal plan by dieticians or physicians and communication challenges. I will explore each of those in the following sections.

Traditional medicine. One aspect of the cultural gap arose when the physician had no knowledge of Iranian traditional or herbal remedies for diabetes. Traditional medicine has long been utilized in many cultures, including Iranian and Chinese cultures, to treat diabetes. There is substantial research on the positive effects of herbal medicines from walnut leaves to ginger or cinnamon tea in the management of diabetes (Jelodar, Mohsen, & Shahram, 2007; Kirkham, Akilen, Sharma, & Tsiami, 2009). Most studies published in Iran have shown a statistically significant decrease in blood glucose when traditional remedies are employed (Hasani-Ranjbar, Larijani, & Abdollahi, 2008). Some of my participants complained that health care professionals did not have any advice or enough knowledge about herbal remedies for controlling blood sugar. For example, when they asked about the effect of cinnamon tea or ginseng on blood sugar, their physicians were not aware this was a common herbal remedy. This issue was also seen in Latino immigrants with diabetes as reported by Ransford, Carrillo, and Rivera (2010). There was widespread use of traditional medicines among their participants. Latino immigrants believed US doctors did not have enough information about traditional treatments and therefore Latino immigrants had greater trust in Mexican doctors (Ransford et al., 2010).

Non-practical (culturally-based) meal plan by dietician or physician. Generally, my participants were not happy with their written meal plan provided by the dietician. The meal plan did not have any examples of their traditional foods and every day ingredients, such as traditional bread and rice. They were unable to make substitutions for traditional foods. For example, how many tablespoons of Basmati rice is equal to one portion of carbohydrate? Some of them were even shocked when they saw portions of pork or lard in their meal plan, as this is a prohibited food for practicing Muslims. They were also confused about dining out and the amount of foods they could eat in Persian restaurants. Lack of knowledge about the ability to fast in Ramadan for people with diabetes left many women in my study with confusion and questions. Carter (2011) discussed the challenges between Middle Easterners' approach to life and Westerners approach in terms of relevant religious customs. When health care professionals offer different types and portions of pork in the meal plan of Muslim people, it causes distrust and a feeling of disconnection between Muslim patients and health care professionals.

Communication challenges (cultural consideration). Lastly, some of the women in this study identified very different expectations and norms in communications. For example, Islam prohibits handshakes or any contact between men and women. However, in Canada, my participants worried that refusing to shake hands as part of greeting in a diabetes consultation might offend the health care professional. Another important cultural and religious chasm is women's difficulty in talking about personal or private issues. Women in Iran are often more hesitant to talk about their personal or private issues with health care professionals. If health care professionals do not consider this issue, they will miss important information. This issue was also addressed in Pierre's epidemiological study (2012) on Haitians Americanwhere there was also a hesitancy to discuss personal and private issues including sexual issues.

Language difficulties. Like many immigrant groups, feeling lonely and having a lack of English were major issues for the majority of my participants. The dream of finding a better life in Canada was eroded for many women due to immigration challenges, particularly for those who could not speak English. Many of my participants stated cultural and language differences as perceived negative contributors to the relationship and trust between them and health care professionals. These domains are consistent with current conceptualizations of patient trust in the literature (Hall, Camacho, Dugan, & Balkrishnan, 2002; Peek et al., 2013; Rowe & Calnan, 2006). Some of my participants did not understand what their health care professionals were telling them, and they were unable to communicate with them directly. Being misunderstood by health care professionals and failure or delay in the process of adaptation to the illness and self-management behaviors is commonly reported in immigrant health research (Hu, Amirehsani, Wallace, & Letvak, 2013; Samarasinghe, 2012). My participants felt they could not do whatever they wanted and they had very challenging and frustrating lives with diabetes in this different country. Language barriers were very frustrating for my participants and prevented many of them from knowing about the progress of their diabetes. Lack of a common language between client and provider can also result in diagnostic errors, inappropriate treatment and delays in seeking or refusal to seek medical treatment (Lara, Gamboa, Kahramanian, Morales, & Hayes- Bautista, 2005; Ngo-Metzger et al. 2007). Some of my participants told me they had many questions to ask doctors but it was very hard for them to go to the appointment with one member of the family. Instead they preferred to ask their family or friends for help. This issue is also commonly addressed in the literature (Ransford, Carrillo, & Rivera, 2010; Samarasinghe, 2012). Children were often the main interpreters for my participants. A major disadvantage to this was breaches of confidentiality and omission of relevant information. For example, no woman was comfortable talking about intimate physical or relational aspects impacted by diabetes in front of their child. This finding is consistent with the large body of research literature on language insufficiency in the process of illness management. Inability to communicate with medical team creates a barrier to access the health care system (Brach & Fraser, 2000; Eckstein, 2011) and the consequence was often compromised self-management effectiveness (Iten & Jacobs, 2014).

Living status in Canada (reason for immigration). One of the important inhibitors in my participants' transition process was their residency status in Canada. Some women were in Canada on a visitor's visa. This meant they had an uncertain life here and could not access health care services without charge. This group of women came to stay with their children who were studying here. They struggled with important aspects of their lives that they considered missing. For example, all of these women expressed feelings of depression from being isolated from their extended family and friends. Aroian (2010) also described this issue. Some of the participants in Aroian's study identified unresolved grief, such as missing their homeland as contributing to their "feeling displaced" or "between two worlds" (p. 237). The women in my study expressed constant concerns about being in Canada and they had to travel to Iran many times a year. Travelling to Iran also brought them many difficulties related to uncontrolled blood glucose. My participants perceived that their inability to apply for an employment permit because of their visitor's visa meant they were less active in society, resulting in a more sedentary lifestyle. Women who were Permanent Resident or Canadian Citizen struggled less. They could easily go to the clinic or medical offices for free. They were mostly employed and actively engaged in society.

In summary, it is almost impossible for health care professionals to anticipate all the barriers in attempting diabetes self-management behaviors in a multicultural country, such as Canada. The health care provider may intervene with their clients in culturally sensitive ways such as viewing culture as a facilitator rather than a resistant force. While we see the similarities, not just differences, cultural sensitive practice grows our capacity and finally invites our clients to dialogue (Sermeno, 2011). In this regard, Rumi, a 13th century Persian poet and Islamic scholar provides thoughtful guidance developing respectful and sensitive ways of working with people from different cultural backgrounds, despite their differences or commonalities *"Out beyond ideas of wrong doing and right doing, there is a field. I will meet you there."* (Rumi, 2004)

Considering a factor as a facilitator or inhibitor in the transition process in living with diabetes varies for each person. Perceived control over these facilitators and inhibitors can affect the extent to which they adjust to their chronic illness. The theme of control, or inability to control, various factors of their life journey with diabetes is important in understanding why some women experienced being stuck in the dark days of diagnosis. Although transition theory helps us to explain the uphill battle for the majority of my participants, Locus of Control theory is also useful as a lens to explain this behavior. Locus of control can be valuable in predicting behaviors in people with chronic illness. In the following section, I will discuss the concept of locus of control in chronic illness management.

Health Locus of Control

A causal mechanism underlying variation in self-management behaviors is Health Locus of Control (HLC), a construct derived from social learning theory. Social learning theory describes how individuals think and react in social situations (Bigge & Shermis, 1992). A central hypothesis of social learning theory is that people will engage in health protective behaviors if they are concerned about their health and believe they have control over it (Wallston & Wallston, 1982). Social learning theory is a health behavior theory frequently employed for diabetes health intervention assessment and planning. The interaction between health value and perceived control over health results in health related behaviors (Wallston, 1992). Control is a concept that plays an important role in this theory as well as several other psychological theories. Locus of control (LOC) is one aspect in Rotter's social learning theory (1966). It refers to "the person's belief as to whether control over valued reinforcements is internal or external to the person" (Wallston, p. 151). The HLC construct has played a key role in the prediction of the physical and psychological adjustment to chronic disease (Wallston, 1992).

Based on the LOC framework, our actions are dependent on what we do (internal control orientation) or on events outside our personal control (external control orientation) (Zimbardo, 1985; Seligman, 1975). LOC means that individuals may feel that events in their life are under their control (internal) or unrelated to their own behaviors (external) (Dupen, Higginbotham, Francis, Cruickshank, & Gibson, 1996). HLC explains why individuals believe health outcomes are the result of their actions (internal LOC), luck or chance (powerful others HLC). LOC can tell us a lot about how our clients view their chronic illness and their role in controlling their illness. LOC construct has helped to shape our thinking about the role of beliefs in the context of health behaviors and health outcomes (Luszczynska & Schwarzer, 2005). According to Wallston and Wallston (1982), one can simultaneously hold both internal and external LOC beliefs about control of an event.

Based on the locus control construct, people who tend toward more internal control believe that hard work and focus will result in successful progress. They tend to seek more information about their illness and actively engage in maintaining their health. They are more likely to take responsibility for their actions and tend to be less influenced by the opinions of other people. People with internal LOC focus feel confident in the face of challenges (Lioyd & Hastings, 2009). In my study, the women who considered their lives as a “bumpy road” appeared to have a strong sense of confidence, ability and engagement about self-managing their diabetes.

On the other hand, those with an external LOC, tend to blame outside forces for their circumstances. They believe an individual’s health is influenced by supernatural sources, powerful others and fate (Brincks, Feaster, Burns, & Mitrani, 2010). External LOC prefers the belief that some events in people’ lives are caused by uncontrollable factors such as the environment, other people, or a higher power. Those people who were identified as more externally controlled, believing that their future depended upon luck or fate, tended to have more effective performance (Rotter, 1966).

A study by Nugent, Carson, Zammitt, Smith, & Wallston (2015) explored the internal/external dimensions of the LOC construct in people with type II diabetes. Participants described conflicts between their internal and external LOC beliefs when discussing their diabetes self-management behaviors. The majority of their participants emphasized that life’s irregularities impact their control and their ability to self-manage diabetes effectively. This type of external LOC may prevent some self-management activities. I speculate that external LOC may an underlying mechanism that might explain my participants' behaviors and a significant influence in their ability to self-management. People with a high external LOC feel they cannot change their lives or the outcome of their illness, leading to feelings of helplessness and hopelessness, which contribute significantly to depression. It may also contribute to the phenomenon called "Learned Helplessness" in which a person has learned through experience that they are powerless to change or control things or remove himself or herself from harm or danger (Seligman, 2006). Feeling helpless was manifested when some of my participants experienced poor control of their blood glucose despite their self-management activities, and they quickly felt nothing they did had any effect on their health situation. Learned helplessness may also be associated with depression, anxiety and loneliness (Hommel, Chaney, Wagner, & Jervis, 2006; Seligman, 2006). Over time, when they were later faced with any type of diabetes complication, my participants experienced a sense of helplessness. Life for these people was an uphill battle. According to Burish, Carey, Jamison, & Lyles (1984) having mixed orientations of internal and external LOC can reduce stress and is an effective way to adapt to illness. External LOC factors that, for the majority for my participants, directly and indirectly had positive (buffering) or negative effects on self-management activities included: level of family and social supports, immigration issues, cultural and religious beliefs, and the influence of cultural and religious feasts. For example, some women believed that living in a country with different cultural and religious practices and beliefs caused them to have more responsibilities in their personal life. They could not therefore carry out self-management activities properly due to lack of time. Family and social support is another example of external LOC that played an important role in initiating and maintaining self-management activities by proving constructive support in the transition process. In summary, LOC beliefs of individuals with type II diabetes should be included in clinical assessments to determine peoples' choice of self-management activities, how much effort they will expend, and how long they will sustain that effort in dealing with stressful situations.

Locus of control and religious beliefs. The link between religious beliefs and self-management is important for a number of reasons. According to Schieman (2008), there are mixed results including positive, negative or null associations between God-related control and personal control related to self-management in chronic illness. Essentially it is about an individual's belief in the divine that can empower individuals or contribute to whether they feel powerless to control their situation. According to Islam, in any unpleasant life event such as illness, people should do their best to solve their problem while continuously rely on God (Tawakkul):

> "And your Lord says: 'Call on Me; I will answer your (prayer)…" (Quran 40:60)

However, this is often dependent on other components of their religious beliefs. Personal understanding of God's destiny can be another explanation. Pudrovaska (2015) argued the belief in divine control could empower the individuals through the belief that health and illness is a gift from God and causing them to assume personal responsibility for health maintenance. This belief enhances personal control over the illness. The results of my study illuminated how some women believed their illness was a test from God and they were responsible for taking care of their bodies. Religious beliefs for this group of my participants were a source of power and hope. My findings support similar findings for women with type II diabetes in Iran reported by Aghamohammadi-Kalkhoran et al. (2012). Their participants referred to the importance of a God-centered life with respect to health issues. This religious attitude helped their participants to cope with and to accept their diabetes. The main difference between my participants and the participants in Aghamohammadi-Kakhoran et al.'s study is that believing in God and destiny paradoxically resulted in depression and passiveness in some of my participants. This remarkable contrast reflects highly variable personal understanding about religious beliefs. Pudrovaska (2015) also proposes that individuals with higher levels of religious commitment experience a stronger positive relationship between divine control and personal control. According to Islam, all diseases –as well as their cures–are in Allah's hands. Tawaakul (توکل) as one of the Islamic beliefs (i.e. putting one's trust in Allah) is not contradicted by seeking medical advice. However, some women in my study believed having diabetes was something out of their control and within God's control (pre-destiny), thus they did not try to do their best in terms of self-care management behaviors. They sought explanations for the cause of their diabetes and focused on external factors that posed barriers to maintain self-care management behaviors. One possible explanation is those with less education were most likely to believe in the role of powerful supernatural others. This finding supported the idea that individuals with diabetes who are less educated are more external in their LOC orientation than those who are more educated (Kalantarkousheh, Mohagheghi, & Hosseini, 2013; Morowati Sharifabad et al., 2010).

Cultural and religious values are also related to internal LOC (Champagne, Fox, Mills, Sadler, & Malcarne, 2015; Engqvist- Jonsson & Nilsson, 2014). For example, when women in my study strongly believed that their illness was a test from God and that they had the responsibility to take care of their body, they were strongly internally motivated, they tried to learn about diabetes and maximize their self-management behaviors. On the other hand, when my participants believed their illness was a punishment or predestined, they felt they could not have any control over their illness. This generally resulted in depression and they did not actively engage in their diabetes self-management plan. Overall, women in my study who appeared to have high internal LOC were more interested in self-management activities; for example, they had regular physical activity and followed recommended meal plans.

A study by Holt, Clark, Kreuter, & Rubio (2003) is useful in interpreting my participants' behaviors based on health LOC. These authors distinguish between an active religious belief, based on health LOC, in which belief in God empowers individuals to take action for managing their illness; and the converse, people who leave everything to God take care of and have a more passive religious or spiritual health LOC. The level of LOC is also associated with the cultural background. According to Vidal (2010), people with internal LOC have grown up in families that modeled typical internal beliefs that emphasized effort. In contrast, people with external LOC believed they have less control over their environment. The health LOC framework is used to assess adherence to a diabetes regimen in some studies. Individuals with diabetes may adhere more closely to their regimen if they experience an increase in perceived or internal LOC. According to the Morowati-Sharifabad et al's (2010) study, Iranian women were more likely to manifest an external LOC and less internal LOC. Moreover, the attribution of external LOC increases as age increases. Many studies indicated that there is a positive association between internal LOC and adherence to diabetes regimen and there was a negative association between external LOC and adherence to diabetes regimen (Kretchy, Owusu-Daaku, & Danquah, 2014; Morowati Sharifabad et al., 2010; Omeje & Nebo, 2011). Religious beliefs are related to LOC (external) in many studies in different countries with different cultural backgrounds.

Different individuals with diabetes have different attribution styles, so it is the health care professionals' responsibility to consider LOC in their treatment and education plans. Based on the results of my study and similar studies, it can be suggested that interventions aimed at improving internal LOC may improve adherence to diabetes self-management. To improve internal LOC, we need to develop decision- making and problem solving skills, providing positive feedback to clients for their small successes, as any feeling of success will build self-confidence and a sense that they have some control of what happens in their everyday life with diabetes (Morowati Sharifabad et al., 2010; Rotter, 1966). Recognizing their patients' LOC orientation would enable health care professionals to offer the treatment compatible with individuals' specific needs. If a patient is internally oriented, they will most likely benefit from medication. Alternatively, when a patient has an externally oriented LOC, health professionals may need to focus on social or family support rather than drugs (Omeje & Nebo, 2011).

Collectively, the findings from my study and other studies reinforce and refine a need for health care professionals to consider the complex interplay between religious and cultural beliefs and clients' perceived self-efficacy in diabetes self-management. Health LOC and self-efficacy are also considered valuable predicators for effective diabetes self-management in the literature (Keedy et al., 2014; Morowati Sharifabad et al., 2010; O'Hea et al., 2009).

Overall, there is no doubt that the LOC construct has been useful in expanding our understanding of my participants' responses to diabetes, but there are some limitations to use of LOC to explain health related behaviors in people with chronic illness. According to Stenström et al. (1998), when people with diabetes, for example, suffer from retinopathy, beliefs about control over progress in retinopathy might be unrelated to beliefs about control over adherence to nutrition regimens or regular physical activities. For example, while people think they have control over their illness by themselves, when chronic complications arise, they feel they no longer have control over anything related to their condition.

Thus, while health LOC framework is very helpful to explain the role of beliefs in different behaviors in women in my study, perceived efficacy in particular, remains a powerful construct in explaining how people think, feel and act (Bandura, 1997).

Study Contribution to Nursing Knowledge and Practice

As articulated in Chapter 2 and this chapter, researchers investigating in self-care management by people with chronic diseases agree that religious beliefs and cultural background significantly influence people's experiences and perceptions of chronic illness, as well as their self-management behaviors. Despite this understanding, health care professionals who work directly with patients may tend to oversimplify the importance of culture and religion in self-care management for diseases like diabetes that require significant lifestyle changes.

The result of this study revealed the importance of cultural sensitivity and application of cultural knowledge by nurses and other health professionals so as to enhance communication with people with diabetes from different cultural backgrounds. Health care professionals, based on the stories from the women in my study, usually focused on diagnosis, prescriptions and response to medications, while the focus for my participants was on the everyday challenges of living with their chronic condition far from their home country. In order to achieve evidence based and artful practice for people with diabetes, we need to align self-management recommendations, such as diabetes meal planning and physical activity, with the individual's socio-cultural beliefs.

This research adds to nursing knowledge in two additional ways. First, this study specifically focuses on Iranian Muslim women in Canada and provides insight into the role of religion and culture for Muslim people with chronic illnesses who live in Western countries. The findings in this study add to the body of nursing knowledge by exploring how the concept of ‘predestination’ and belief in God gives important spiritual guidance, meaning to life, comfort and supports the majority of Muslim people. Second, this study highlights that the perception of one’s illness does not stay the same, thus health care professionals need to explore patients’ illness perspectives with them and set a strategy to assist them to stay on the right track as defined collaboratively by the individual and their health care team. Transition Theory and Shifting Perspective Model offer frameworks that will enable health care professionals to move beyond the bio-medically oriented concepts of care, toward a holistic approach to illness management.

My findings indicate that levels of education, English competency, status of living in Canada, as well as family culture and relationships are all important in understanding how individuals respon to the challenge of living with diabetes. Health care professionals consider these barriers to effective transition processes for people with diabetes. The findings of my study warrants continued support of health care professional in using a culturally sensitive approach for their everyday practice to assess and eliminate or ameliorate these barriers to foster te best possible diabetes management. It is essential that health care professionals be able to openly discuss issues related to stigmatization and fear of chronic complications with their clients.

I also found that each individual had her own transition process and perspective about diabetes, which reveals that greater attention for each person must be given in designing an appropriate care plan. This study also provides support for the use of transition theory and shifting perspective model in explaining the outcome of self-management and health seeking behaviors in people with diabetes. Transition theory was particularly helpful in understanding how Iranian Canadian women with diabetes undergo different transitions, including their response to migration with diabetes, and the factors that influence diabetes self-management especially which individual, community and societal conditions facilitate or restrain a healthy transition.

Implications

I have indentified a range of issues as a result of this study which might be usefully considered by health care professionals. While my study was limited to one specific context, this work should be extended to more heterogeneous settings and backgrounds over a longer period of time to identify other possible aspects of diabetes experience.

Transition is a life-long experience in diabetes that includes changes and challenges from one's personal and family life, and continually shifts individuals with diabetes back and forth in successful or unhealthy transition. The results of the study draw our attention to our important role as health care professionals to explore illness perspective (illness in foreground or background) and transition process in our clients with chronic conditions.

Family relationships and support were also significant factors that assisted the women to integrate diabetes into daily life patterns. It seems that presenting sufficient information about diabetes to the people who are close to the individuals with diabetes and encouraging their involvement and cooperation in the care plan can facilitate successful diabetes self-management behaviors. Nursing assessment should include a functional evaluation of the level of support in the family, friends or community of individual with chronic illness.

Explanatory models are part of the social and cultural context of the individual and it is vital to use such models, like those put forth by Kleinman (1980) and Helman (2007), in an effort to understand the individual's beliefs, avoiding the pitfall of making rough generalizations between cultures or even people from the same culture. As a result, a health care provider who understands the explanatory model of their clients with attention to the variations of perception may be able to bridge any gap in understanding and to negotiate interventions that are acceptable and relevant. Only through understanding the social and cultural context can the health care professional be facilitator and be considered culturally competent.

Teaching and using culturally competent care in undergraduate nurses'education entails sensitizing future nurses and health care professionals to the diversity among and within cultures, focusing the nursing curricula on cultural competency. Moreover, nursing curricula should encourage undergraduate nurses to examine how their own explanatory models of illness and care may or may not overlap with the clients' explanatory model.

The results underline the importance of considering religious traditions in the care of diabetics. For example, it is important to be aware that Muslim patients with diabetes, like some of the women of this study, may insist on fasting even though they have no obligation to do so according to Islamic rules. Cultural and religious beliefs influence the acceptability of recommendations from health care professionals for diabetes management. Health care professionals should not be surprised if people with chronic illnesses resist following their medical plan or prefer to try traditional remedies before starting medical treatment. Culturally sensitive approaches are more effective for increasing self-management activities. Moreover, there is a need to further explore cultural barriers to diabetes self-management and evaluate the impact of both cultural beliefs and immigration. As some women may be reluctant to talk about their feelings and experiences in public settings, a peer support group could be a better choice for them. Creating support groups for people within diabetes in Iranian or Muslim communities may also help the quality of diabetes management by referring women to 'women only' facilities where they can participate in physical activities, such as swimming.

Overall, my participants had very diverse views regarding the existing diabetes education program. When I went through the interviews again and had an opportunity to meet some of participants for a second time, I came to understand that the teaching plans I had used in my earlier practice for my clients were not “time matching” or “stage matching.” I had designed many educational booklets, but I considered only one stage of their diabetes journey (acceptance of illness). Now I understand each one of my participants was in a different stage of their life after having diabetes and that these stages influence what they are able to learn. In the future I think that a “transition clinic” or “transition–focused clinic,” where the education for participants can be structured and tailored according to these various phases in their transition journey in learning about and living with diabetes may be more appropriate. If people who are newly diagnosed with diabetes, for example, are supported effectively they can pass through the “dark days” more easily which in turn can facilitate movement through the other stages of their life transition. Integral to the transition-focused clinic is the composition of the “transition team.” This team should include diabetes educator/nurse, dietician, physician, social worker, and religious cleric, as needed. Accurate assessment and tailoring of the educational program by the team will help ensure that our clients have a better opportunity to understand and integrate diabetes by learning effective and culturally based self-management strategies before it is too late and complications arise. As I mentioned previously, family has an important effect on diabetes management activities, thus family meetings and on call services would be very useful so that concerns by the family and individual with diabetes can be addressed by the diabetes clinic team as they unfold.

Recommendations for Future Research

When I started my study, I thought immigration would be a central phenomenon to explain my participants' experiences. Now, however, I am not sure. My clinical experience indicates that many women living in Iran still have great difficulty living with diabetes. Immigration certainly was a major influence, but the influence of culture (social roles, social structures and social norms) and religion were possibly a greater influence. Some aspects of immigration were clearly evident-language differences, distrust of the health care system, sense of isolation, but essentially, the core process of learning to live with diabetes was not attributable solely to immigration. It was interesting that there were differences in perceptions and experiences of those women in Canada temporarily and those who had made Canada their permanent home. In order to evaluate the effect of immigration solely on diabetes self-management, there is need for a more comprehensive study on immigrants with diabetes already living in Canada in comparison with those with similar illnesses back in their home country. This will assist in expanding the body of knowledge regarding these perceptions and will be beneficial to improving the treatment of individuals with diabetes, or any other chronic illness from diverse backgrounds. It can also help to understand how immigration experiences affect self-management abilities. This study identified the impact of family roles on the cultural understandings and experiences in diabetes self-management, but did not explore in-depth the impact of diabetes on the family itself and thus ethnographic studies with this focus are recommended.

Although the influences of culture, religion and family context were elicited in my study, an in-depth work on the same is necessary to provide clarity to the effect of these issues on illness perception.

In this study, significant proportions of women were stuck in the early stages of diabetes transition and did not move forward. Further study needs to be conducted in Iran so that we can compare the results to find out about the effects of immigration on changing the social and cultural context of diabetes self-management behaviors.

There is a need to further explore cultural barriers to diabetes self-management and evaluate the impact of both cultural beliefs and immigration specific to the growing numbers of Muslims and Iranians in Canada.

Ethnic groups are not uniform. While it is useful to explore the generally held beliefs of a group, it is equally, if not more important, to investigate whether individual beliefs are similar or different. There is a need to explore the specific demands of each ethnic group and investigate the similarities and differences between and within them.

Some women in my study believed in predestination and God's will which led them to not make extensive efforts in self-management. For some, religious beliefs were a source of hope and empowerment, providing them with motivation to be active participants in any decision concerning diabetes self-management. Further exploration needs to reveal what types of spiritual or religious beliefs help promote a sense of empowerment in individuals with chronic illnesses.

Overall, transition theory and the shifting perspectives model could be the key to changing and extending our perspective when we encounter an individual with chronic illness. Health care professionals need to recognize transition to diabetes self-management as socio-culturally constructed and influenced by the interaction of relationships, society and personal of perception of illness.

Limitations

This study has a number of limitations. This study was qualitative and as such did not have a goal of generalizability. The sample, by necessity was small and involved women who mostly go to the mosque, community feasts or supermarkets and may not apply to all Iranian women living with diabetes in British Columbia. Moreover, Iranian immigrants in Vancouver do not represent a random sample of the population from Iran or beyond the communities of my study area. The sample was entirely female, and there may be important differences in the perceptions and transitions experiences of the male diabetic population. The study contained both insulin dependent and non-insulin dependent diabetics, which may also limit the study results.

It is obvious that acculturation can influence migrants' beliefs and behaviors. It was not possible to compare various levels of acculturation in the current study. However, the ability to speak English fluently, years of living in Vancouver, and other demographic characteristics were collected and could help illuminate some of the differences in diabetes self-management practices among my participants. This exploratory work offers only tentative implications for health professionals in supporting patients in diabetes self-management.

Conclusion

Diabetes is not only a physical event. It is an event that affects every aspect of the lives of people with diabetes; their spiritual, psychological, relational and social selves. Diabetes is an individual experience, thus we need our educational programs to enable goal setting for the individual rather than for a "representative norms". Personalized care tailored to meet the specific needs of our clients with chronic illnesses seems one of the most appropriate approaches to help them. Diabetes is a family issue and so education needs to involve the family too. This gives our clients sufficient opportunities to speak about challenges they encounter every day. As cultural beliefs vary, cultural competence and nonjudgmental acceptance of folk illness beliefs will enhance the quality of the interaction and trust between the patient and the health care system. The high level of distrust of the Canadian health care system in women by my study indicates the necessity of health care professionals to build trust between themselves and their clients.

This study was unique in that it provided insight into how Iranian Canadian women with diabetes understand and construct meaning about their transition to self-management of diabetes. Focused ethnography assisted me in describing how Iranian culture and immigration experiences influence these women's understandings of diabetes and their experiences in managing diabetes in Canada. The results of this study suggest transition to diabetes self-management is an evolving process as women struggle with their life issues related to living with a chronic illness and immigration; adapting to new roles and responsibilities, and confronting the challenges of learning to live with diabetes.

At the end of my dissertation journey, I return to my core values and beliefs as a Registered Nurse.Nursing is an art; a practical art of caring. We must look at the person not just the disease in our everyday nursing practice. We need to look at our clients as complex individuals who have husbands, wives and children, larger circles of family and friends and larger social and community contexts. We need to focus not only on their medical history, but also on their personal stories and social identities within these networks. Each relationship is a privilege but also may carry expectations about values, roles and behavioral norms. As a nurse, it is hard to uncover how each person's context will influence their priorities and preferences around the way they feel they can or should live with diabetes. Seeking personal stories can help us understand the larger context in which our clients live their lives and the opportunities, resources as well as challenges they face. What a marvelous opportunity we have as health care professionals to support our clients in finding their best life road to health and wellbeing with diabetes.

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APPENDICES

Appendix A- Poster Advertisement (English and Farsi Versions)

You are invited to participate in the study about

Your Experience of Having Diabetes

In this study we sit together to explore your understandings of diabetes in your view

I am looking for:

- **Women between 30-60 years old**
- **Not pregnant**
- **Have diabetes for at least 3 years**
- **Been in Canada for more than 2 years**

If you are interested to participate in this study please reach me by 604-737-3936

Note: our conversation will remain confidential and it will be reported anonymously

About the researcher:

I am PhD student in University of Alberta and I have my RN license from CRNBC. I was diabetes educator for number of years. This study helps me to understand different aspects of diabetes in your view. This study has been approved by health research ethics board in University of Alberta.

از شما دعوت میشود در مطالعه ای تحت عنوان زیر شرکت نمایید

تجربه شما از زندگی با دیابت

در این مطالعه ما با م صحبت میکنیم تا
دریابیم دیدگاه شما از زندگی با دیابت
چگونه است

ما به دنبال افرادی با مشخصات زیر هستیم:

- زنان بین 03 تا 03 ساله
- که باردار نباشند،
- دست‌کم به مدت 0 سال یا بیشتر دیابت داشته باشند،
- بیش از 2 سال در کانادا اقامت داشته باشند

اگر تمایل به شرکت در این مطالعه دارید لطفاً با من با شماره 036 070 0030 تماس بگیرید.

توجه: تمام صحبت‌های شما محرمانه باقی خواهد ماند و به هیچ وجه نام شما آشکار نخواهد شد.

درباره محقق:

من دانشجوی دکترای پرستاری در دانشگاه آلبرتا هستم. من دارای مجوز پرستاری در بریتیش کلمبیا هستم و سالها به عنوان آموزشگر دیابت تجربه دارم. این مطالعه به ما کمک خواهد کرد درک بهتری از دیدگاه زنانی که با دیابت زندگی می کنند داشته باشیم. این مطالعه توسط کمیته اخلاق پژوهش دانشگاه آلبرتا بررسی شده و مورد تصویب قرار گرفته است.

Appendix B- Informed Consent (English and Farsi versions)

UNIVERSITY OF ALBERTA

INFORMATION SHEET

Title: **Exploring the Experience of Iranian Women who live with diabetes in Canada: A focused ethnography**

Principal Investigator(s): Zahra Komeilian, RN, Doctoral Candidate Phone: (604)737-3936
Dr. Judith Spiers RN, PhD (Co-Supervisor) phone: (780) 492-9821
Dr. Marion Allen RN, PhD (Co-Supervisor) Phone (780) 492-6411

You have shown an interest in being in this study. This sheet explains the study and what will happen if you choose to take part. This copy is yours to keep. I will ask you to sign a consent form. If you would like to know more, or have any question at any time, please ask me.

Background

Living with diabetes may be different for men and women. Moving from one country to another country may also change how you are able to live with diabetes. Understanding your experiences of having diabetes will help us provide the best care appropriate to your needs.

Purpose

Your participation in this study will help our research team to understand Iranian women's experiences of living with diabetes. This may help us improve health care services.

Procedures

The interview study is designed to explore your experiences and perceptions of what it is like to live with diabetes.

Participating in this study will involve:

a) One interview (60-90 minutes) and short 30 minute follow-up interview (by phone or in person) for clarification if needed. The interview will be recorded. The interview will be scheduled at a time and place that is convenient for both of us. I will ask you to provide some general information about yourself, such as your age, education and family. This will allow me to describe who participated in our study. This information will only be reported as a group. You will not be identified by name.

During the interview, I will ask you to talk about your experiences with diabetes. I may take brief notes to help me track important ideas. You are free to talk about any issues or questions that you want to. You do not have to answer any questions you do not want to. The questions are about your daily life with diabetes, and how you manage it. I am interested in knowing how you combine all the different roles in your life (e.g., mother, wife or worker) with diabetes. There are no right or wrong answers. We want to understand your experience. The conversation in the interview will be audio-taped, then typewritten later. I will use a code to protect your identity. The researchers will review the information to see if others have had similar or different experiences.

Your participation in the interview is your choice. You may leave the interview at any time or withdraw from the study. You do not have to answer any questions or discuss any topic in the interview if you do not want to. Your name will not be linked to the research data. The researchers will maintain confidentiality about what is said in the interview. You will not be identified in any report or presentation arising from this study. Taking part in this study or dropping out will not affect your diabetes care.

Possible Benefits:

There are no direct benefits from being in this study. You may enjoy the opportunity to talk about your experiences. The goal of this study is to gain knowledge and insight into your experiences.

Possible Risks:

There are no anticipated risks of being in this study. We will explore your experiences of having diabetes. Talking about some experiences may make you feel uncomfortable. If you become uncomfortable, we can stop the interview. You can decide if you want to continue then or at a later time. If you want, we will refer you to the Social Worker at your diabetes center

Confidentiality:

I will not need any information other than the information I collect in the interview. I will not access your personal health records. Any research data collected about you during this study will not identify you by name, only by a coder. Your name will not be disclosed to anyone. Any report published as a result of this study will not identify you by name.

Voluntary Participation:

You are free to withdraw from the research study at any time, and your continuing medical care will not be affected in any way. If you want to withdraw, we will destroy your information.

Costs

There are no costs for you to participate in this study. We would like to offer you a token gift in appreciation of your time and effort. You will receive this gift at the end of the first interview even if you decide to stop the interview or not to do another interview. I can reimburse travel costs if you need to travel to the interview.

Contact Names and Telephone Numbers:

For more information you may contact my supervisors: Dr. Jude Spiers (email: jaspiers@ualberta.ca) or Dr. Marion Allen (email: marion.allen@ualberta.ca) at the Faculty of Nursing, University of Alberta, Canada. If you have a concern about this research study, you can contact the Faculty of Nursing Research Office at 780-492-3769. The plan for this study has been reviewed for its adherence to ethical guidelines and approved by Research Ethics Board 1 at the University of Alberta. For questions regarding participants rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615."

CONSENT FORM

Title of Project: Iranian Women's' experiences of living with diabetes: A focused ethnography

Investigators: Zahra Komeilian, RN, Doctoral student Phone: 604-737-3936
Dr. Judith Spiers RN, PhD (Co-Supervisor) phone: 001-(780) 492-9821
Dr. Marion Allen RN, PhD (Co-Supervisor) Phone 001-(780) 492-6411

Part 2 (to be completed by the research participant):

		Yes	No
1.	Do you understand that you have been asked to be in a research study?	☐	☐
2.	Have you read and received a copy of the attached Information Sheet?	☐	☐
3.	Do you understand the benefits and risks involved in taking part in this Study?	☐	☐
4.	Have you had an opportunity to ask questions and discuss this study?	☐	☐
5.	Do you understand that you are free to withdraw from the study at any time, Without having to give a reason and without affecting your future medical care?	☐	☐
6.	Has the issue of confidentiality been explained to you?	☐	☐
7.	Do you want the investigator(s) to inform your family doctor that you are Participating in this research study? If so, give his/her name ___________________	☐	☐

8. Who explained this study to you? ____

I agree to take part in this study: **YES** ☐ **NO** ☐

Signature of Research participant ____

(Printed Name) ____

Date: ________________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Witness ____

Signature of Investigator or Designee __________________________________ Date __________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH SUBJECT. "The plan for this study has been reviewed for its adherence to ethical guidelines and approved by Research Ethics Board 1 at the University of Alberta. For questions regarding participants rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615."

بررسی تجربه زندگی زنان ایرانی مبتلا به دیابت در کانادا: یک مطالعه کیفی

مدیران تحقیق:

Dr. Judith Spiers RN, PhD (سرپرست) تلفن: ۷۸۰-۴۹۲-۹۸۲۱

Dr. Marion Allen RN, PhD marion.allen@ualberta.ca

زهره کمالی تلفن ۶۰۴-۷۳۷-۳۹۳۶

اطلاعات اولیه:

شما نشان داده اند علاقه به شرکت در این مطالعه دارید. این فرم توضیح می دهد که در این مطالعه چه اتفاقی خواهد افتاد. برای شرکت در این مطالعه، این فرم رضایت را باید پر و امضا کنید. اگر می خواهید بیشتر بدانید، و یا هرگونه سوال در هر زمانی داشته باشید، لطفا از ما بپرسید.

زمینه

زندگی با دیابت ممکن است برای مردان و زنان متفاوت باشد. درک تجارب شما از داشتن دیابت کمک خواهد کرد که بهترین مراقبت های مناسب برای زنانی مثل شما را فراهم کنیم.

هدف

مشارکت شما در این مطالعه تیم تحقیقاتی ما را به درک تجربه های زنان در زندگی با دیابت کمک خواهد کرد.

رویه

این مطالعه طراحی شده است تا به بررسی تجارب و برداشت های شما در مورد زندگی با دیابت بپردازد.
شرکت در این مطالعه شامل موارد زیر است:

الف) یک مصاحبه (۹۰-۰۹ دقیقه) و کوتاه مدت ۰۹ دقیقه پیگیری مصاحبه (از طریق تلفن یا حضوری) برای روشن شدن در صورت نیاز. مصاحبه در اتاق آموزش و پرورش در دانشگاه برگزار می شود. مصاحبه ضبط خواهد شد.

ب) از شما برخی از اطلاعات کلی در مورد سن، آموزش خود و خانواده پرسیده خواهد شد. این اطلاعات فقط به عنوان یک گروه منتشر می شود و نام و مشخصات فردی شما منتشر نمی شود.

در طول مصاحبه، من با شما در مورد تجربیات شما در مورد دیابت بحث خواهم کرد. ممکن است من یادداشت های کوتاه از صحبت های شما بردارم که به من در پیگیری ایده ها کمک می کند. شما آزاد هستید تا در مورد هر موضوع و یا سوالی که می خواهید صحبت کنید. شما لازم نیست به همه سوالات پاسخ دهید. سوالات در مورد زندگی روزمره شما با دیابت هستند، و اینکه چگونه شما آن را مدیریت می کنید. من علاقه مند به دانستن چگونگی ترکیب تمام نقش های مختلف زندگی شما (به عنوان مثال، مادر، زن، کارگر) با دیابت هستم. هیچ پاسخ درست یا غلطی وجود دارد. ما می خواهیم تجربه شما را درک کنیم. گفتگو در مصاحبه ضبط و سپس تایپ خواهد شد. نام شما به صورت کد در متن داده خواهد شد تا از هویت شما محافظت شود.

مشارکت شما در مصاحبه به انتخاب شما بستگی دارد. شما می‌توانید مصاحبه را در هر زمان ترک کنید یا از مطالعه خارج شوید. شما می‌توانید از پاسخ به هرگونه سوال یا بحث هر موضوع در مصاحبه امتناع کنید. نام شما در اطلاعات تحقیق ثبت نمی‌شود و هر آنچه در مصاحبه گفته شود محرمانه حفظ می‌شود. شما در هر گزارش یا ارائه اطلاعات ناشی از این مطالعه قابل شناسایی نمی‌شوید. عدم تمایل برای شرکت در این مطالعه و یا حذف از مطالعه بر مراقبت شما از کلینیک دیابت تاثیر نمی‌گذارد.

مزایای احتمالی :

هیچ مزایای مستقیم از بودن در این مطالعه وجود ندارد. شما ممکن است از فرصتی برای صحبت در مورد تجربه های خود لذت ببرید. هدف از این مطالعه به دست آوردن دانش و بینش نسبت به تجارب شما است.

خطرات احتمالی :

هیچ خطر پیش بینی شده در این مطالعه وجود ندارد. اگر بیان تجربیات شما از داشتن دیابت و یادآوری برخی از تجارب باعث شود که شما احساس ناراحتی کنید ، ما می‌توانیم مصاحبه را متوقف کنیم. شما می‌توانید تصمیم بگیرید که آیا شما مایل به ادامه آن و یا در زمان دیگری هستید. اگر شما مایل باشید ، ما شما را به مددکار اجتماعی در بیمارستان ارجاع می‌دهیم

محرمانه بودن اطلاعات :

ما به هیچ اطلاعات دیگری غیر از اطلاعات جمع آوری شده در جدول جمعیت شناختی و مصاحبه نیاز نداریم. ما به پرونده سلامت شخصی شما در درمانگاه دسترسی نداریم. هرگونه اطلاعات در مورد شما که در این مطالعه جمع آوری شد با نام شما مشخص نمی‌شود و تنها با حرف اول و شماره رمزی مشخص خواهد شد. نام شما در خارج از محیط پژوهش فاش نمی‌شود. هرگونه گزارش نتایج منتشر شده به عنوان نتیجه این مطالعه به شما با نام مشخص نخواهد شد.

مشارکت داوطلبانه :

شما آزاد هستید که از مطالعه پژوهش در هر زمان خارج شوید و این ادامه درمان شما را به هیچ وجه تحت تاثیر قرار نخواهد داد. اگر مطالعه انجام شده یا اگر آن را در هر زمان قطع کنید کیفیت مراقبت های پزشکی شما تحت تاثیر قرار نمی‌گیرد.

هزینه ها

هیچ هزینه ای برای شما برای شرکت در این مطالعه وجود ندارد. هدیه کوچکی به منظور تقدیر از وقت و تلاش شما تقدیم خواهد شد. شما این هدیه را در پایان مصاحبه و حتی اگر شما تصمیم به توقف مصاحبه بگیرید دریافت خواهید کرد. پارکینگ مجانی است. اگر شما نیاز به مراقبت از کودکان در طول مصاحبه با ما ، لطفا به ما بگویید. ما برای سرویس مراقبت از کودکان مراقبت روزانه از طریق بیمارستان هماهنگی لازم را انجام می‌دهیم.

نام و شماره تلفن تماس :

اگر شما نگرانی هایی در مورد حقوق شما به عنوان شرکت کننده در این مطالعه دارید می‌توانید با کمیته اخلاق پزشکی برای کسب اطلاعات بیشتر می‌توانید با مدیر محقق تماس بگیرید. در صورت داشتن هرگونه سوالی درباره حقوق شرکت کنندگان و اصول اخلاق پژوهشی این مطالعه می‌توانید با دفتر اخلاق پژوهش دانشگاه با شماره تلفن ۲۰۵-۵۰۶۲ (۰۸۹) تماس بگیرید

فرم موافقت

قسمت ۱ (توسط محقق اصلی تکمیل میشود) :

عنوان پروژه : بررسی تجربه زندگی زنان ایرانی مبتلا به دیابت در کانادا: یک مطالعه کیفی

مدیر تحقیق:

Dr. Judith Spiers RN, PhD (سرپرست) تلفن: ۷۸۰-۴۹۲-۹۸۲۱

Dr. Marion Allen RN, PhD marion.allen@ualberta.ca

زهره کلیمی تلفن ۶۰۴-۷۳۷-۳۹۳۶

قسمت ۲ (توسط شرکت کننده تکمیل میشود) :

	بله	خیر
آیا متوجه میشوید که از شما خواسته شده که در مطالعه شرکت کنید؟	☐	☐
آیا شما یک کپی از اطلاعات جدول پیوست را دریافت و مطالعه کرده اید؟	☐	☐
آیا شما را در ست متوجه منافع و خطرات مربوط به شرکت در این مطالعه هستید؟	☐	☐
آیا تا به حال فرصت بحث و سوال در مورد این مطالعه داشته اید؟	☐	☐
آیا میدانید که شما آزاد هستید تا از مطالعه در هر زمان بدون نیاز به ارائه دلیل و بدون ترس از تاثیر بر مراقبت های پزشکی خارج شوید؟	☐	☐
محرمانه بودن مطالعه برای شما توضیح داده شده است؟	☐	☐
آیا می خواهید محقق (ها) به اطلاع پزشک شما برسانند که شما در این مطالعه شرکت کرده اید؟	☐	☐

اگر بله، نام پزشک خود را بنویسید ______

چه کسی این مطالعه را به شما توضیح داد : ؟ ______

من موافق شرکت در این مطالعه هستم : بله ☐ خیر ☐

امضا شرکت کننده ______

(نام و نام خانوادگی)

______

تاریخ : ______

امضای شاهد ______

من باور دارم که کسی این فرم را امضا کرده از آنچه در مطالعه است درک کامل دارد و به طور داوطلبانه با شرکت در آن موافقت می کند.

امضای محقق یا نماینده ____________________ تاریخ __________

برگه اطلاعاتی باید به این فرم رضایتنامه پیوست شده و یک نسخه به شرکت کننده تحویل شود

کمیته اخلاق دانشگاه آلبرتا (HREB) در دانشگاه آلبرتا، ادمونتون آلبرتا که مدیریت فرایند بررسی اخلاقی برای همه استادان، کارکنان، و دانشجویان در دانشگاه آلبرتا را به عهده دارد این مطالعه را تایید کرده است.
یک نسخه امضا شده از این فرم رضایت شده است به شما داده را برای ثبت و مرجع خود را نگه دارید.

امضا و تاریخ	نام و نام خانوادگی شرکت کننده (ها)
امضا و تاریخ	امضاء نام و نام خانوادگی محقق زهرا کاظمیان
امضا و تاریخ	**شاهد**

Appendix C- Interview Guide

FACULTY OF NURSING

Dr. Judith Spiers

Associate Professor

Telephone: (780) 492-9821

Interview Guide

Note: these are guiding questions only. Some or all of the probes will be used, depending on the flow and direction of the conversation.

Ground tour question:

1. Tell me about your experiences of living with diabetes

2. Could you describe what having diabetes is like for you?

3. Have your views about diabetes and diabetes management changed over the course of illness? 4. Can you compare your experience of having diabetes before and after you moved to Canada?

5. What beliefs do you have about women with diabetes?

6. How diabetes self-management does fit into your outside or inside the house job?

7. Tell me about the challenges you have with everyday life?

8. Tell me how your life has changed since you developed diabetes?

    9. How has your family life and routines changed. Is this change positive or negative – why, in your view?

10. How has diabetes improved your life? Why, why not?

    11. What is it like living with diabetes each day? What is more difficult? What is easier?

    12. When you are with old friends/family, what do tell them about your diabetes and diabetic needs? Why? When you meet a new friend, what do you tell him/her?

    13. How do you feel about having diabetes? What are your views or feelings about diabetes?

    14. What do you understand about exercise in diabetes? What helps/stops you from doing this in your life?

15. Do you exercise- when, how, where?

16. Can you tell me about your challenges when you moved to Canada? Do you still struggling with those?

Can you tell me how do you adjust yourself with different issues in different country?

Follow-up Question

16. Can you tell me how you discovered that you have diabetes?

17. How has your condition changed since that time?

18. Has this changed how you carry out your usual activities? How so?

19. Describe how you feel about your health?

20. What comes to mind when I mention diabetes?

21. How does religion or faith affects what do you do to care for our diabetes?

22. Tell me about getting care for your diabetes?

23. Is there any special belief or ritual (specific behaviors, practices, dietary) you do to deal with your illness?

Closing out Question

24. is there anything else would you like to tell me about diabetes?

In order to elaborate some part of interview, I will use the following tips:

25. Can you elaborate on that idea?

26. Would you explain that further?

27. I’m not sure I understand what you’re saying.

28. Would you give me an example?

Appendix D- Evolving questions

Some women in my study believed diabetes is a ball and chain I would like to know about your opinion in this regard?

Can you tell me more about the earlier days of diagnosis?

Have you met any problem to find your preferred exercise?

Do you believe in Evil Eyes? Do you think it effects on your illness?

Can you tell more about your opinion on how God’s will or pre-destination affected your view of your illness?

Have you ever tried to hide your illness from family, friends, colleagues or manager?

Appendix E- Confidentiality Agreement Form

UNIVERSITY OF ALBERTA

FACULTY OF NURSING
Dr. Judith Spiers
Associate Professor
Telephone: (780) 492-9821
Fax: (780) 492-2551

Confidentiality Agreement

As a team member of the research project team, I understand that in the performance of my responsibilities, certain types of confidential information shall be disclosed to me. In consideration of this, I hereby agree to the following:

1. All data received while working in the research project are to be used only for research purposes.
2. All research staff and trainees are subject to removal from the project if they compromise the confidentiality of the documents and/or use the data for purposes beyond the scope of the proposed research project.
3. Access to the data is at the discretion of Dr. Jude Spiers and Zahra Komeilian
4. The data will not be reproduced in any form other than that which has been specified in the proposal without the consent of Zahra Komeilian and Dr. Jude Spiers.
5. Unless approved by Zahra Komeilian and Dr. Jude Spiers, all information disclosed in the research project related meetings will be confidential.
6. Transcriptionists agree not to reproduce or permit reproduction of any data.
7. All researchers and research staff are prohibited from using unsecured communication methods (such as E-mail) to transmit data. In addition, data can only be disseminated to other approved members of the research team if approved by Zahra Komeilian and Dr.

Jude Spiers.

8. Data will not be released to third parties unless there is a data sharing and confidentiality agreement between the parties, and is approved by Zahra Komeilian and Dr Jude Spiers.

9. The release of findings, conclusions, reports, or products will not take place without the consent of Zahra Komeilian and Dr. Jude Spiers.

10. These data dissemination and confidentiality obligations shall survive the completion of the research project.

I hereby acknowledge that I have read and agree to all of the above conditions.

_________________________________ _________________________________

Signature Date

_________________________________ _________________________________

Print Name Position

Zahra Komeilian (witness)

Sources (agreement was compiled using the following sources):

- University of Houston (Office of the Counsel General): http://www.research.uh.edu/downloads/Word_format/Unilatera_Confidential_Agrmt.doc
- University of Illinois at Chicago Medical Centre: http://www.hospital.uic.edu/its/faq/security/access_agreement.doc
- Institute for Clinical Evaluative Sciences (ICES): Privacy Code-July 2001

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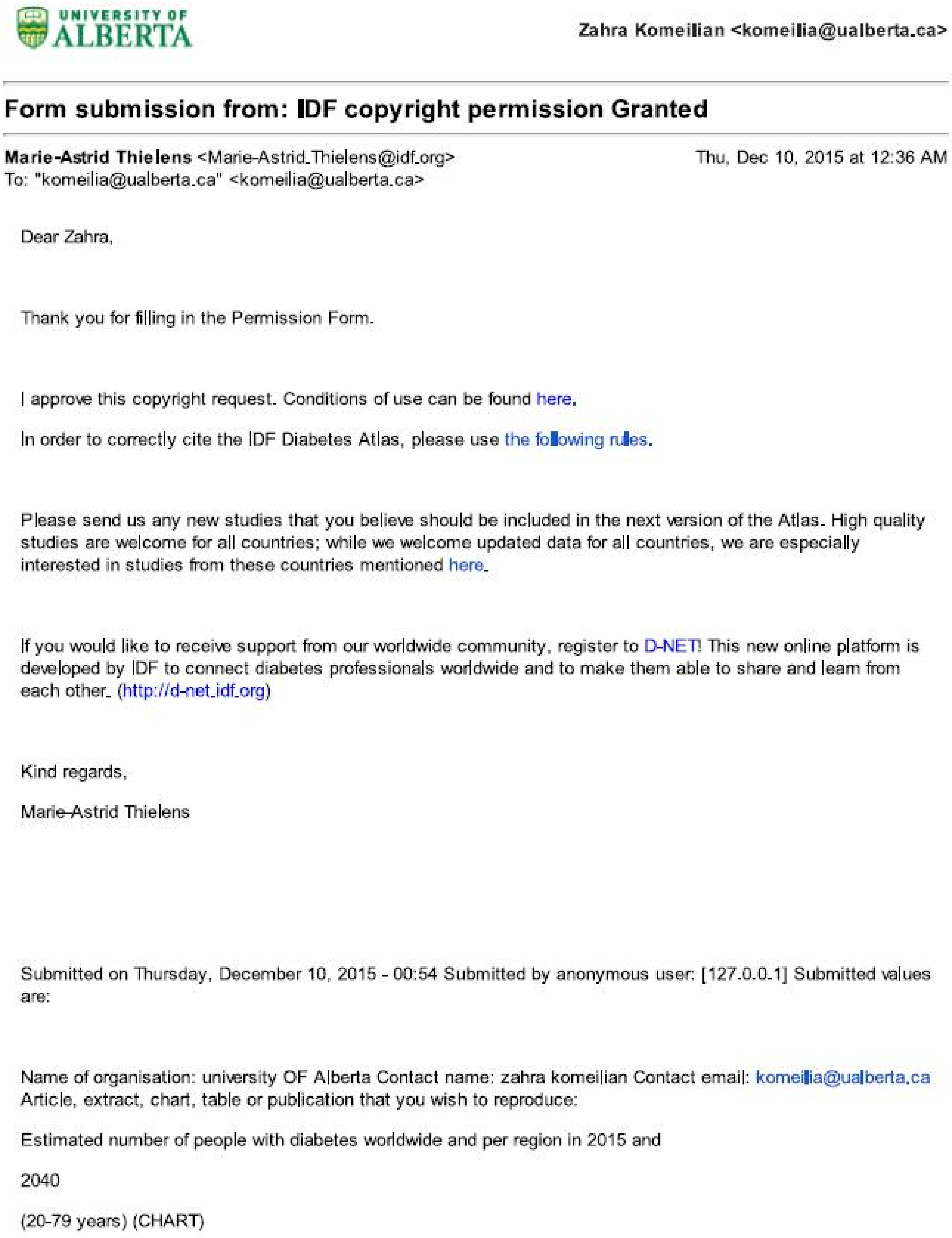

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If you would like to receive support from our worldwide community, register to D-NET! This new online platform is developed by IDF to connect diabetes professionals worldwide and to make them able to share and learn from each other. (http://d-net.idf.org)

Kind regards,

Marie-Astrid Thielens

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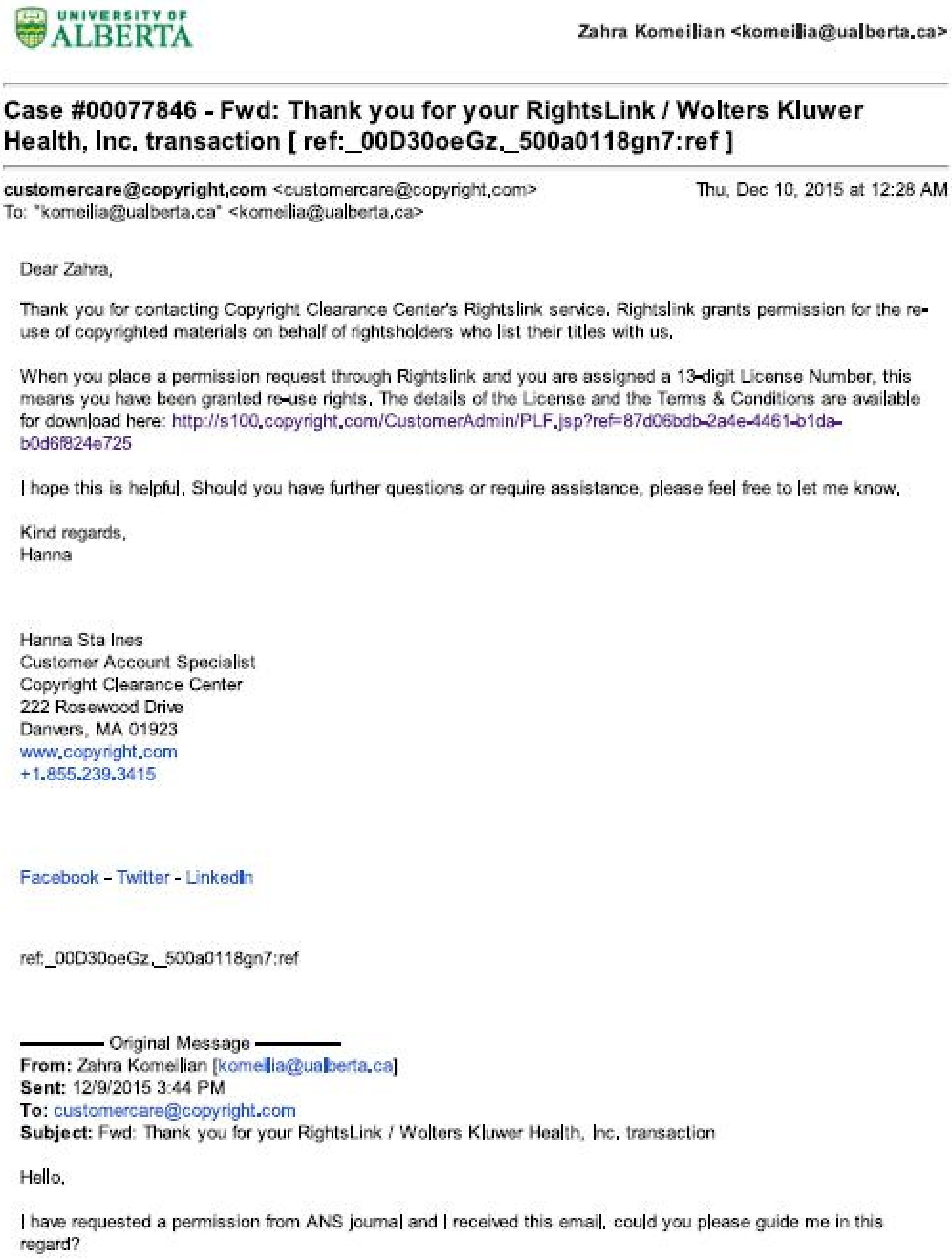

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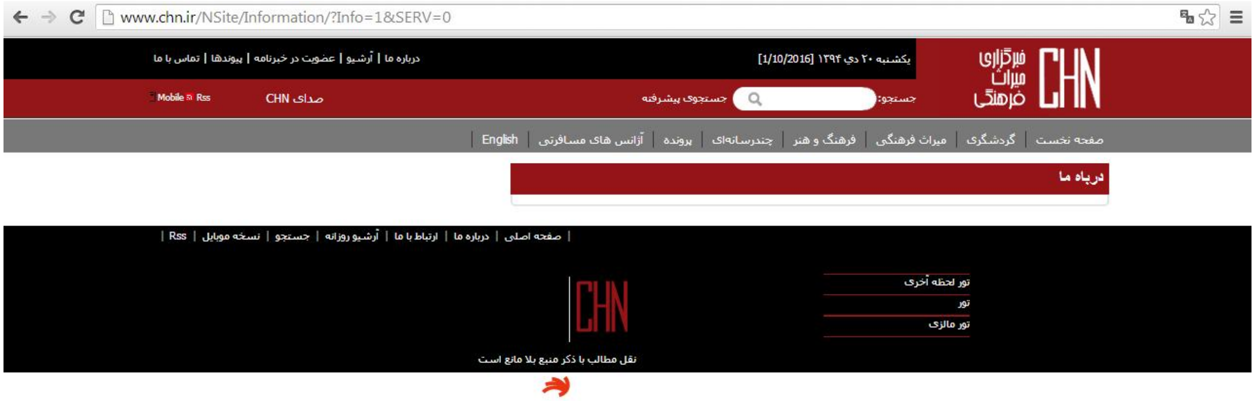

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