

A CRITICAL EXAMINATION OF THE LIVED EXPERIENCES OF SOMALI REFUGEES
AND IMMIGRANTS DIAGNOSED WITH TYPE 2 DIABETES AND THEIR FAMILY

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A DISSERTATION SUBMITTED TO THE FACULTY OF GRADUATE STUDIES IN
PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR
OF PHILOSOPHY

GRADUATE PROGRAM IN KINESIOLOGY AND HEALTH SCIENCE
YORK UNIVERSITY
TORONTO, ONTARIO

August 2021

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ABSTRACT

This narrative study explores how the process of resettlement impacted the management/care of type 2 diabetes (T2D) among Somali immigrants and refugees living with T2D and/or family members of Somali immigrants and refugees living with this condition residing in Toronto. It also examines how the participants described their and/or family member/s illness. Family members were included in this study since research indicates that they can play a significant role in the care of individuals living with T2D (Black, Maitland, Hilbers, & Orinuella, 2016; Mayberry & Osborn, 2012; Protudjer, Dumontet, & McGavock, 2014). In total, 37 face-to-face interviews were conducted with 19 family members and 18 individuals living with T2D from Fall 2017 to December 2018. Data analysis involved analysis of narratives (Creswell, Hanson, Plano Clark, & Morales, 2007; Polkinghorne, 1995), which resulted in three themes across all participant narratives. These themes were then organized and presented through restorying three participant experiences. This study also included found poetry, displaying participants' words from their interviews as a poem (Butler-Kisber, 2020).

The first theme, 'precarious settlement,' describes the participants' experiences dealing with stressors, such as unsafe neighbourhoods, un/underemployment, and poverty. The second theme, 'gendering of T2D,' illustrates the gendered ways in which the participants described T2D (as mainly a woman's disease) and the gendered forms of care that were enacted by family members. Lastly, the third theme, 'diabetes as bitter-sweet,' explores how T2D was narrated and perceived by participants in this study, which included positive and negative accounts. This study recommends that further attention be placed to address the structural inequalities and barriers

experienced by the participants. Mental health supports that are inclusive of the participants' religious/cultural worldviews are also needed to support family members and individuals living with T2D in this population in dealing with diagnosis, care, and resettlement stressors that they may be experiencing.

DEDICATION

For my parents, the participants, and my dear nephews Omar and Zakariya.

ACKNOWLEDGEMENTS

The completion of this dissertation would not be possible without the support and guidance of several individuals. I am grateful for the time and contributions of the participants in this study. This dissertation would not be possible without your trust and faith in me, and the seeds that you have planted here through your stories. *Mahadsanid*.

I would also like to thank my graduate supervisor and committee members for their ongoing support over the years. Dr. Yuka Nakamura, I could not have made it this far without your support. I will never forget our meetings downtown, and the inspiring conversations that we shared over the years. I am grateful to have had the opportunity to work with you on this project. Dr. Michaela Hynie and Dr. Beryl Pilkington, thank you for supporting my growth as a researcher and for always being there for me.

Dr. Joseph Mensah and Dr. Nimo Bokore, I am so grateful for the opportunity to meet you on this journey. Thank you for taking the time to serve on my examination committee, and for your truly valuable insights and recommendations for this study.

I am also thankful for the support of the resettlement agencies, mosques, and individuals that helped with the study recruitment process: Mohamed Duale, Farhia Warsame, Mahad Yusuf, Dr. Habon Farah, Iiman Darman, and Imam Imran Ally. Thank you for all of your guidance with this study. And to Idil Burale, Anab Mohamud, Allyson Adley, Dr. Emilia Nielsen, and the wonderful Somali women at the Hooyo Initiative Hub; thank you for your encouragement and for taking the time to meet with me.

Lastly, I thank my family and friends, for supporting me throughout this entire experience. I could not have done this without you.

TABLE OF CONTENTS

Abstract	ii
Dedication	iv
Acknowledgements	v
Table of Contents	vi
Abbreviations	viii
Chapter One: Introduction	1
Somali History.....	1
Migration and Resettlement.....	2
Research Objectives	6
Outline of Dissertation	6
Chapter Two: Literature Review	8
Type 2 Diabetes (T2D)	15
Summary	16
Chapter Three: Theoretical Approach	19
Resettlement	20
Social Determinants of Refugee Health	21
Assimilation Theory	22
Acculturation Theory.....	23
Diaspora Theory	27
Culture Care Theory	33
Summary	36
Chapter Four: Methodology	37
Stories of Change.....	38
Narrative Research.....	39
Poetry	44
Found Poetry	46
Recruitment	50
Data Collection	52
Participants	54
Data Analysis.....	55
Creation of Found Poetry	57
Ethics	60
Validity	61
Summary	62

Chapter Five: Findings	63
Family Trees & Diabetes	63
A Walk into the Forest.....	64
Precarious Settlement	66
“Second Home”	71
Aaliyah’s Story	72
Gendering of T2D	83
Hooyo.....	86
Bishaaro’s Story	87
Diabetes as “Bitter-Sweet”	94
“Bitter-Sweet”	100
Guleed’s Story	101
Summary	113
Chapter Six: Discussion and Conclusion	114
Resettlement Space: Environmental Context.....	116
Impacts on Health.....	118
Neighbourhood Stigma	121
Education Factors.....	122
Kinship and Social Factors	128
Care	129
Summary and Recommendations	135
Macro.....	136
Meso	138
Micro.....	141
Culturally Congruent Care	142
Strengths of the Study	143
Limitations of the Study	145
Conclusion.....	148
References	150
Appendices	170
Appendix A: Recruitment Poster	170
Appendix B: Interview Guide	171
Appendix C: Demographic Questionnaire	172
Appendix D: Informed Consent	173

ABBREVIATIONS

CCT Culture Care Theory

T1D Type 1 Diabetes

T2D Type 2 Diabetes

UNHCR United Nations High Commissioner for Refugees

CHAPTER ONE: INTRODUCTION

Somali History

Somalis represent ethnic and cultural groups in Djibouti, Ethiopia, Kenya, and Somalia (Lagacé, Charmarkeh, & Grandena, 2012; Lewis, 1988; Spitzer, 2006). They are Cushitic and largely pastoral nomads, bearing close relations to other Cushitic tribes in the Horn of Africa (Abdela, 2015; Lewis, 1988). Islam is a significant part of not only Somali culture but also identity and has served as a means to unite Somalis regardless of clan affiliations (Koshen, 2007; Langellier, 2010; Spitzer, 2006).

Despite this unity, colonization of Somalia has increased the divide between clans, ones with far-reaching impacts on present-day Somalia. The colonization of Somalia has contributed to the dissolution of the central government of post-colonial Somalia and the forced displacement, poverty, and trauma experienced by Somalis in the past three decades (Bokore, 2016a, 2016b, 2018; Elmi & Barise, 2006; Hopkins, 2010; Issa-Salwe, 1996). Through colonization, historical Somalia was divided into five parts by the British, Italian, and French colonizers (Elmi & Barise, 2006; Hopkins, 2010). Subsequently as Elmi and Barise (2006) indicate, “the partitioning of Somalia permanently damaged the Somali people” (p. 36).

This “colonial legacy” is believed to have been one of the contributing factors of the Somali civil war (Elmi & Barise, 2006, p. 36). The Somali civil war, contrary to popular belief, did not only begin as a result of clan disputes but is also rooted in the breakdown of traditional Somali society. Previously, traditional Somali society functioned through social systems established between clan elders who resolved

disputes (Bokore, 2018; Elmi & Barise, 2006; Hopkins, 2010; Issa-Salwe, 1996).

However, following the independence of Somalia from British and Italian rule, these traditional systems of governance were replaced with a centralized system of government established by the British and Italian colonizers (Elmi & Barise, 2006; Hopkins, 2010; Issa-Salwe, 1996).

When Siad Barre seized power through a *coup d'état* in October of 1969, Somalis began to experience the impacts of his dictatorship, as he favoured members of his clan and silenced the voices of other clans and sub-clans (Elmi & Barise, 2006; Hopkins, 2010). In January 1991, Barre was ousted from the seat of government in Mogadishu (Hopkins, 2010; Issa-Salwe, 1996; Koshen, 2007). With the collapse of the government, there was increasing conflict, political instability, and violence in Somalia (Hopkins, 2010). Thus Kusow (1998) states that “the Somali civil war has produced one of the most horrible human tragedies in the history of contemporary Africa” (p. 64). From 1988 to 1995, it is estimated that about 350,000 people died during this conflict (Spitzer, 2006).

Migration and Resettlement

Due to the civil war in Somalia, many Somalis were forced to migrate to other countries for refuge and safety. Subsequently, an increasing number of Somalis migrated to countries in the West, such as Canada. By the mid 1990s, there were an estimated 40,000 to 50,000 Somalis living in Toronto (Berns-McGown, 2013; Mohamed, 2016). The majority of Somali refugees had arrived between 1992 to 2007, following the dismantling of the Siad Barre government (Mohamed, 2016). Most Somalis had come to

Canada as refugees, settling in Ontario in cities such as Ottawa and Toronto (Berns-McGown, 2013; Bokore, 2016a; Mohamed, 2016).

Many Somalis experienced resettlement challenges which were further compounded by amendments to the Immigrant Act outlined in Bill C-86 in 1993. Specifically, Somali refugees experienced barriers achieving permanent residence in Canada because of requirements that they provide 'satisfactory identity documents' (Fellin 2015a; Mohamed, 2016, p. 69; Naji, 2012; Stewart et al., 2008). For many Somali refugees, this was a difficult task, as there was no government in Somalia, and they therefore had no way of acquiring this documentation to prove their identities (Fellin, 2015a). Those without appropriate documents were required initially to wait for five years before they could apply for permanent residency in Canada (Fellin, 2015a; Spitzer, 2006). Thus, Somali refugees unable to provide this documentation experienced barriers accessing post-secondary education and employment, and were unable to pursue family reunification (Fellin, 2015a; Mohamed, 2016; Spitzer, 2006; Stewart et al., 2008). Most impacted by Bill C-86 were women and children who together represented 80% of refugees unable to provide this documentation and the majority of Somali refugees in Canada during this period (Fellin, 2015a; Mohamed, 2016; Spitzer, 2006).

These resettlement stressors created health disparities for members of the Somali diaspora, as many Somali refugees experienced barriers accessing these social determinants of health (Spitzer, 2006; Stewart et al., 2008). The term social determinants of health refers to the "social conditions" that impact an individual's and/or groups health and wellbeing (Hynie, 2018a, p. 211). Due to these barriers, many

Somalis were and continue to be at an increased risk of developing T2D, by virtue of their migration journeys, experiences with trauma, stress, and low socio-economic status (Agyemang, Goosen, Anujoo, & Ogedegbe, 2012; Kelly & Ismail, 2015; Kinzie et al., 2008; Spitzer, 2006). Indeed, refugee status, in particular, has been demonstrated to be a risk factor for T2D (Abukhdeir, Caplan, Reese, & Alema-Mensah, 2013; Goosen, Middelkoop, Stronks, Agyemang, & Kunst, 2014). Studies also indicate that low socioeconomic status presents barriers for those living with T2D in the self-management of their disease (Pilkington et al., 2010). Furthermore, there is a plethora of research available highlighting increased prevalence of T2D amongst Black Canadians compared to White Canadians (Gagné & Veenstra, 2017; Patterson & Veenstra, 2016; Veenstra & Patterson, 2016). It is postulated that increased risk of T2D among Black Canadians may be due to ongoing experiences with racism in their daily lives (Veenstra & Patterson, 2016).

According to Stewart et al. (2008) newcomers' perspectives of social support is shaped by their previous experiences of social support in their country of origin. In their study of immigrant and refugee newcomers in Canada, Somali newcomers were shown to implement a holistic understanding of social support that included "informal social networks", such as family and friends (Stewart et al., 2008, p. 141). The significance of social support among newcomer refugee and immigrant populations in Canada has also been displayed in other studies (Hynie, Crooks, & Barragan, 2011; Makwarimba, Stewart, Simich, Makumbe, Shizha, & Anderson, 2013).

Qualitative studies have been utilized to shed light on the social context and lived experiences of individuals diagnosed with T2D (e.g., Henderson, Wilson, Roberts, Munt,

& Crotty, 2014; Protudjer et al., 2014). While the qualitative literature on T2D is extensive, the perspectives of Somali immigrants and refugees are seldom included. There is very little qualitative research available to date that includes the experiences of Somalis living with T2D in Canada. Research on the impact/s of T2D on the family in this population is also needed since there is no literature examining the impact of social networks on T2D management/care in this group. This is especially important, as there is research that shows that social networks can provide health benefits to those living with T2D (Black et al., 2016; Cockerham, Hamby, & Oates, 2016). There is growing literature that examines the positive influence of formal support systems in the care of individuals living with T2D; however, fewer studies explore the impact of social support systems that are informal, such as the family (Black et al., 2016; Stopford, Winkley, & Ismail, 2013). The few studies in this area highlight the significant role that family members play in the care of individuals diagnosed with T2D (e.g., Black et al., 2016; Mayberry & Osborn, 2012; Protudjer et al., 2014).

Through analysis of resettlement context and informal support systems, this study aims to address the paucity in the literature regarding the experiences of Somali immigrants and refugees and their families, and their lived experiences with T2D in Canada. This is a group that presents multiple risk factors for T2D, such as ethnicity, refugee status, and marginalized social status in Canada. However, there is little literature available regarding their (and their families') experiences with this chronic health condition.

Research Objectives

The purpose of this doctoral study is to explore the lived experiences of Somali immigrants and refugees diagnosed with T2D and their families living in Toronto. The main objectives are:

- To better understand how settlement impacts their management/care of T2D.
- To examine how the participants narrate and make sense of their T2D diagnosis.

Outline of Dissertation

Chapter Two includes an overview of the literature on the resettlement context of Somali families in Canada. The impacts of immigration policy on Somalis in Canada are also explored in this chapter, in addition to resettlement stressors faced by Somali families. This chapter concludes with a brief review of the diabetes literature on Somalis in Canada.

Chapter Three reviews the literature on refugee resettlement. It also explores a brief discussion on integration theories. To gain more insight on the process of resettlement as experienced in this study, this study implemented diaspora theory. This lens brings into focus not only the participants' stories of the homeland, but also the diaspora space in which the participants live and where their stories take place (Brah, 1996). Culture care theory (CCT) was used to understand how the participants managed/cared for their and/or family member/s' T2D (Leininger, 2006). This theoretical framework provides analysis of constructs of care in accordance to culture, highlighting how these constructs influence one another. It offers an open approach that is inclusive of the participants' worldviews.

Chapter Four provides an overview of the methodological approach implemented in this study, including recruitment, data collection and analysis. This study employed qualitative narrative research methods and found poetry as a form of data analysis (Butler-Kisber, 2020; Hanauer, 2010). This chapter also includes ethical approaches utilized in this study and methods of assuring validity.

In Chapter Five, the findings of this study are discussed. Three stories are integrated in this chapter representing each of the three themes in this study. Narrative excerpts are also integrated into these stories of these three participants to highlight the perspectives of the other participants in this study. Each section of this chapter includes found poetry depicting the theme being discussed.

In Chapter Six, I review the findings using the theoretical frameworks implemented in this study in relation to existing literature on these topics. This study provides insights on how precarious settlement was experienced in the diaspora space and the resettlement stressors faced by the participants in this study. The diasporic community is also discussed in relation to the cohesive networks built to provide support/s and care for those living with T2D. This chapter also includes a discussion on how care was enacted by the participants in this study, along with strengths and limitations of this study, and recommendations.

CHAPTER TWO: LITERATURE REVIEW

This chapter presents a review of the literature on Somali families in Canada. It begins with a brief history of the resettlement stressors experienced by first- and second-generation Somalis. The discussion of resettlement stressors mainly explores those faced by Somali women and children, as they comprise the main area of focus in the literature on Somalis in Canada to date. The adverse impact of immigration policies are then examined, along with challenges faced by Somali women, men, and youth resettled in Canada, and how resettlement has altered traditional Somali family roles and dynamics. This chapter concludes with a review of the diabetes literature on Somalis in Canada.

The majority of the Somali resettlement literature in Canada is focused on Somali women in the diaspora, which is reflective of the demographic composition of Somali households in this country during the early period of resettlement (Affi, 2004; Berns-McGown, 2003; Tiilikainen, 2020). For the most part, during the initial stages of resettlement in Canada, many Somali women managed their household as newcomers to Canada, an experience that is informed by their previous traumas (Bokore, 2013). These can include the loss of a spouse during the civil war, or the breakdown of their marriage due to separation from their spouse during the migration process (Affi, 2004; Arte, 2015; Fellin, 2015a, 2015b; Jibril, 2011). Furthermore, as Bokore's (2016a) doctoral thesis on the lived experiences of Somali Canadian women in Toronto and Ottawa highlights, many Somali women, like the women in her study, live in "toxic environments" that are impacted by poverty and stressful living conditions, even after more than two decades following their settlement in Canada (Bokore, 2016a, p. ii).

Indeed, this was also shown to be the case by Fellin (2015a), who revealed through her ethnographic study conducted from 2010-11, that Somali mothers and their families residing in Kitchener-Waterloo and Toronto experienced poverty, poor quality housing, and neighbourhood violence.

The poor quality of life of Somali refugees have also been greatly impacted by Canada's immigration policy, which has limited their ability to integrate in Canada (i.e., Bill C-86, See Chapter 1). Furthermore, Spitzer (2006) states that Canada's immigration policy may have also impacted Somali women's health negatively "through the induction of chronic stress" due to the separation of family members, precarious living conditions, and poverty (p. 52). Moreover, Somali women's intersectional experiences as Black, African, Muslim women, have resulted in further marginalization (Ellis et al., 2020; Kusow, 2004; Mohamed, 2016). Specifically, under the gaze and scrutiny of the government and media, many Somali women were viewed as outsiders (Maynard, 2017; Mohamed, 2016; Spitzer, 2006). Somali women have had to deal with overt racism as well, and experiences of Islamophobia and violence in public spaces (Berns-McGown, 2013; Bokore, 2018; Mohamed, 2016; Spitzer, 2006). In addition, Somali women have expressed feelings of helplessness as they witnessed their children go through adversities due to racism in the education system (Spitzer, 2006). They along with their community have learned firsthand the negative perceptions that are sometimes associated with Black identity (Arte, 2015; Mohamed, 2018; Spitzer, 2006). For many, this racialization was very much a traumatic process in itself, since it was the first time they have had to deal with this form of othering in their lives (Berns-McGown, 2013; Bokore, 2018; Kusow, 2004; Mohamed, 2016).

In navigating this unfamiliar terrain of being racialized as Black, Somalis in Canada had limited social support. As Berns-McGown (2013) explains,

...Somalis had no previously established diasporic community to guide them, to help them retrain, to teach them English, to find them housing, to help them cope with the racism in the wider society or with the trauma. They have had to do it alone. (p. 17)

Somalis construct their identity in accordance with their faith, ethnicity, culture, kin, and tribe (Bokore, 2013; Kusow, 1998, 2004; Mohamed, 2018; Naji, 2012). Given the prolonged exposure to resettlement stressors among diasporic Somalis in Canada, more research is required exploring the impacts of resettlement and the development of health disparities in this group, particularly Somali women who not only deal with the trauma of war, but also struggle with intersecting forms of oppression as Black, African, Muslim, refugees, and women (Bokore, 2016a; Collins, 1993; Mohamed, 2016).

In addition to an examination of the adversities faced by Somali women in Canada, the extant literature also highlights their strength and resilience as they navigated resettlement stressors. Driven by hope for a better future, many Somali women chose to advocate for resettlement services in their community for their children (Berns-McGown, 2013; Bokore, 2013; Fellin, 2015a; Tiilikainen, 2015). According to Berns-McGown (2013), “until 1991, for instance, refugees were not eligible for social housing in Toronto. It was Somali women who fought the battle that changed that rule” (p. 7). During the early period of resettlement, many Somali families relied primarily on the private housing market (Mohamed, 2016). Somali women have also been critical in the formation of cultural and religious spaces for their communities, such as Quran

schools (*dugsi*), “traditional loaning circles (*hagbad*),” and the creation of businesses that support the Somali diaspora in the Greater Toronto Area (GTA) (Spitzer, 2006, p. 52; see also Berns-McGown, 2003; Bokore, 2016a; Fellin, 2015a; Jesow, 2016; Mohamed, 2016).

It is the continuous advocacy of Somali and Afghani women that helped lead to reforms in immigration policy (Mohamed, 2016). Through Bill C-11, the government in 2001 mandated changes that finally took into consideration the plight of Somali refugees, particularly women and children, permitting identity confirmation through a statutory declaration (Mohamed, 2016; Spitzer, 2006; Stewart et al., 2008). This change in policy has allowed Somali families to access education, employment, and apply for permanent residency in Canada (Mohamed, 2016).

As Somali women forged the way for resettlement for their communities, it is important to acknowledge that Somali men nonetheless experienced barriers and resettlement stressors, such as the breakdown of family structure, social isolation, racial discrimination, underemployment/unemployment, poverty, and language barriers (Abdela, 2015; Affi, 2004; Danso, 2001; Jibril, 2011; Hussein, 2016; Mohamed, 2018). They have also had to re-evaluate traditional roles in society and their identities as Black Muslim men in Canada (Hussein, 2016). Many men have had to deal with downward social mobility in Canada, as their credentials were overlooked (Affi, 2004; Berns-McGown, 2013; Hussein, 2016). The subsequent underemployment and unemployment during the resettlement period prevented them from fulfilling traditional roles and responsibility as a breadwinner of the family (Kusow, 2007). Somali men were not immune to the stresses of living on low income, but also had to deal with feelings of

hopelessness and devaluation of their role in the family. As a result of their diminished social status, many men became alienated from family members, contributing to elevated divorce rates in the diaspora (Affi, 2004; Kusow, 2007; Mohamed, 2018).

Kusow's (2007) analysis of gender dynamics in the Somali diasporic family is integral, given the contextual difference between country of origin and place of settlement of this group. It opens up much needed discussion on how migration and resettlement impact traditional gender roles of the Somali diaspora in Canada. However, there is a need to explore gender dynamics in subsequent generations of the Somali diaspora in Canada. The literature in this area is limited, and more research is warranted given the unique migration history of the Somali diaspora and the scholarly focus on women and children, as noted earlier. This study begins to address this gap by highlighting the ways in which care is expressed by female and male family members of Somali immigrants and refugees living with T2D in Toronto.

It also extends our understanding of family dynamics beyond spousal relationships. According to Kusow (2007), tensions may arise between Somali parents and their children as youth perceive their parents as not so understanding of life in the West, and parents see their children growing to accept Western norms (Kusow, 2007). The tensions go beyond cultural differences, however. The resettlement process has also posed new challenges for Somali families living in inadequate housing and neighbourhoods that experience violence (Bokore, 2016a; Fellin, 2015a; Mohamed, 2018). Many Somali parents are concerned about their children's safety and futures here in Canada. It has required Somali parents to become more vigilant and undertake the difficult task of learning new ways to parent in Canada (Bokore, 2016a; Koshen,

2007; Mensah & Williams, 2014). As a means to manage their worries, Somali parents have drawn on their faith to help them navigate their new lives in Canada (Berns-McGown, 2003, 2013; Fellin, 2015a; Kusow, 1998; Tiilikainen, 2020). Their faith provides a way of making sense of change, and a means of holding onto their identity, and value systems in a new country (Berns-McGown, 2003, 2013).

The experience of forced migration and resettlement has resulted in Somalis to re-negotiate meanings of family as well, in addition to family roles, which may include new responsibilities for each member of the family, such as youth who may serve as English translators for family members and/or support their family financially (Arte, 2015; Fellin, 2015b; Naji, 2012; Stewart et al., 2008). Research exploring the dynamic and meaning of family in Canada for this group needs to be examined in a way that goes beyond Western notions of the nuclear family, as traditional Somali households are also inclusive of extended family members (Koshen, 2007; Mensah & Williams, 2014; Spitzer, 2006).

In addition to navigating these shifting family dynamics, Somali youth must also learn how to negotiate the multiple ways in which they are categorized in society. As Berns-McGown (2013) states, for Somali youth, like other diasporic youth, “‘back home’ is a strong influence in their lives, and they are under very real pressure from their parents not to ‘lose their culture’” (p. 21). While their religious identity constitutes a part of their self-image as Somali Canadians, Somali youth may also experience discrimination as a result of Islamophobia (Berns-McGown, 2013; Bokore, 2016a; Mohamed, 2016).

The stereotypes experienced by Somali youth are in part due to the ways in which the Somali community is disproportionately portrayed in the media as suspect people who are involved in piracy, gangs, or religious extremism (Berns-McGown, 2013; Fellin, 2015b; Mohamed, 2016; Mohamed, 2018; Naji, 2012; Tiilikainen, 2015). Although a small number of Somali diaspora youth have gone to join Al-Shabaab, they do not represent their community, nor the youth therein. However, it is often these stories of Somali youth in the media that have come to overpower the media discourse over the reality of their experiences in Canada, which are often not included in media accounts (Fellin, 2015b).

For example, there is research that highlights racism faced by Somali youth within the education system in Canada (Berns-McGown, 2013; Fellin, 2015b; Jibril, 2011; Mohamed, 2015; Mohamed, 2018). Somali youth recall experiences with racism at school and doubts from educators regarding their academic potential (Berns-McGown, 2013; Mohamed, 2018; Tiilikainen, 2020). These negative experiences within the education system have served as contributing factors to the high school drop-out rate amongst Somali youth in Toronto (Berns-McGown, 2013; Bokore, 2013; Fellin, 2015b; Jibril, 2011; Mohamed, 2018).

Another structural barrier that Somali youth face is related to their difficulty accessing meaningful employment due to their limited social capital, experiences with racism, and a lack of employment opportunities (Jibril, 2011; Mohamed, 2018). From 2005 many Somali male youth in Ontario moved to Alberta in hopes of securing employment in the growing economy and oil industry (Jibril, 2011). Some were also

motivated to leave their homes as a means to support their families and improve their financial standing (Jibril, 2011; Mohamed, 2018).

According to the report, *“Another Day, Another Janazah: An Investigation into Violence, Homicide and Somali-Canadian Youth in Ontario,”* more than 50 Somali male youth in Alberta and Ontario have lost their lives due to violence since 2000 (Aden, Issa, Rayale, & Abokor, 2018). These murders involve youth connected to crime but also those that were targeted due to mistaken identity and racism (Aden et al., 2018; Jibril, 2011). Many of these homicide cases remain unsolved (Aden et al., 2018; Jibril, 2011; Mohamed, 2018; Tiilikainen, 2020). As one of their key recommendations, Aden, Issa, Rayale, and Abokor (2018) highlight the need for increased supports to address the mental health needs of Somali families in Canada (Aden et al., 2018).

Type 2 Diabetes (T2D)

The various social, economic, structural conditions outlined above that frame the lives of Somali people, coupled with their status as refugees and their ethnic background, predispose the Somali diaspora to the development of chronic health conditions (Gele, Torheim, Pettersen, & Kumar, 2015; Goosen et al., 2014; Kumar, Beeler, Seagle, & Jentes, 2021; Njeru et al., 2016). Spitzer (2006) further argues that although lifestyle factors can contribute to the development of these conditions, “continuing high levels of stress may also by themselves, or in interaction with these other determinants, create significant health implications” (p. 51). The effects of chronic stress on the body are well documented in the literature (Kelly & Ismail, 2015; Yaribeygi, Panahi, Sahraei, Johnston, & Sahebkar, 2017), with research showing that Somali women in Ottawa, Toronto, and Edmonton report a decline in their health, such as

hypertension, heart conditions, elevated cholesterol levels, and T2D, as a result of factors related to migration and resettlement (Spitzer, 2006). Other studies outside of Canada have found increased prevalence of T2D among Somali immigrants, refugees, and asylum seekers compared to the general population in host countries, such as the United States (Kinzie et al., 2008; Kumar et al., 2021; Njeru et al., 2016; Westgard et al., 2020), Netherlands (Goosen et al., 2014), and Finland (Etchi, Lilja, Koponen, & Laatikainen, 2019), for example.

There is also research that highlights elevated risk for T2D among Somali women in Norway with increased length of residence in the country of resettlement (Gele, Pettersen, Kumar, & Torheim, 2016). Somali women in the diaspora experience barriers accessing culturally appropriate care for diabetes, such as accessible preventative health services that are inclusive of their cultural and religious beliefs, as well as other barriers related to time and financial constraints (Gele et al., 2015).

Summary

This literature review explored the resettlement context of Somali refugees and immigrants in Canada and its impact on their health/integration in Canada. Previous work highlights how inadequate access to social determinants of health, such as income, education, employment, and housing has limited the ability of Somali families to fully integrate into Canada. As a result, resettlement has changed the dynamics within the Somali family and Somali identity in Canada (Kusow, 2007). Bokore's (2013, 2016a) research has laid much of the foundation for understanding the intergenerational impact of trauma amongst Somalis in Canada and offers additional insight into the nuances of dynamics within Somali families (Jackson-Best, 2019).

Furthermore, this literature review revealed disparities experienced by the Somali diaspora during resettlement as a result of unresolved mental health needs due to the civil war (Jackson-Best, 2019; Mohamed, 2018; Naji, 2012). Most of the literature on Somalis in Canada has focused on the resettlement challenges and the trauma faced by first- and second-generation Somalis (Jackson-Best, 2019; Mohamed, 2016). Without adequate social support, the mental health needs of first-generation Somalis were not appropriately addressed (Jackson-Best, 2019; Mohamed, 2018; Naji, 2012). This created living conditions, as noted previously, which promote chronic stress in the Somali diaspora and the development of adverse mental health outcomes (Mohamed, 2016; Spitzer, 2006). Bokore (2013, 2016a) suggests that further inquiry should be implemented into the development of culturally informed practices to address the mental health needs of Somali families. In addition to examining culturally competent care for Somali Canadians, it is imperative that further research be devoted to the study of health needs more broadly of the Somali diaspora.

More research is needed to examine how precarious settlement of Somali refugees and immigrants in Canada has impacted other health outcomes, such as their physical health and the development of chronic disease. At the time of writing, Spitzer's (2006) research on the impact of policy on Somali women's health is the only available literature that highlights the connection between resettlement stressors and the development of chronic health conditions. As noted previously, there is very little research to date on how resettlement impacts Somali immigrants and refugees' management of T2D and/or the experiences of Somali families with T2D in Canada. This study aims to address this gap and examines how resettlement influences Somali

immigrants and refugees management/care of this illness. The next chapter examines the theoretical approach implemented in this study.

CHAPTER THREE: THEORETICAL APPROACH

This chapter provides an overview of how refugee settlement has been conceptualized in the literature, and the specific approaches chosen to pursue the research questions explored in this study. It begins with a discussion of refugee resettlement and the social determinants of health impacting refugees. In addition, a brief overview of processes by which refugee/immigrants interact with the host culture are also discussed. The theoretical frameworks implemented in this study are then introduced, specifically diaspora theory and the culture care theory (CCT). Diaspora theory is relevant for understanding the experiences of Somali refugees and their families, given the historical motivations for their migration, which began primarily as a result of the civil war in their homeland (See Chapter 1). Social and environmental conditions of this diaspora and of resettlement are explored through the lens of diaspora space (Brah, 1996). Diaspora theory is used to gain more insight into how the process of resettlement impacts the participants' management/care of their and/or family members' T2D, while analysis of diaspora space includes settings where care occurs and is enacted. To understand how care/management of T2D was experienced and conceptualized by the participants in this study, a second theoretical approach referred to as culture care theory was applied (Leininger, 2006). The CCT integrates constructs of both care and culture in its analysis of health, displaying their mutually intersecting relationship. It was chosen due to its open-ended approach to inquiry and its inclusiveness of diverse worldviews (Leininger, 2006). The CCT was used to explore the multiple ways in which care manifested through emic and etic means and the meanings held by the participants (and their respective culture) (Leininger, 1997, 2007).

Resettlement

The resettlement process begins once an individual seeking asylum is officially granted refugee status and permanent residency by a third country (Hynie, 2018a). It is the final stage of migration that marks new beginnings for refugees and one which has occupied much consideration in diaspora and refugee studies. The process of resettlement is also one of three durable solutions mentioned by the United Nations High Commissioner for Refugees (UNHCR) to address issues faced by refugees (FitzGerald & Arar, 2018; Hynie, 2018a; Malkki, 1995). As FitzGerald and Arar (2018) note, when refugees are settled in a host nation according to the UNHCR, they are no longer deemed “populations of concern” and cease to be a refugee (p. 397). They note that “the end of the refugee category for the UNHCR marks the beginning of the refugee category for the resettlement state” (FitzGerald & Arar, 2018, p. 397). However, the lines between being refugees and resettled individuals are not always clear cut, and FitzGerald and Arar (2018) recommend that a sociological lens be used to avoid being “analytically hobbled by this artificial disruption” to examine a “multisite, multigenerational process of integration across countries of mass hosting, asylum, transit, resettlement, and repatriation” (FitzGerald & Arar, 2018, p. 397). This is the lens that this thesis takes in the examination of resettlement, by conceptualizing it as a process that occurs across time, space, and generations of a diaspora. The process of resettlement is not something that happens over a fixed number of years but is a rather unique experience for individuals based on their personal circumstances and their ability to integrate into the host society.

Much of the literature on refugee resettlement has focused on trauma and the impact of war on the mental health of refugees (Colic-Peisker & Tilbury, 2003; Patil, Maripuu, Hadley, & Sellen, 2012). Such an approach, as Colic-Peisker and Tilbury (2003) argue, views resettlement via a Western lens of psychological well-being, and tends to pathologize refugees by virtue of their experiences with trauma and forced migration. However, as Malkki (1995) states, “thus, although many refugees have survived violence and loss that are literally beyond the imagination of most people, we mustn’t assume that refugee status in and of itself constitutes a recognizable, generalizable psychological condition” (p. 510). Moreover, Colic-Peisker and Tilbury (2003) relay that refugees may experience trauma not only prior to settlement in the host country but also during the resettlement process, for example through barriers incurred because of language, poverty, and marginalization.

Social Determinants of Refugee Health

Indeed, as the discussion on resettlement of refugees reflects, the manner in which refugees integrate into a host society depends on a multitude of different factors including social determinants of health, politics, and public opinions surrounding their movement (Hynie, 2018a; Mikkonen & Raphael, 2010). The experience of forced migration often leaves refugees with limited resources resulting in their precarious position within the country of resettlement (Hynie, 2018a). Many refugees in Canada struggle with poverty, which in large part is due to a lack of accessibility to employment opportunities, as their credentials and education are often not considered (Hynie, 2018a, 2018b). Thus, experiences of unemployment and/or underemployment are not uncommon amongst refugees, which creates structural inequalities for this group that

limits their accessibility to critical determinants of health (Hynie, 2018a; Mikkonen & Raphael, 2010).

The social determinants of health experienced by refugees include material needs, such as access to basic resources such as food, adequate and safe housing, health care, and employment (Hynie, 2018b). In addition, these determinants influence their access to “interpersonal” resources, which plays a role in ones belonging in society and their health (Hynie, 2018b, p. 7). Refugees that experience social exclusion may be limited from accessing basic needs and resources critical for their health (Hynie, 2018a; Mikkonen & Raphael, 2010).

Deprivation of social and material resources can also influence the quality of life and the lifespan of refugees (Mikkonen & Raphael, 2010). As mentioned in Chapter One, refugees in particular encounter unique risks factors for T2D stemming from their experiences with forced migration, such as, trauma, stress, and poverty (Agyemang et al., 2012; Kelly & Ismail, 2015; Kinzie et al., 2008). The social determinants of health experienced by refugees highlight the specific challenges endured by this diverse group of individuals not only during the pre-migration phase of their journeys, but also during the resettlement stage, which have an influence on their overall health and wellbeing as well as their integration in the host society (Hynie 2018a, 2018b).

Assimilation Theory

Resettlement may also be conceptualized as a linear process, where a refugee progresses from one stage to the next, and their past and homeland is discarded. These assumptions are reflected in theories for understanding resettlement, in particular, classical assimilation theory (Lee, 2009). Once resettled, classical

assimilation theory asserts that, over time, ethnic groups and newcomers will possess more commonalities with the general population in the country of settlement (Bean & Brown, 2015). The process of assimilation is regarded as an inevitable outcome that occurs across time and generations (Birman & Simon, 2014).

Contemporary understandings of assimilation recognize differences in assimilation pathways amongst individuals and groups (Birman & Simon, 2014; Lee, 2009). In a process referred to as segmented assimilation, ethnic groups achieve assimilation in various ways and aspects of society, differences that reflect the relationship between majority and minority groups (Bean & Brown, 2015; Portes & Zhou, 1993). Portes and Zhou (1993) identify three ways in which segmented assimilation occurs: 1) integration into White middle class society, 2) integration into the economically disadvantaged “underclass” of society, and 3) economic integration while maintaining cultural identity and values (p. 82). Although different pathways for assimilation are acknowledged, the responsibility of assimilation is placed on newcomers, requiring them (and not the host society) to embark on personal change for successful integration into mainstream society (Lee, 2009; Sayegh & Lasry, 1993). This approach also offers limited analysis into the relationships between newcomers and the country of settlement.

Acculturation Theory

This gap in the literature is addressed by acculturation theory, which examines the interactions between diverse cultural groups and individuals, and the changes that occur as a result of these exchanges (Ngo, 2008; Phillimore, 2011; Sayegh & Lasry, 1993). Similar to assimilation theory, acculturation was once regarded as a linear

process, but has evolved to include “bidimensional and interactive perspectives” that describe diverse acculturation pathways (Bhatia & Ram, 2009; Ngo, 2008, p.1).

Acculturation theory includes two central theoretical approaches (Phillimore, 2011). The first approach incorporates a “social psychology” focus (Phillimore, 2011, p. 578) also known as the “bidimensional” perspective (Ngo, 2008, p.1), which examines the process by which immigrants and ethnic groups acquire “permanent settlement within the host society” (Phillimore, 2011, p. 578). Berry’s acculturation model is perhaps the most recognized in this category (Berry, 1997; Ngo, 2008). According to Berry (1997), individuals may respond to a new society in four ways: 1) assimilation: the voluntary acceptance of the new culture and dismissal of the heritage culture; 2) separation: the opposite of assimilation, that is, the acceptance of the heritage culture and the dismissal of the culture of the host country; 3) marginalization: a dismissal of both one’s heritage culture and the culture of the country of settlement, and 4) integration: the acceptance of the heritage culture and the culture of the country of settlement (Berry, 1997; Bhatia & Ram, 2009; Birman & Simon, 2014; Schwartz, Unger, Zamboanga, & Szapocznik, 2010).

Birman and Simon (2014) mention that individuals can undergo acculturation in ways not depicted in Berry’s acculturation model; they may combine their heritage culture and new culture/s. Moreover, this model has been questioned on the applicability of these four categories to diverse groups (Birman & Simon, 2014) because it implements a “one size fits all approach” (Ngo, 2008; Schwartz et al., 2010, p. 240). In Berry’s (1997) model, for example, the former culture and the culture of the host nation are treated as static, contained, and oppositional factors in an individual’s life (Bhatia &

Ram, 2009; Phillimore, 2011). This model does not account for the dynamic and complex nature of people's ties to homeland and culture which may serve as resources for resettlement, and individuals' intersecting multiple identities that link both 'here' and elsewhere.

The process of acculturation is dynamic influencing both individuals and groups (Phillimore, 2011). Groups may be impacted prior to acculturation, as a result of the social, economic, political, and cultural conditions that they experience, which influences the manner and degree in which they are able to acculturate (Phillimore, 2011). Group members may also be impacted as a result of their interactions with the host society, and "the extent of support they receive from their own ethnic community and wider society" (Phillimore, 2011, p. 580). Factors influencing the acculturation of individuals include "moderating factors prior to acculturation" such as an individual's "age, gender, status, and cultural distance" and "prejudice; discrimination, coping strategies, resources and social support received, as moderating factors during acculturation" (Phillimore, 2011, p. 580).

Birman and Simon (2014) state that "acculturation is a different phenomenon when applied to immigrant adults, immigrant children, and children of immigrants born in the new country" (p. 208). First generation immigrant adults arrive in a new country with direct experiences in their country of origin and are enculturated (acquiring their cultural heritage through family and their community) in their heritage culture. They engage with the new culture in the country of settlement and must learn new customs, norms, language, and so on, a process that is often difficult to grasp for adult learners (Birman & Simon, 2014). First generation adult immigrants, having been socialized in their

country of birth, will most likely have a deeper understanding of what it is like to live in their homeland unlike immigrant children raised and/or born in the country of settlement (Schwartz et al., 2010).

Immigrant children born in another country but raised in the country of settlement (referred to as “1.5-generation”) or second-generation immigrants (those born and raised in the country where their parents immigrated) will experience cultural change in a different manner from their parents who were born and raised in their homeland (Birman & Simon, 2014; Portes & Rumbaut, 2001, p. 24). The acculturative process for immigrant children is a bit more difficult to understand as they are still developing and undergoing enculturation whilst learning the culture of the country of settlement (Birman & Simon, 2014). These youth may struggle less with language acquisition but may be more challenged with aspects related to their identity given their exposure to multiple cultural influences (Birman & Simon, 2014). According to Birman and Simon (2014), more distinction is needed regarding the acculturation process amongst different generations of immigrants, such as diasporic ethnic communities.

Critical acculturation theories, which form the second main theoretical acculturation approach, address this limitation by including “diaspora studies and cultural identity” to gain a deeper understanding of the acculturation process (Phillimore, 2011, p. 578) This approach to acculturation examines not only individuals undergoing acculturation, but also the contexts in which this process occurs, such as the historical, social, and political realities of immigrants and refugees for example, because they play a role in their engagement and/or ability to acculturate in the host society (Bhatia & Ram, 2009; Ngo, 2008). According to Bhatia and Ram (2009) acculturation is a process,

“that involves continuous, contested, negotiations that will forever be in progress as an immigrant grapples with his/her place in the larger structures of the history, culture, and politics” (p. 148). Therefore, in order to gain a deeper understanding of the dynamic and complex nature of people’s ties to homeland and culture which may serve as resources for resettlement, an individuals’ intersecting multiple identities that link both ‘here’ and elsewhere, must be examined. The present study utilizes diaspora to gain more in depth understanding of the formation of the Somali diaspora in Canada, as well as the unique resettlement contexts, and spaces that shape the experiences of this group.

Diaspora Theory

Although the term diaspora is used widely, there is still confusion as to what exactly constitutes a diaspora or who qualifies for membership in a particular diaspora (Butler, 2001). Most of the research on diasporas is focused on the experiences of a single diaspora, such as Jews, Greeks, and Armenians, also known as “classical diasporas” (Brah, 1996; Brubaker, 2005, p. 2; Butler, 2001). Derived from the Greek words “dia” which means “through” and “speirein” which means “to scatter,” the term diaspora has come to signify a collective journey of peoples from their country of origin (Brah, 1996, p. 181). This transition from place of origin to site of settlement is not a temporary occurrence but involves long term displacement of two or more generations across multiple states (Brah, 1996; Brubaker, 2005; Butler, 2001). Diaspora includes a temporal element, because it involves extended displacement from one’s origins (Butler, 2001). It is also a local and global phenomenon occurring within and across borders,

raising questions about displacement, culture, politics, and belonging (Brah, 1996; Butler, 2001; Wahlbeck, 2002):

The question is not simply about *who travels but when, how, and under what circumstances?* What socio-economic, political, and cultural conditions mark the trajectories of these journeys? What regimes of power inscribe the formation of a specific diaspora? (Brah, 1996, p. 182)

Thus, examination of diaspora involves three sites of analysis, “forcible dispersal, settlement in multiple locations and the idea of a homeland” (Wahlbeck, 2002, p. 229). According to Brubaker (2005), it is this historic motivation for the migration of individuals (and Brah would add, their economic, political, and cultural context) that culminates in the creation of a diaspora and how it is formed. There are many reasons which motivate individuals to disperse from their country of origin and embark on a journey to seek a better life. For example, some may leave due to exile, trade, and forced migration (Brubaker, 2005; Butler, 2001). These motivations may result in different types of diasporas.

While historic migration is a defining feature of diaspora, questions remain as to what qualifies as membership in a particular diaspora. This is indeed the tricky landscape in which diaspora researchers tread, as they look for ways to determine what a diaspora is and the boundaries it embodies. A diaspora may be defined on the basis of ethnicity for example; however, focus should instead be placed on the social dynamics and features of the group (Butler, 2001). By focusing on the social formation of diaspora, one can gain further insight into the mechanisms through which a diaspora

operates both locally and globally over time (Butler, 2001). In the case of this study, the process of diasporization occurred as a result of political tensions in Somalia and the civil war.

Furthermore, the Somali diaspora is created through relationships. It cannot exist with just one sole member; rather, it is dependent on the unique ties which bind members of a group across states (Wahlbeck, 2002). It is these relationships that connect members together that form a critical role in their identity (Butler, 2001). These relationships are also a fundamental aspect of the ways in which networks are built within diasporas and are created through the dispersal of a group and its members (Butler, 2001). These relationships and networks play a role in members' perceptions of the group's identity and the connections members have with each other and their country of origin (Butler, 2001).

However, that is not to say individuals within a diaspora do not possess multiple identities outside of the collective group identity, in fact they do (Butler, 2001). These identities are not static but are always changing and being negotiated (Brah, 1996). As Brah (1996) explains, "identity, then, is simultaneously subjective and social, and is constituted in and through culture" (p. 21). Butler (2001) provides an example of how multiple identities can be derived in a diaspora through the case of an individual who is born in Jamaica and of African descent. Upon migrating to England, this individual finds themselves as part of the African and Caribbean diaspora (Butler, 2001). Butler (2001) poses questions regarding the identities of this individual and how they engage with other members of the African and Jamaican diaspora:

To fix this person's identity as part of an undifferentiated African diaspora does not allow for the complexity of multiple identities, the salience of any of which at any given time is conditioned by sociopolitical exigencies. Nor can such an individual be exclusively considered part of a Caribbean, or even Jamaican, diaspora. (p. 193)

From this example, one can see how identity is a process which occurs at an individual and group level, one that is ever-changing and dependent on one's context (Brah, 1996). Identities are also not fixated on the homeland but incorporate an individual's lived experience.

This is contrary to early discussions in diaspora research which were centered on the premise that all individuals should yearn to go back to their homeland, and situated the homeland as a critical part of the identity of a diaspora (Butler, 2001). With regards to the presumed central role of homeland, Butler (2001) argues that focus should be placed on the "issue of return, and the related sense of connection to the homeland, that is intrinsic to the diasporan experience, rather than a specific orientation toward physical return" (p. 205). Thus, the homeland is not the centre around which identity and cultural formations orbit, nor does displacement from a homeland necessarily culminate in a loss of identity or culture of a diaspora (Brah, 1996; Malkki, 1995). Furthermore, one needs to consider how the relationship to the homeland is not static and changes over time and even within generations (Butler, 2001). Some individuals may be actively engaged in events in their homeland, such as sending money to support causes or to foster development, while others may only view the homeland as

an imagined space from which they derive their ancestral origins (FitzGerald & Arar, 2018). Indeed, the relationship to the homeland is complex and discussions of diaspora involve clear tensions between displacement and where home lies, whether or not it is within the place of origin or outside this context and within the country of resettlement (Brah, 1996).

The discussion of home/homeland and diaspora has implications for how refugees and the appropriate 'solution' for the 'problem' of refugees are constructed. Brah (1996) suggests that the concept of a diaspora can be related to how belonging itself is conceived, in which individuals are only tied to a particular space. Indeed, there can be more than one home, as home encompasses feelings of peace and belonging which may be experienced in more than one location (Brah, 1996; Malkki, 1995). To think of identity as being fixed by national borders reinforces problematic views of citizenship as being singular and bound by nation, reinforcing xenophobic sentiments that place refugees outside of the new host state, and the assumption of return to their homeland as the only option (Malkki, 1995; Rajaram, 2002). If home is where an individual feels a sense of belonging and peace, surely the boundaries of home should extend beyond a specific location and include spaces in which refugees can construct new meanings of home (Malkki, 1995; Rajaram, 2002)? Home is not only a place of origin but can also include the lived contexts in which a diaspora is situated (Brah, 1996).

The lived realities of a diaspora or the current spaces where individuals live and where diaspora is constructed may be overlooked, despite their critical role in its

formation and construction (Butler, 2001; Wahlbeck, 2002). It is this context that this study explores, the historical, social, and cultural settings in which diaspora are situated that play a role in the development of their identity (Bhatia & Ram, 2009; Butler, 2001). Such an examination, as Wahlbeck (2002) states, requires us “to remember the structural context and the unequal power relations in which the identity has developed. In addition, it is not only the structure of the society of settlement one needs to take into account” (p. 234). One should also acknowledge the relationship of the diaspora group with others in the country of settlement (Brah, 1996). These relationships occur within what Brah (1996) describes as the “Diaspora space,” “the point at which boundaries of inclusion and exclusion, of belonging and otherness, of ‘us’ and ‘them’, are contested” (pp. 208-209). It is within the diaspora space that individuals within a diaspora interact with others, and where power dynamics play a role in their everyday engagements and position in society and even within the diaspora group itself.

Thus, diaspora theory was chosen as a theoretical approach in this study to help with answering the first research question of this study, namely how the process of resettlement impacted the care and/or of management of T2D of the participants in this study. This theory includes in its analysis, the homeland, migratory journey, and context of settlement of the Somali diaspora (Wahlbeck, 2002). All of these factors are important considerations as they play a role in understanding the formation of the diaspora, their experiences pre-migration, during migration, and in the settlement process in the host country. Through diaspora theory, one is able to access the story of resettlement as a whole, and not only its parts. Further, diaspora theory facilitates

greater understanding of the participants' access to social determinants of health, and resources within the diaspora, diaspora space, and in mainstream society.

The research questions also focus on the experience of T2D, in terms of management and caring for individuals with this illness and what T2D means. Where diaspora theory is the lens for understanding the context and conditions in which this care/management occurs, in what follows, I present CCT as a way to examine how Somali immigrants and refugees in this study care and manage T2D, demonstrating its alignment with the second research question, diaspora theory, and with Somali cultural beliefs and worldview.

Culture Care Theory

According to CCT, care is more than the engagement of acts; it also comprises various “symbolic” and “cultural” components (Leininger, 2006, p. 12). Care is viewed as a human quality, one that propels individuals to aid others, producing positive health benefits in the recipient (Leininger, 2006). It includes “those assistive, supportive, and enabling experiences or ideas towards others with evident or anticipated needs to ameliorate or improve a human condition or lifeway” (Leininger, 2006, p. 12). Thus, care is viewed as being integrated within culture (Leininger, 2006; McFarland, Mixer, Webhe-Alamah, & Burk, 2012), where culture is defined as “the learned, shared, and transmitted values, beliefs, norms, and lifeways of a particular culture that guides thinking, decisions, and actions in patterned ways and often intergenerationally” (Leininger, 2006, p. 13). Like care, culture is also viewed as a human phenomenon.

Leininger's theory is unique in that it includes both emic and etic care in analysis, unlike most research and theoretical orientations which situate themselves only within emic or etic viewpoints (Leininger, 1997, 2007). This division has largely separated the field of health into two paradigms, one involving etic approaches, which promote universal expressions of illness, and a second applying emic approaches, which arise out of the meanings derived from one's social and cultural context (Patel, 1995). Thus, Leininger's theoretical framework and accompanied research bridge both approaches, thereby taking into account the unique cultural and social contexts of the participants of this study, and the universal expressions of care across cultures (Leininger, 2007). In other words, CCT acknowledges the diversity of care, and also recognizes that there are universal elements to care across all cultures around the world (Leininger, 2006).

Another strength of CCT is that it challenges healthcare providers to reconsider Eurocentric assumptions towards care and to also consider the diverse ways in which care could be implemented in various cultures (Leininger, 1997). For example, CCT is cognizant of diverse cultural worldviews and is open to the use of culturally meaningful terms rather than exclusively using those from a dominant Western paradigm (Leininger, 2006). In doing so, this theory takes a more ethical approach because it is attentive to the ways in which cultural groups view and see themselves.

Accounting for spirituality makes CCT unique because it is attuned to cultural meanings that are connected with religion/spirituality, which are often excluded or not fully acknowledged within health research. It is also relevant for this study, as noted earlier, because the religious identity of the participants is a significant part of their cultural identity (Koshen, 2007; Langellier, 2010; Spitzer, 2006). Thus, the inclusion of

the focus on human beings as a whole and care as recommended by Leininger is not only congruent with cultural norms of the participants but also their religious worldviews.

Moreover, the CCT includes analysis into the many ways in which environments are understood by cultural groups (Leininger, 2006). Leininger defines the environment as the “totality of geophysical situation(s), or about the lived-in geographic and ecological settings of cultures” (Leininger, 2006, p. 10). Accordingly, understanding individuals’ environment is critical, since it helps derive the meanings individuals attribute to these settings and, as Leininger (2006) notes, may provide “clues about care expressions, meanings, and patterns of living for individuals, groups, and families” (p. 10). Her theory analyzes how different settings can influence the care of human beings, and how individuals and groups use these settings for their care. The CCT examines both lived contexts and the environments in which care takes place. It has also been useful in understanding rituals that occur in particular contexts (Leininger, 2006). While diaspora theory considers the environment of individuals, it is more focused on structural conditions such as one’s sense of belonging within the host country, which fosters connections to the homeland and other diasporic members. However, the CCT includes in its focus the physical spaces where people live and care for others. These physical spaces are shaped by structural conditions that diaspora theory considers in its analysis. Further, while the diaspora theory and CCT may conceptualize environment and its impact on cultural groups in different ways, they are nonetheless complementary.

Summary

This chapter focused on refugee resettlement, the different ways refugees may interact with the host society, as well as the theoretical frameworks implemented in this study, diaspora theory and the CCT. I decided to implement these approaches in this study since they provide a more expansive analysis of settlement and care/management of T2D for the participants of this study. Diaspora theory offers a broader approach to the study of resettlement, since it includes analysis into the homeland, but also the diaspora space (Brah, 1996). This theory reflects the complex ways in which refugees interact with the country of settlement, allowing for analysis of resettlement beyond categorical and rigid assumptions that refugees are fixed to one place, or that refugees are all the same (Malkki, 1995).

CCT was chosen as a theoretical approach in this study since it integrates a more in-depth analysis of how environments and settings are understood by cultural groups. It was critical to choose a framework that was open to the diverse ways in which care manifest and are enacted amongst cultural groups. CCT focuses on culture and factors related to care, but also integrates within its analysis the ways in which one engages in culturally congruent care within research. Thus, this theory incorporates an ethical approach that is respectful of the diversity in worldviews of the participants in this study. In the next chapter, I discuss the methodological approach implemented in this study.

CHAPTER FOUR: METHODOLOGY

This study employed a qualitative approach to explore the meanings that the participants articulated regarding their and/or family member/s' experiences with T2D, with a specific focus on the following research questions:

1. How does the process of settlement impact the management of T2D for Somali immigrants and refugees living with T2D and their family members in Toronto?
2. How do participants narrate and make sense of their T2D diagnosis?

Qualitative research approaches utilize “text as empirical material (instead of numbers)” (Flick, 2007, p. 2). This line of inquiry is especially significant for this study given that most of the literature on T2D among members of the African diaspora is quantitative and focused on examining the prevalence of this illness. Through the usage of qualitative research methods, this study aims to go beyond a statistical focus to include the perspectives of the research participants and their experiences with T2D. Narrative research and found poetry were used in this study since they privilege the participants' subjective accounts of the phenomenon under study, and they reflect ethical approaches that are focused on participants' words/stories. This is significant because it makes space for diverse understandings and worldviews in the process of inquiry, including those within the oral based and collective Somali culture (Andrzejewski, 2011; Jama, 1994; Lewis, 1988; Stewart et al., 2008).

I start this chapter by describing narrative research and its use within health and illness research. This is followed by a discussion of the application of poetry in research, participant recruitment, data collection and analysis processes, the ethical

considerations involved in the coordination of this study, and procedures for ensuring validity.

Stories of Change

For communities such as Somalis who are impacted by colonial division, forced migration, internal tribal hate and recent religious practice changes, stories are what will unite them. Stories ease the tension, fear, mistrust and establish a common goal, which in their case is overcoming persistent poverty and a life filled with toxic stress. (Bokore, 2016b, p. 77)

I begin with this quote by Bokore (2016b) since she has inspired me in so many ways throughout this study, through her stories of hope and resilience in light of adversities that she has experienced as a Somali mother, refugee, social worker, and academic living in Canada. In her own work, Bokore (2013) describes how she used storytelling with a small group of Somali women in the west end of Toronto, with whom she met weekly. The women in this group used stories to deal with their past and create “stories of what the future for their children in Canada will/could look like” (Bokore, 2013, p. 105). These stories also included the homeland and futures of family back home (Bokore, 2013). Storytelling became a means for Bokore and the women in her group to make sense of their lives in Canada, and offered a space where they could share resources, and move towards envisioning “positive stories” and a future for themselves and their families (Bokore, 2013, p. 105). By focusing on these positive stories, Bokore (2013) was able to survive the adversities that she had experienced in her journey of settlement in Canada as a refugee (p. 105).

Bokore's storytelling approach involved an analysis of the past, present, and future, as she and the women in her group arranged their experiences chronologically to better understand them and move forward with their futures in Canada (Creswell et al., 2007). Thus, the process of storytelling is an interpretive act that depends on one's ability to process events in their lives (Bruner, 2004; Polkinghorne, 2004). Stories also offer a means for understanding life better (Lai, 2010). Inspired by Bokore's emphasis on positive stories of the future, I have chosen to implement an adapted narrative research approach for this study and thus examined stories as a medium of understanding the participants' experiences with T2D.

Narrative Research

Stories are a part of our everyday lives. We can find them in history, fairy tales, legends, religious texts, and in traditions passed onto future generations (Charon, 2004; Clandinin, 2020; Lee, Fawcett, & DeMarco, 2016; Polkinghorne, 2007). They are also shared by individuals as they recount their personal experiences to others, spanning across time and space (Lee et al., 2016; Stephens, 2011). Stephens (2011) notes that "people use stories to work through and explain how this event turned out, why it happened this way, what sort of self they were, and now are, in relation to the events and why they behaved in certain ways" (p. 64). When shared with others, stories can be especially valuable pieces of knowledge revealing insights into a storyteller's life (Bleakley, 2005). Furthermore, the stories held by cultures and societies influence how we see ourselves or even how we tell our own story (Bruner, 2004; Polkinghorne, 2004). Due to this, stories also have a profound impact on not only the storyteller but

also the audience, as they reveal the impact of one's position in society (Stephens, 2011).

Although the terms "story" and "narrative" are often believed to hold the same meaning, they are, as Riley and Hawe (2005) state, "analytically different" (p. 227). For it is through the analysis of the meanings and events in stories that researchers construct narratives (Riley & Hawe, 2005). A narrative is defined as:

A distinct form of discourse: as meaning making through the shaping or ordering of experience, a way of understanding one's own or others' actions, of organizing events and objects into a meaningful whole, of connecting and seeing the consequences of actions and events over time. (Chase, 2013, p. 56)

Key elements of narrative research then are to examine how, in its telling, an experience is organized so that we may understand it as a distinct unit, but also in relation to other events and experiences over time; understand the actions therein; and most significantly, examine how we construct meaning and ourselves through storytelling. Narrative research requires a focus on "individual stories" (Creswell et al., 2007, p. 244), or as Chase (2013) notes "narrated lives" (p. 56), in order to produce narratives (Riley & Hawe, 2005). These 'stories' or 'lives' may be derived from diaries, in-depth interviews, case studies, field texts, audio and/or video recordings (Bleakley, 2005; Charon, 2004; Chase, 2013; Stephens, 2011). Interviews are the most common form of data within narrative research (McCance, McKenna, & Boore, 2001; Stephens, 2011). Within the age of technology, the boundaries of what constitutes a narrative have also been expanded to include many other media, such as emails for example, which can include stories (Chase, 2013; Stephens, 2011). Photos captured by research

participants in studies using photovoice as a method can also be a means of storytelling (Stephens, 2011). While these various forms of data may be included in narrative research, the specific elements that are examined are the content, structure, and/or how stories are produced (Esin, 2011). Individuals relay their story, using a plot, conveying setting, characters, and a beginning, middle, and end (Creswell et al., 2007; McCance, McKenna, & Boore, 2001; Polkinghorne, 1995).

Because narrative research diverges from traditional scientific approaches, some scholars regard narrative research as “more art rather than research” (Lieblich, Tuval-Mashiach, & Zilber, 1998, p. 1). They view narrative research methods, like other qualitative methods, as being “soft” in comparison to quantitative research approaches (Bleakley, 2005, p. 535). However, narrative research is far from being soft; it can be very enlightening in its own right, revealing the “hard realities” of people’s lives (Bleakley, 2005, p. 535). As Lieblich et al. (1998) indicate, this is because narrative research involves storytellers in the process of research rather than objectifying them as subjects, thereby promoting “pluralism, relativism, and subjectivity” (p. 2).

The particular type of narrative research approach used depends on one’s epistemological and ontological orientations toward content, structure, and/or how stories are produced (Esin, 2011). The diversity of approaches is reflected in how narrative research has been taken up in different disciplines (Riley & Hawe, 2005). For example, narrative inquiry was created in 1990 to understand the experiences of teachers within educational settings, but its application has since expanded to other disciplines within the social and health sciences (Clandinin, 2020; Wang & Geale, 2015). Researchers implementing this approach are interested in examining the

everyday stories and lives of individuals (Clandinin, 2020). Narrative inquirers also focus on the stories that human beings are “living in” such as those that exist within personal, cultural, and/or institutional settings (Clandinin, 2020, p. 219). Regarding this, Clandinin (2020) states that “the stories we live by, and the stories we live in, over time, are indelibly marked for all of us by stories of school” (p. 219). Indeed, narrative inquirers reveal how institutions such as schools can impact the lives of students, but also those who are connected to these spaces, such as teachers and families (Clandinin, 2020).

In addition to education, narrative methods are also employed within health and medical studies. Within the field of psychology, for example, narrative therapists work with individuals to adjust “internalized culture stories into ones that are more inclusive and appreciative of clients’ personal power and responsibility” (Polkinghorne, 2004, p. 59). Through interpretation of “life stories”, individuals undergoing therapy focus on their strengths to address issues in their lives (Polkinghorne, 2004, p. 63). Narrative methods are also used to improve clinical practice and rapport with patients (Bleakley, 2005). Narrative medicine, for instance, is a “clinical practice fortified by narrative competence – the capacity to recognize, absorb, metabolize, interpret, and be moved by stories of illness” (Charon, 2007, p. 1265). Through narrative medicine, healthcare professionals “treat the patient, not the numbers” (Bleakley, 2005, p. 534). By engaging with the patient in this way, clinicians are able to access much more information about their patient’s health and open up their practice to patients’ stories (Charon, 2007; Lai, 2010). The alignment between narrative research methods and medicine is evident in how “medicine attends to words” (Charon, 2007, p. 1266). Through dialogue and

understanding, only then can the distance between the doctor and patient be minimized (Charon, 2007).

In addition to improving communication and understanding between physicians and patients, narrative research methods can also offer insight into illness narratives or patients'/caregivers' stories of illness (Bleakley, 2005; Sools, 2012). Thomas (2010) defines illness narratives as the “storied accounts told by ill people and their informal carers” (p. 647). For example, they can be a useful means to describe the progression and impact of chronic disease in an individual (Bleakley, 2005; Stephens, 2011). Illness narratives do not only focus on the adverse effects of illness but can also provide opportunity for reflection of the changes brought on by illness to one’s physical body and the meanings of these events in one’s life (Stephens, 2011). They may also uncover the ways in which individuals living with illness change or adapt their stories to accommodate perhaps their new identity due to illness (Stephens, 2011). These stories may reveal moral dilemmas faced by individuals as they come to terms with their new social location and/or are subjected to negative stereotypes attached to their illness, such as “being seen as a nonfunctioning member of society and not a virtuous citizen” and subsequent pressures “to position themselves as a good person” (Stephens, 2011, p. 66).

In addition, illness narratives can help bridge the space between healthy and unhealthy individuals through story as a medium of understanding, such that, “[w]hether sick or well, the reader of an illness narrative is summoned by the author to join with the teller—to form community that can combat the isolation of illness” (Charon, 2007, p. 1266). This is the hope of this study: to bridge the worlds between those living with T2D,

caregivers, family members and readers, and embark on a journey of understanding using the universal medium of a story. The participants' stories offer insights into their experiences, how they narrate and make sense of T2D, and how the process of resettlement has impacted their and/or family member/s care/management of this illness, through their own words and sentiments. In addition to narrative research, the present study also incorporated poetry which is discussed in the next section.

Poetry

It was not my intention to implement poetry at the beginning of this study, but in the words of Glesne (1997), my decision to do so is “connected to other serendipitous happenings” which occurred during the recruitment phase of this study when I began to attend a Somali women’s health group in Toronto in the Fall of 2017 (p. 204). I was fortunate to be given the opportunity to join this group because it opened up for me a new avenue of inquiry, one that involved a focus on language and meaning.

At one particular meeting, a member of the group, who is diagnosed with T2D, used the analogy of a tree and termites to describe her condition. She illustrated the process of diabetes as the encroachment of termites in the root of a tree that worked its way outwards towards the branches. Surrounding trees were also impacted by the infestation. She described diabetes as an infestation which affected her roots (as a tree) or her foundation, as well as the other trees around her. Even as a noncommunicable disease, diabetes was depicted as something that could spread to others. Like wildfire engulfing a forest of trees, it seemed to me that no one was spared by this inevitable outcome. Her illustration moved me as well as the other members of the group, who agreed with her depiction.

I realized afterwards that this individual had used a metaphor to compare “two dissimilar things” as being one and “the same”, that is, her body as the tree (Lahman, Richard & Teman, 2019, p. 221). I heard other participants use vivid images and metaphors in their speech as well, to convey aspects of events in their lives and sometimes in their descriptions of T2D, such as comparing T2D to “a burn”, or referring to Mogadishu as being the “heart and root of Somalia.” When translated back to me in English (for those that required a translator for interviews), metaphors and/or other literary devices such as images were often relayed by the older participants in this study.

I began to learn more about and truly appreciate the rich oral history of the Somali language. I was surprised to learn that it was only until recently, in 1972, that a writing system was officially adopted for the Somali language (Jama, 1994; Lewis, 1988; Mansur, 1998; Samatar, 1982). Somali poetry in particular remains a cherished part of Somali culture even to this day (Mansur, 1998). Poetry is used in Somalia as a medium to celebrate everyday life, to convey messages of peace, disputes, and/or describe issues in society (Andrzejewski, 2011; Mansur, 1998).

Poetry is also part of nomadic life in Somalia, and traditionally served as a means of communication between clans, where it was memorized by poets and others interested in learning these verses (Mansur, 1998). Mansur (1998) notes that historically poetry was “circulated from mouth to mouth” serving a similar function to the “press or television in Western society” (p. 94). In fact, trees, in particular hold a special place within Somali poetry and life as they are where traditional gatherings, referred to as “*shir*,” are held (Samatar, 1982, p. 28). As Samatar (1982) explains, “[s]o important is

the refreshing shade of a tree in the barrenness of the land, that the term 'tree' (geed) has come to assume a synonymous meaning with 'assembly' (shir)" (p. 28). This "pastoral metaphor" or "tree speech (hadal geed)" within the Somali language is also used to refer to a site where materials are made/and distributed, and a place where legal and religious matters are discussed (Samatar, 1982, p. 28). Poetry continues to be used widely today by the Somali diaspora.

I have relied on poetry to survive, evolve, and grow as a human being. I am inspired by many Somali poets who are recognized for their spoken word and incredible talent. In learning about the rich oral history of Somalia, I was prompted to consider alternative approaches for data representation for this study, methods that align more with the oral forms of communication and knowledge dissemination of this group. While I have utilized primarily Western approaches to poetry in this study, I have incorporated poetry in this research as a form of knowledge representation, that is oral and focused on the participants' experiences.

Found Poetry

According to Fabb (2015), a poem is "a text divided into sections (such as lines), which are not determined by linguistic structure" (p. 1). These lines, he explains, "are held as whole units in working memory" (Fabb, 2015, p. 1). Poetry is a distinct literary form that can touch many lives through its "universal truths" (Furman, 2006, p. 562). It is these truths that resonate with readers of the poem and, much like stories, often produce emotional responses. In fact, Furman (2007) likens poetry to an "emotional microchip" because it "may serve as a compact repository for emotionally charged experiences" (p. 1) and because when written, spoken, or read, poetry can charge

someone's memory or mind in ways that are truly unique. Poetry also has the ability to serve many functions, both affective and spiritual (Furman, 2006; Shapiro, 2004). There is also another element to poetry which is "embodied" (Sparkes, 2020, p. 46). Poetry may rely on intuitive processes that tap into unconscious knowledge, or as Sparkes (2020) calls it, "corporeal knowledge that does not necessarily presume consciousness" (p. 46). Richardson (1993) elaborates on this corporeal knowledge, stating that "because of its rhythms, silences, spaces, breath points, poetry engages the listener's body, even when the mind resists and denies it" (p. 704). Indeed, there is research that provides evidence of the healing benefits of poetry, where poetry has been used by individuals as a means to overcome adversities, loss, illness, and death (Furman, 2006, 2007; Leggo, 2020; Shapiro, 2004). Specifically, Sparkes and Smith (2014) state:

Poetic representations are able to create evocative and open-ended connections to the data for the researcher, reader, and listener. This kind of creative analytical practice can touch both the cognitive and the sensory, recreate moments of experience, and show another person how it is to feel something, with an economy of words. (p. 162)

Due to this ability to tap into individuals' lived experiences, poetry has been used within qualitative research, mainly within the fields of nursing, sociology, and social work (Hanauer, 2010; Sparkes, 2020), and in the form of poetic transcription, research poetry, and more recently poetic inquiry (Butler-Kisber, 2020; Glesne, 1997; Hanauer, 2010; Richardson, 1993).

There are two main ways in which poetry is used in research (Furman, 2006). The first involves including poetry in research through "generated poetry" (Butler-Kisber,

2020, p. 23), which refers to poetry as a means of data collection via the author/researcher's voice, such as in autoethnographic research (Hanauer, 2010). For example, this method has been used by clinicians to reflect upon their practice, or by those coming to terms with the cancer diagnosis of a loved one (Furman, 2004, 2007).

The second method of incorporating poetry in research involves qualitative data representing the participants' words through poetry (Furman, 2006). Referred to as 'found poetry,' this occurs "when words are extracted from transcripts and shaped into poetic form" (Butler-Kisber, 2020, p. 22). What is meant by poetic form is that there is a "rearrangement of words, phrases, and sometimes whole passages" of data which is then "reframed as poetry by changes in spacing and/or lines (and consequently meaning), or by altering the text by additions and/or deletions" (Butler-Kisber, 2020, p. 23). If there are substantial changes to the data, the final poem can be described as being "treated" (p. 23). Alternatively, if the poem comprises text that is essentially in the "same order, syntax, and meaning as in the original," then it is considered to be "untreated" (Butler-Kisber, 2020, p. 23). This is the format that the poems were presented in this research, as phrases used were not changed in anyway but may have been shortened to include only key points in the line/stanza of a poem. There was also variability in the order in which stanzas/whole sections of meaning were presented within the poem as they did not always coincide with the manner in which they occurred in the interview.

There are two ways in which found poetry can be integrated into a study (Hanauer, 2010; Richardson, 2001). The first way involves a narrative or story composed of the participants' words, poetic structure and devices. The second is

referred to as 'lyric poetry' which "offers the option of exploring situations in which life experiences are not fully coherent and well-integrated into narrative frames and allows flexibility in exploring personal lived experience" (Hanauer, 2010, p. 88). These poems are not composed of stories but are snapshots of memories and their related emotional responses (Hanauer, 2010). This is the format used in this study, as the poems include memories, emotions, and perspectives relayed by the participants in relation to the theme explored in each of the three results sections.

It is important to note that while found poetry is gaining more recognition within qualitative research, there is no formal method for producing this form of poetry (Butler-Kisber, 2020; Glesne, 1997). Nonetheless, this has not deterred qualitative researchers from implementing this approach within their studies. Sociologist Laurel Richardson is perhaps the most well known for being the first to push the boundaries of sociology by including poetry in her study of a mother named Louisa May (Furman, 2007; Richardson, 1993). She created a five-page poem using the words of the participant, specifically "words, repetitions, phrases, hill-southern rhythms, and narrative strategies, such as multi-syllabic words, embedded dialogues, and conversational asides" (Richardson, 1993, p. 696). Richardson (1993) was driven to write a piece that is true to both the life and art of her participant's life story. She described her struggles of introducing poetry within social sciences, which was fraught with tensions as poetry is seen as more of an art than a science since it does not conform to traditional quality criteria employed in the field of sociology (Butler-Kisber, 2020; Hanauer, 2010; Richardson, 1993). However, this has not deterred others from following Richardson's

(1993) postmodern approach to qualitative research, which pushes the boundaries of traditional research methods to include alternative forms of data representation.

In the case of found poetry, the approach used in this study, the process of creating a poem using the interview data involves analysis of the data to produce the final product. It is noted that no further analysis of the data is needed at this point once the poem has been analyzed and presented by the researcher (Hanauer, 2010; Poindexter, 2002). This is because the poem is “a co-interpretive production by the participant and researcher” (Hanauer, 2010, p. 76). In other words, as Glesne (1997) mentions, each found poem “creates a third voice that is neither the interviewee’s nor the researcher’s but is a combination of both” (p. 215). As the researcher writes the poem using participants’ words, there are “glimpses” of the researcher there as well (Glesne, 1997, p. 216). The final product, the poem, provides a form of knowledge dissemination, which may be a more appealing format for quantitative researchers due to its concise format (Furman, 2004, 2006; Poindexter, 2002).

Recruitment

I began the recruitment for this study in late Summer of 2017 using purposive sampling. Purposive sampling involves the “deliberate choice of a participant due to the qualities the participant possesses” (Etikan, Musa, & Alkassim, 2016, p. 2). The participants were chosen due to their experiences and knowledge of the topic under study (Etikan, Musa, & Alkassim, 2016). I initially visited two Somali agencies located in the west end of Toronto.

Participant recruitment was conducted for the most part via word-of-mouth and through information posters placed at these centres (Appendix A). I provided my phone

number and email to key informants at these sites and remained in close contact with them during the weeks of recruitment. I had initially recruited participants based on their ability to adhere to the eligibility criteria, which required that they were able to speak and understand English, resided in Toronto, were over the age 16, and were Somali refugees living with T2D who had arrived to Canada between the years of 2012 and 2017, and/or were the immediate family members of a Somali refugee living with T2D (who had arrived to Canada during this period). This period was chosen because I had believed that it would allow for an examination of their recent settlement upon arrival to Canada. I soon learned, however, through conversations with Somali community leaders, that my initial recruitment criteria (i.e., limited to Somali refugees who had arrived in Canada within five years) did not reflect the migration histories of the Somali population here in Toronto. Given the slow recruitment process, the community leaders' suggestions, and those of my graduate supervisory committee, I revised the time period in the recruitment criteria since most of Somali refugees in the Greater Toronto Area (GTA) had migrated to Canada in the 1990s and early 2000s as a result of the civil war in Somalia (Mohamed, 2016). Thus, to facilitate with recruitment of potential participants, I decided to expand my scope of study to include those who identified as Somali immigrants and/or refugees regardless of how long they have resided in Canada, and included in my recruitment sites, community refugee agencies in Toronto, student campus groups/clubs in Toronto, and faith-based institutions (mosques in Toronto). I also requested the assistance of three translators to resolve barriers incurred due to language (two were affiliated with Somali settlement agencies in Toronto and one was a neighbour of the participants).

Although the recruitment process took longer than expected, it was indeed a moment of learning for me, since it enabled me to learn more about the resettlement history of the Somali community in Toronto. I was finally able to complete the recruitment process in December 2018, as I reached more participants and was able to answer the research questions posed in this study, achieving data saturation (Josselson & Lieblich, 2003). I found that the best route to reach individuals was not over the phone, or through my attendance at workshops and meetings, but rather through word-of-mouth. Through my colleague Muhsin, who is a Somali man, I was also able to reach male participants as well, as many were reluctant to speak with me alone as a woman. In total, 37 participants, 19 family members and 18 individuals living with T2D were interviewed for this study.

Data Collection

This study utilized semi-structured interviews, which broadly followed a set of questions to provide for more opportunities for the creation of narratives (McCance, McKenna, & Boore, 2001; Thomas, 2010). Careful consideration was put into how the interviews were structured since this has an impact on the way participants respond to questions and the production of knowledge during the interview process (Bleakley, 2005). For example, an open and flexible approach to the interviews was used to allow for more in-depth responses from the narrator (Gregory, 2010). During the interview process, participants were asked questions about their and/or their family's migration experiences, upbringing, life in Canada, health, their opinions about T2D, and the impact of T2D in their lives. Probes about factors in the CCT were also included (See Appendix B for full interview guide). Throughout the interview process, I took field notes

of the interview context, pertinent details to the stories and participants, as well as study procedures such as recruitment.

As Bleakley (2005) states, “interviewing is too often treated as a means to an end, and as a transparent process of information-gathering (data collection), rather than a social medium where there is active construction of knowledge (data generation)” (p. 537). This active form of knowledge production is especially relevant within narrative research where the audience member/s are often researchers themselves who must be aware of how their presence and engagement with participants promotes the creation of stories (Chase, 2013; Stephens, 2011). Thus, I endeavoured to treat the interview as much more than a means to an end, but rather, to be ever mindful that it serves as a “window” into the “narrative environment external to the interview” (Chase, 2013, p. 63). I remained attentive to the events in the participants’ story and by doing so, I was able to enter their world, following their speech and/or nonverbal cues to glean the meanings that these events and experiences held for them (Chase, 2013). This required me to re-evaluate often my role as not just the interviewer but as an active listener in this process of engaging with the participant narrator of the story (Chase, 2013).

Interviews took place in participants’ homes, settlement agencies, educational institutions, cafes, restaurants, and libraries. An honorarium of \$20 was provided to all the participants in this study. Although I had initially anticipated doing a family interview with the participants living with T2D and their families, I learned during the recruitment phase that many of the participants were not interested in doing a group interview. As a result, I decided to interview individuals living with T2D and family members of those living with T2D separately. However, there were also some group interviews conducted

in this study which were requested by some participants. Although I worried about issues of anonymity, I respected their decisions for group interviews (for both male and female participants), since it aligned with cultural frameworks where dialogue is shared and meaning is produced interactively in group settings (Bokore, 2013; Langellier, 2010).

All but two of the interviews were audio-recorded with the permission of the participants. Two participants disclosed that they did not feel comfortable with recording their interview, so I made sure to take detailed notes as they spoke. Audio recordings were uploaded onto my computer which was password protected and kept in my personal possession. Once the audio files were transcribed verbatim, I deleted all audio-files from my personal laptop and saved and stored them on a password protected USB key. I also collected demographic information of each participant to understand the specific context of the participants and other intersecting contextual factors through a demographic questionnaire (Appendix C). Information collected included the participant's: gender, age, marital status, number of children, number of years in Canada, immigration status, and diabetes management (if applicable). Data will be kept for a period of two years following study completion, after which time transcripts and notes will be shredded and files will be deleted from the USB key.

Participants

In total, 37 face-to-face interviews were conducted with 19 family members and 18 individuals living with T2D. Most of the participants in this study self-identified as female (15 family members and 12 individuals living with T2D). Four family members and six individuals living with T2D self-identified as male. Family members were

considerably younger compared to participants living with T2D, with an average age of 24.4 years compared to an average of 53.4 years. The majority of family members were single/not married (n=17) and two participants in this group were married. All of the family members recruited for this study were Canadian citizens and had lived in Canada for an average of 20.9 years. The average number of years of residence in Canada for the participants living with T2D was 18.7 years. In the group of individuals living with T2D, 13 were Canadian citizens, 4 were landed immigrants/permanent residents, and one was a refugee claimant.

Data Analysis

This study incorporated both “narrative analysis” and “analysis of narratives” (Creswell et al., 2007; Polkinghorne, 1995, p. 12). The analysis for this study began during the transcription stage when I began to immerse myself in the data and context of the narratives.

Narrative analysis for this study involved “restorying” the participants’ narratives and “analyzing them for key elements (e.g., time, place, plot, and scene), and then rewriting them to place them within a chronological sequence” (Creswell et al., 2007, p. 244; Ollerenshaw & Creswell, 2002). My focus at the beginning of data analysis was to understand the perspectives of each of the storytellers in this study across time and their lived/diaspora space (McCance, McKenna, & Boore, 2001; Polkinghorne, 1995; Riley & Hawe, 2005).

I also paid attention to factors included in Leininger’s “Sunrise Enabler”, which “serves as a cognitive map of the culture care theory” (McFarland et al., 2012, p. 264) and illustrates the ways in which nurses and researchers acquire new knowledge of the

factors influencing care and culture (Leininger, 1997; McFarland et al., 2012). The Sunrise Enabler does not encompass everything in the CCT but does include factors related to care (Leininger, 2002; McFarland et al., 2012) and the basic theoretical tenets of the CCT, namely:

the universal and diverse features of culturally based care; factors connected to culturally congruent care such as worldview, cultural, and social structure factors, and other factors in the Sunrise Enabler; generic and professional care; and the three action and decision modes of the CCT (culture care preservation and/or maintenance, culture care accommodation and/or negotiation, and culture care repatterning and/or restructuring). (Leininger, 2002, p. 192; McFarland et al., 2012, p. 262)

These three modes guide researchers/practitioners on how to provide culturally congruent care (McFarland et al, 2012). Each narrative was analyzed in accordance to these factors, and chronologically storied with a focus on three broad categories: the participants' upbringing, settlement, and health (pre-diagnosis, diagnosis and care/management of T2D of the participant and/or family members). Three stories are presented in the findings sections of this thesis using this approach. I begin each of the stories with a broad background of participants' demographics and contexts in which interviews were conducted.

Given the large number of interviews completed (37), I also conducted an analysis of narratives by exploring themes presented across participant interviews (Esin, 2011; Polkinghorne, 1995). Thematic analysis was employed which involved coding of interview data and looking for patterns and themes in accordance with the

theoretical frameworks implemented in this study via a four-stage process outlined by Esin (2011) (Riessman, 2008). In the first step, “selection of subtext/segments,” all of the “relevant sections” that were related to the research questions/factors in the Sunshine Enabler were assembled in a MS Word document for each of the participants in this study (Esin, 2011, p. 108). The second step, “definition of thematic categories,” involved multiple readings of these sections and “defining the themes that emerge from these readings” (Esin, 2011, p. 108). After preliminary themes were identified for each participant, I then proceeded to the third step, “sorting the material into categories” (Esin, 2011, p. 108). This stage involved grouping themes that were similar and including participants’ words/sentences under these categories in a chart. I continued to refine the themes to ensure they were representative of content presented within each category. The last stage, step four, involved “drawing conclusions” on the content presented in each theme to describe the meanings derived from them more broadly (Esin, 2011, p. 108). The conclusions from the analysis of narratives were then used to structure the findings chapter. Chapter 5 includes each of the central themes that emerged from the analysis of narratives. The three stories noted above were then each placed in the chapter that best represented the theme discussed in their respective section. Within these stories, excerpts from the participants narratives were also integrated in the story, to highlight aspects/points of the theme being discussed.

Creation of Found Poetry

In my opinion, poetry is a distinctly human form of expression; one does not need to be an expert to be a poet. However, it does take time to immerse yourself in your own feelings, to understand them, which in itself is an intuitive process and a journey of self-

reflection. When I write poetry, I try to tap into my unfiltered self. I believe the reason why many people share poetry is because it signifies the multiple ways human experiences are conveyed. This thesis has opened my eyes to a world that I never knew existed and I am inspired by the passion of poet-scholars that have come before me. I agree with the sentiments of the late Canadian poet, academic, and educator, Leggo (2020) who said that "...living with hope means living with poetry." (p. 85). Indeed, this is what poetry continues to do for me, and this is what I set out to do in this study.

Sparkes (2020) argues that one does not need to be an expert to write poetry and that "poetic representations can be viewed as not-quite poetry or poemish and still accomplish their representational task" (Sparkes, 2020, p. 44). Lahman, Richard, and Teman (2019) define "poemish representations" as possessing "features of poetry and [reflecting] an effort to blend the aesthetics of poetry and science of research into something which may be said to be poem-like" (p. 215). In order to do this, they recommend researchers first become acquainted with the different forms and applications of poetry by reading poetry, for "reading of poetry sparks the writing of poetry" (Lahman, Richard, & Teman, 2019, p. 219). In addition to reading, researchers should also devote time to revising their work (Hanauer, 2010; Lahman, Richard, & Teman, 2019; Richardson, 2001). The process of revising poetry helps to "'tighten' the text so that it functions poetically" (Hanauer, 2010, p. 14). By tightening the text, this leads to a clearer product that portrays the essence of the poem concisely (Hanauer, 2010).

I aimed to accomplish these tasks and have, since deciding to include poetry in this study, been reading about poetry and seeking to understand the rich oral history of Somali poetry. I also drew inspiration from Glesne (1997), Poindexter (2002), and Langer and Furman (2004), who outline how to go about creating found poetry. I started the process with select transcripts of participants with stories that best represented each of the three themes noted above. I returned to my preliminary analysis of participants' narratives to guide my analysis of the selected transcripts. With these notes and participants' transcript in hand, I began to identify "phrases, sentences, or paragraphs that seemed to highlight the unique personality or perspective of the respondent and transferred them into another computer document" from anywhere in the transcript text (Poindexter, 2002, p. 708). With these highlighted interview texts, I then arranged these lines together in the order in which they appeared in the interview text. I followed Langer and Furman's (2004) approach of "keeping discrete units of meaning together and to the sound of the newly forming poem" (Langer & Furman, 2004, p.5). In this stage, I re-read each of the highlighted interview texts and arranged them into lines, which as noted above included "one level of section small enough to fit into working memory" (Fabb, 2015, p. 19). Stanzas include sections of lines that were grouped together (Fabb, 2015). As noted previously in this chapter, the participants' words were not altered in any way; however, some words in stanzas and/or sections may have been removed to provide a more concise format of knowledge dissemination. Further, lines did not always appear in the exact order that they occurred in the interview text. The order in which the participants' words/phrases appeared in the poem were sometimes rearranged to provide flow and fluidity. After each poem was completed, I then titled the

poem according to the contents and meanings produced through creation of the found poetry. The process of writing found poetry also involved multiple drafts, revisions, and tightening of poems over time. These representations were also shared with the participants to inquire if they were in congruence with what they believed to be representative of their experience/interviews.

Ethics

This study abided by the research protocols outlined in the York University Graduate Student Human Participants Research Protocol. In July 2017, The Faculty of Graduate Studies Human Participants Research Protocol Form was approved from the York University Research Ethics. Six participants diagnosed with T2D requesting a translator were provided with one to ensure that they were able to understand all aspects of the research process. Prior to the collection of data, all of the participants in this study were given a letter (Appendix D) containing information about the purpose of the study, methods, and the potential risks and benefits. Participants also gave informed consent verbally and in writing through the completion of the consent form to participate in this study, as well as permission for the researcher to use direct quotes.

I ensured that informed consent was ongoing and obtained throughout all points of the research process. It was imperative that the participants understood the information that was being conveyed to them prior to recruitment and during the research process; this is also in accordance with the goals of transparency promoted by CCT of all research processes. Due to the sensitive nature of this study, and questions that could reveal personal details of their lives, all participants were also provided with a

list of community mental health and settlement resources, whom they could contact if they required further assistance and/or counseling.

All of the participants in this study were provided with the interview transcript, and data analysis for their feedback to provide an opportunity for them to participate in the data analysis process as well. Pseudonyms have been used throughout to ensure anonymity wherever possible, unless participants gave permission to use their real names.

Validity

Creswell and Miller (2000) define validity as “how accurately the account represents participants’ realities of the social phenomena and is credible to them” (pp.124-125). Establishing validity of findings is an integral part of conducting qualitative research, and is aligned with the CCT, which promotes transparent and respectful approaches to research (Polkinghorne, 2007). I implemented two quality criteria in this study. The first approach that I implemented to establish validity includes thick description, “to provide as much detail as possible” of participants and events that occurred in the research process (Creswell & Miller, 2000, p. 129). By striving for thick description of interviews (which also included correspondence with participants before and/or after interviews), I was able to contextualize the results and narratives. Thick description was an important part of this study since it offered a means for me to re-create research events, settings, and interactions with participants with accuracy and clarity. Writing down details about participants (for example, as in the case of Guleed’s story), allowed me to recreate the scenes including the serendipitous events that occurred leading up to the interview. The second approach involved communicating

with participants to get their interpretation of study findings. Participants were provided with transcripts, notes, and a summary of findings. Given the limitation noted previously related to recruitment challenges, member checking offered an opportunity to connect with the participants to see if the findings were representative of their experiences, which is an important aspect of ensuring validity for narrative research (Creswell & Miller, 2000; Polkinghorne, 2007).

Summary

This chapter presented an overview of the methodological approach implemented in this study. Qualitative narrative research methods were used to answer the research questions posed in this study. In addition, this study included poetry in the form of found poetry. From this process, three main themes were identified which included the precarious settlement of the participants in this study, the ways in which T2D dialogue and care were gendered (gendering of T2D), and the multiple perspectives of T2D (both good and bad) in the last theme, 'diabetes as bitter-sweet.' The following chapter explores the themes uncovered in this study.

CHAPTER FIVE: FINDINGS

Family Trees & Diabetes

A Walk into the Forest...

Three central themes were derived using the process outlined in Chapter Four. These findings follow the metaphor of a tree. The narratives begin with seeds, or the stories themselves, which were planted by the participants. These seeds offered hope as they grew in their unique way, illustrating the participants' distinct experiences.

The first theme, precarious settlement, describes how the participants established roots within the settlement context of the study and how personal, familial, socioeconomic realities impacted their own and/or family's wellbeing. Also included are narratives of the family tree, diabetes, and the plots in which the participants nestled their roots. The progression of the seeds and establishment of roots offer a point of entry into an examination of the participants' precarious settlement as first, second, and 1.5 generation (born abroad but raised in Canada) Somalis. This section describes not only the process of growing roots in these contexts but also how the participants sought out light within these landscapes, through their faith, community, and pursuit of education and safety to live and/or thrive in these settings.

The second theme, gendering of diabetes, illustrates how the construction of T2D and the depiction/enactment of care are gendered. This theme explores gender as related to T2D, such as how the participants viewed T2D as mainly a woman's disease, due to increased prevalence of this condition in the lives of Somali women in their family tree. This theme also highlights how women cared for others living with T2D, caring not just for family members, but even beyond – tending to the forest beyond their family tree.

The last theme, diabetes as “bitter-sweet”, explores how T2D is perceived amongst the participants. Just like the fruit on a tree, the participants had varied and complex views about and reactions to T2D. For example, they had diverse viewpoints regarding their own and/or family members’ diagnosis, such as: acceptance, fear, shock, denial, and/or gratitude. They also discussed both the positive and negative aspects of T2D and their perceptions of T2D were dynamic and changed with time. Many reflected on the adversities that were part of managing the disease, such as restrictions to diet, stigma, loneliness, shock, fear, discipline, and denial. Other participants showed gratitude that their condition was not worse and appreciated the fact that they were granted another day and were able to stay connected to family member/s. Still, some participants chose to hide their diagnosis while others shared their diagnosis with family members and friends.

It is clear from these narratives that T2D not only impacted individuals living with this condition but also members of their family and community – that is, other trees and the forest – in that sometimes the disease eroded the foundation of the tree and caused distress to and/or conflict with individuals (i.e., other trees). When the disease struck big trees, sometimes smaller trees were left without shade. In order to survive, they strived to support the bigger trees while also caring for themselves as best as they could.

This chapter is organized in accordance with each of these three themes. Each story in the three sections in this chapter begins with a found poem that reflects the theme and an explanation of the key elements of the theme. This sets the stage for a participant’s story that depicts the theme but also integrates within the main story, narrative sections from different participants.

Precarious Settlement

The first theme describes the participants' process of precarious settlement which did not cease once they gained entry into Canada or became Canadian citizens but was rather an ongoing part of their stories. Precarious settlement is the context in which their narratives are situated as first, second and 1.5 generation Somali immigrants and refugees. This theme examines the circumstances in which the participants and/or families live and grow, the schools they attend, and the cities and landscapes they call home. It is these details of the places in which the participants' stories are told and take place, that play a role in their and/or family members' care/management of T2D. Specifically, many of the participants, who have multiple identities as Somali-Canadian, Black, and Muslim individuals, live in poverty, and consequently struggle with immediate challenges to their personal and families' health.

The participants in this study (particularly those living with T2D) experienced the burdens of settlement which included poverty, trauma, and loneliness as they established roots in Toronto with their families. Many of the participants living with T2D described their memories of Somalia and their initial experiences adjusting to life in Canada. For example, Hibaaq, aged 60, explained:

I'm never go to school because my kids small all. I came, that time I have six kids, three born in Canada [begins to name them]...three born in Canada, now my English is broken... I don't speak English very well... That time I, I, I give my time's my kids.

Though she laughed when she recounted this, it is clear that Hibaaq prioritized her children in the process of settling in Canada. To provide for her family, Hibaaq worked

in hospitality and manual labour. Similarly, Shamsi, a family member aged 25, described this burden of settling and its implications on the health of parents in the Somali diaspora:

A lot of people came, and you know this, had this burden of settling. As you know, some of them came with young children and settled learning a language, learning a new language completely. So, health kind of takes a back seat to all of that. So...and if you're raised in that kind of environment, you just don't see umm like okay this isn't probably the healthiest thing to eat...

Idman, aged 58, also shared her struggles when she came to Canada in 1989 while seven months pregnant, alone without her husband. She conveyed, "Coming here at that time, the job was very hard to get it. It is under, under social assistance living with the social assistance. And I was middle class in, in, in Somalia...So it was, I feel, I feel I'm very down." She struggled to find employment as a teacher because her previous education was not recognized. "Yes I was a teacher. When I came here I can't be a teacher because that skill left to Somalia from. I went to as illegal washing dishes working that. Even though they ask you do you have experience how to wash the dishes?" she said. Ultimately, Idman worked multiple labour jobs to make ends meet for her family for over eight years. She described her life thusly: "So I have to run to a labour to put the bread on the table for my children." Eventually, Idman was able to sponsor her husband and a child that she had left behind in Somalia. Only once they had both come to Canada did Idman feel able to go back to school, despite criticism from others that she was too old. She successfully completed a degree in 2002. With

her whole family in Canada, she stated that she felt that “here, became like my, my, my home.”

However, several of the participants felt uneasiness with the sites in which they set down roots, viewing them as inhospitable places for raising their families. Having fled their war-torn homeland for what was presumed to be a better life, many parents in this study were now faced with living in neighbourhoods that experienced violence and stigma. It is within this context where they worked to build a life for themselves and their children. Barni, aged 29, conveyed how concern over safety in general due to proximity to violence took precedence over her mother’s health who is diagnosed with T2D:

She won’t sleep at night if [Barni’s youngest brother Tahiiil]’s not home. So, her everyday thing is more concerned with child rearing that I don’t even think it’s the focus of her life, her health.

Likewise, Tahiiil, aged 20, confided that he would be rushed inside by his mother when trying to play outside. He commented, “Umm, it I-I-I enjoyed it. Uh, like I already go outside and play like basketball and play soccer and stuff. But like my mom always come outside like chase, tell me to come inside and stuff...” He admitted at the time he did not accept her concerns so well but now understands her reasons for doing so:

Uh because it wasn’t, it wasn’t really a safe neighbourhood at all. But like at a young age like there was like not a lot of bad things would have happened to me. But like, like for people that were older than me...it was a, it was a bad neighbourhood. Yeah, but like I was just a little kid playing basketball and soccer. So nothing really happened to me.

Light ...

Also, a part of this theme is the way/s in which the participants found and fostered light through education, safety, faith, and community. The light reference is used in the participants' stories throughout this chapter to exemplify their resilience and faith as they and their families navigated the resettlement process. Adam, aged 21 outlined the formative role that a mosque executive and mentor played in his life. This mentor helped him find stable ground to build roots as a Somali male youth within this diasporic setting. Adam is now a university student with aspirations of becoming an entrepreneur. He reflected on how grateful he is for being encouraged by this mentor to join a Muslim sports league, which he described as his "second home." This is where he met Hussein, aged 21, one of his closest friends and also a participant in this study. Adam, Hussein, and Bashiir, aged 16, comprise the remaining male family members in this study (in addition to Tahiiil noted above). This energetic trio met with me at a local coffee shop in Fall of 2018. And as they told me about their stories, I was reminded of the hope for the future, and resilience of Somali parents that I had met throughout the course of this study, and their faith in the next generation. It was this light I saw again, throughout the narratives of the participants and in the ways they navigated sometimes difficult terrain, and made sense of T2D diagnosis, a topic I revisit in the last section of this chapter.

After Adam's poem, I present the story of Aaliyah, aged 21, a young nursing student who had approached me via email near the end of the recruitment phase of this study. I chose to focus on her story since Aaliyah's narrative details the precarious settlement – the underlying poverty, trauma, and loneliness – and the parental stress

pertaining to safety of children, and aspirations tied to the pursuit of education in the Somali diaspora in the GTA, experiences common to several of the youth in this study. Moreover, like others in the study, Aaliyah's story conveys how she has stepped into the role of caretaker for three of her family members living with T2D, while also searching for and fostering light so that the next generation of youth may grow and flourish.

“Second Home”

*I could have gone the wrong way
not gone to school
university*

*He showed me
What the future could be*

*Nothing that my mom didn't do already
But he acted I would say like a father figure to me*

*The people that I knew back then
I know them now
They're not really the same
that I am right now*

Adam, aged 21

Aaliyah's Story

I met Aaliyah, aged 21, in the Fall term of 2018 at a local coffee shop following her last exam. There were not that many people in the coffee shop that day, so it was easy for me to spot her. Aaliyah was sitting on a stool facing the entrance of the café near the windows with a cold drink in hand. She did not seem to notice me as I walked into the space because she had her head down and was busy scrolling her phone. As I walked closer to her table, she glanced upwards in my direction and smiled. She had a warmth about her that she exuded instantly. I inquired if we could relocate to the library, where it was quieter to conduct the interview. Aaliyah agreed and we made our way to the library, conversing briefly about her final exams and the end of term. We found a vacant room on the first floor of the library and began the interview process shortly after.

Aaliyah shuffled back and forth in her seat, searching for what to say when asked to describe herself, "Okay... Umm so my name is Aaliyah. I'm a 21-year-old student at [names university] ...Uh umm yeah, I've lived in Canada all of my life."

She was born and raised in the same house in the west end of Toronto. While she yearned to move somewhere new, she was appreciative of establishing roots in a supportive community. "Familiar you feel comfortable in that space...The community is supportive, so I don't really have problems. Very Somali. So it's like a big family" she said.

Aaliyah added, "I have four siblings, all girls. That's just fun!" One of her sisters was attending the same university as her, and her younger sister was still in middle

school. The eldest had just graduated from university and had just secured a job in her field. They were all very close:

Oh my God it's loud but there's a closeness between us, you know. It's like, it gets annoying but then again. It's like we fend for each other more because we're just like... I don't know what, what about us makes us do that but we're all girls and we have to check each other. There's a lot of us. We're at a really vulnerable age group range right.

She mentioned that her parents were very protective of her and her siblings and worried about their safety. "Umm we can't go out alone in the day. Yeah, we have to go with a sibling," she said. "To this day, at 21 yeah. My sister who is a year younger than me has to come with me." Aaliyah explained that she understood why her parents felt the need to implement these rules. "I understand. I feel like I can see, I can see myself maybe doing that if I had five girls who are like same, in early 20's, or young adulthood."

Indoors...

Aaliyah's sheltered upbringing was similar to what Barni, Tahil, and another family member in this study Canab had conveyed in their interviews, as they too were raised predominately indoors, away from the perceived harms outside. Like Aaliyah, Canab, aged 32, mentioned that she was restricted from going out as a child:

...I like the fact I was being sheltered because that led to me protecting my innocence in a way, so I never felt the need to like go to parties and boys and all of that. It was just more about my books and home.

However, this was not the case for her older brother as she recalled:

My older brother did a little like you know the boys like getting into trouble growing up with the wrong crowd and my mom seen that earlier on so she sent him off after he was 20. I think he was struggling to finish his college and then after two years of not going anywhere with that she just sent him to Africa to be with my aunt, her sister, who had a lot of kids. So he became really involved in that and then they moved from Africa to the UK, but he had to go babysit with her, like help.

In this case, just as a tree may be transplanted to improve its growth, Canab's older brother was sent to live with family abroad. Canab mentioned that he now lives in the UK, and is doing very well with a family of his own. She added that her younger brother also now lives a very "restricted" life because of her parents' experiences with the older brother. "The younger one was very restricted, and I travel a lot, so I had introduced him to that lifestyle to get him to not feel like he's missing out..."

Much like how seedlings are one of the most sensitive and delicate of a tree's life cycle, these participants were sheltered differently due to their perceived susceptibility to negative influences. Canab, like many of the female family members in this study, experienced gendered surveillance, as a means to keep them safe. Marwa, aged 21, who like Aaliyah also comes from a family of all girls, explained:

Now I feel like there is less Somalis [in the community], I feel like they are moving out because they have sons and they don't want their sons to get influenced you know peer pressure and all that, gangs, all that bad stuff. I guess we are from Toronto Community Housing so it makes sense that you would move out, maybe go to Somalia, maybe find a better area. Umm my parents never really had a

problem with that because we're all girls. Not saying that girls are better than boys, but like...they didn't, they didn't worry about us being peer pressured or anything.

On the other hand, the gendered surveillance that male family members experienced were from family and others who presume male youth to be more susceptible to being led astray by negative peer influences. For example, Beydaan aged 34, illustrated that her brothers were unable to escape the increased surveillance by security personnel in the store in their building and were often followed and viewed with suspicion. Similarly, Tahiiil noticed that campus security at his university focused on his movements and behaviour more closely compared to other students. As a student, he became increasingly aware of how he was perceived at university as a young Black male.

Concrete walls...

But schools were not the only site of surveillance. Aaliyah explained ambivalently that the police presence in her community served as a reminder of the stigma that never seemed to leave, prompting her to explain that her community has “been kind of tainted by stigma and stereotypes, so it was difficult [referring to when she was growing up].”

The police presence was ever present, in large part because there was a police station just behind Aaliyah's house. For older Somali people who had settled, this only served to unsettle them, reminding them of traumas they had experienced in the past, as reflected in their reluctance to speak with the police. Aaliyah explained:

I don't know I feel like my parents don't speak about their experiences growing up; that's like a void. We don't know anything about that. So, I can only assume

it's really been traumatic. Um I know my dad's father was um, he was in the military but there was like some stuff going on that really affected him.

The older generation, she mentioned, did not get the "full context of why these things [referring to police surveillance] happen."

In comparison, Aaliyah was accustomed to engaging with police on a regular basis, illustrating her routine interactions with them: "Hey we're just doing a scope of the area...how are things?" She breathed deeply, "It's like, hi Jeff you're back again?" She paused,

Umm making sure that if police come to your door to ask questions, which is pretty often. Like a weekend thing. You don't answer, you don't speak... ..to anybody, unless the parents are there. And it was really that telling people that you live in the community like that, it was weird. It was, it was interesting, but it was very protective and closed off yeah.

Despite seemingly being exasperated with their constant presence and the routine way in which she would speak (or not speak with them), Aaliyah was not afraid to engage with the police. She shrugged her shoulders, "You know, we didn't do anything wrong. You know, you can just converse with them."

Like Aaliyah, Ambaro, aged 24, also noticed the police presence in her community. She recalled the time when she was required to complete a survey on violence at school:

I remember asking my teachers, is this something that all schools have to do? And they said no, it's just the two high schools within the [name of neighbourhood] community that have to do this and I thought that was odd.

Umm, umm...but it definitely opened my eyes that this was, this was not something seen in other communities. It seemed very particular to us...

Despite her contemporary understanding of the poverty and stigma associated with her neighbourhood while growing up, Barni was not aware of how her home was viewed.

She reflected on her experience growing up in her community in a more positive light:

Yeah, umm it was nice growing [up] in umm [name of neighbourhood] community... Umm I was kind of unaware of like the stigma or the, or the poverty or whatever. I just thought it was like a normal place to live.

Instead, for Barni, her community was a normal place to live and, as illustrated in the next section, to grow and establish roots.

New Roots...

Although the schools that some of the participants attended were sites of stigma and surveillance, older siblings were still able to set down roots and foster new ways of being and growing in these places, serving as mentors for younger siblings and as support systems. They made sure their younger siblings did not fall through the cracks of the education system which sometimes created adverse outcomes for Black youth, particularly those in low-income neighbourhoods. Some family members mentioned that they were not encouraged to pursue higher education by teachers and school counsellors and were pushed into the applied stream which limits access to post-secondary education compared to the academic stream. Adam instead relied on his sisters for advice on switching from an applied to an academic stream. He reflected on what happened when his mother came to his school to change courses:

She [referring to his mother] told her [the counsellor] um you gotta switch that because... you know... *Alhamdulillah* [Praise be to God] my sisters too had an impact too. Growing up, you're not going to reach, you're not going to have everything, an opportunity, if you take applied. You're only going to have one life, you know what I'm saying? You go academic, you have way more and like... *Alhamdulillah* [Praise be to God] I followed their footsteps; it helped so much. Like they, they did all the trial and error for me.

Likewise, Fowsio (Marwa and Barkhado's sibling), aged 21, credited her sisters for helping her make an informed decision regarding which route she should pursue. At first, she was pressured to go into the applied stream. She explained:

Yeah [laugh]...Yeah when I was applying for high school, um my teacher just cuz the area was bad... he was telling us like "oh you guys can't do academic, just go for applied" ... He was my teacher like you know how you have a grade teacher. Cuz like I feel like there is a stigma, like oh you guys can't really achieve high grades in that type of school.

Fortunately, Fowsio's sisters advised her with regards to navigating the process of negotiating high school and post-secondary education choices (and the low expectations of teachers):

And thank God like I had sisters older and they all did academic [stream] and they were like just don't listen to him. And they went to the same school too. I didn't really listen to him because like my sisters say like the teachers do say that... but they didn't necessarily... they didn't go one on one with you like you should do this... they talk it like a class, 'you guys it's very hard, high school is

very hard'. They don't care about you like... they try to scare you in a way to go for applied. Hmm yeah, I like um... I didn't feel down because at that time I was like aware of like the type of school it was and I knew like just because like... I mean a majority of us were like first generation, you know we were like really all Black or like Somali or like...

In light of the views of her teachers and their lack of specific guidance and care, Fowsio's sisters were integral to her education, not only influencing her to pursue the academic stream but also paving the way for her by going to university. Fowsio stated, "Umm like I guess like, I guess they influenced me in a way because I used to see them studying and do their work and like get good grades."

Aaliyah also worked hard at school, excelling in her studies. She was motivated to pursue nursing because of her older sister, who was 25 at the time of the interview. She recalled the time her sister was diagnosed with T2D:

She was...I was about ten, I think turning 11, she was like 13, turning 14...she uh, it was weird...and I didn't understand it back then. I just knew that she just started becoming really moody and kept to herself. And I just thought it was like just a behavioural thing. Um not knowing the burden that she had to carry at so young...Right and just feeling like it's your fault especially with type 2 diabetes right. It's not genetic you can't put it on that.

As a result of her sister's diagnosis, Aaliyah is passionate about pursuing a career in pediatric nursing. She understands how difficult a diagnosis of T2D can be, through her experiences of watching her sister struggle with her diagnosis over the years. "And it was really bad. I remember I think they took her to the hospital. And she had like a

super low blood sugar. It was like yeah, there was phase where she was just like I'm over it. I don't want to deal with it, like...that's it" she explained.

It was not until her older sister was diagnosed that she understood what diabetes was, and that her parents were also living with the same illness as her sister. While her sister is doing better now and managing her condition, Aaliyah cannot say the same for her parents whom she explains have neglected their condition. The fact that her parents do not manage their T2D is why she was in the dark for many years about their illness. "I was like oh my gosh, you have diabetes? *Aabo* [referring to her father], you have diabetes too?"

Aaliyah felt that her parents normalized T2D to some degree, and rationalized it as being, "not as bad as cancer." She mentioned that her parents seemed to accept their diagnosis in this regard but were adamant that her older sister take care of her health because she was so young. This made Aaliyah wonder about why they did not care about themselves in the same way. Her parents' lives were focused on her and her siblings. There was not much discussion about T2D beyond her sister's condition. And as the second oldest sibling, and the oldest family member without a health condition, Aaliyah felt compelled to take care of her family. The next sibling in line, she worked to stop T2D from negatively impacting her family. Appointed as the "second mom" by her siblings who used this term to taunt her, she now found herself enacting this role. "Like I took that position on myself... I just put that on myself," she said.

Alone in a forest of trees...

As she spoke about her role in the family, she focused her attention on her own health, as a single tree outside her family tree. "I don't think my health is up to par with a 21-year-old female, I don't think it should be where it is. But I don't know..." she said.

Aaliyah added,

I don't know... I just feel like, I have like symptoms. I don't know... I get fatigued really easily, I get tired. I have a lot of burn-out. So after exams right now I just feel like knocking out. I don't feel active like my other classmates and they're out to eat and I'm like no I wanna go home and sleep. So like exhaustion and stuff like that.

She explained, "Yeah I drain easily..." Aaliyah mentioned that this was because she was never really transparent about her feelings because she was perceived as being "that responsible person." Due to this, she never really opened up about how she felt. She mentioned,

I've always kind of forced myself if it's bad don't say anything at all. If it's good then express that. So emotionally there's a lot of undisclosed stuff. I feel like I'll just say that I'm overwhelmed, scared...like oh my gosh family is breaking apart so... So I just feel like I have to be positive.

Aaliyah acknowledged that it was not healthy for her to continue to keep her emotions bottled up like this.

Um it impacts me... umm just having my issues to myself... In a bad way... um it's, it's a lot... I feel like sometimes, I just want to talk ... like who do I go to? If I put myself in a position of being the person that people should come to me. So I

guess that's kind of like a problem...Yeah I can't talk about illness because it's in my family. Emotions umm I think there was like once that I cried to somebody, I was like, oh my gosh, this is too much.

At the end of the interview, Aaliyah expressed her desire to pursue more advocacy for diabetes in her community. She mentioned also that it would be a good idea to have a support group for other students who were caring for loved ones living with T2D like herself.

This section examined the settings in which the participant stories took place, where they planted their seeds, formed roots, and called home. The participants in this study experienced both personal and collective insecurity, as a result of poverty, proximity to violence in their neighbourhoods, police surveillance, and the burden of settlement which impacted their and/or families' management and care of T2D. To be a member of the family came with other responsibilities, as Aaliyah described in her case, her role as the "second mom." It is this role that she 'naturally' assumed. The following section examines in greater detail how diabetes is gendered and how care is expressed and carried differentially by female and male members of the family, this time through Bishaaro's story.

Gendering of T2D

This section describes how the participants integrated gender in their discussions of T2D. This was done in three central ways. First, many of the participants described T2D as a woman's disease. Of the 19 family members interviewed (15 of whom self-identified as female), 15 participants disclosed having a mother living with T2D. Several of the family members could not describe the details of their mothers' diagnoses since they were diagnosed during pregnancy, prior to their birth, and/or when the participants were very young, as was the case for six of the family members interviewed. For these participants, T2D was always something that their *hooyo*/mother lived with, which involved a routine of care throughout the day.

Second, several of the participants narrated reasons why they thought women were more susceptible to T2D, such as an unhealthy diet and/or lifestyle. For example, Barkhado, aged 23, discussed how much her mother had loved *halwa* (a sweet) because it was a food that she had grown up eating. "Yeah...to me, it's her chocolate" she explained, conveying it as her mother's sweet tooth. She laughed as she illustrated how *halwa* was consumed by Somali women while drinking tea.

They put it in, like what Somali people do is that they take the Somali cookies. Yeah it's like a little...it's like a flower shape, made specially. So then they put the *halwa* in it and they eat it like a sandwich. And that's just...*Halwa* and biscuit is what people do and they'll have a cup [of] tea to hit the spot. The three sugars. Similarly, Iftiin, aged 19, shared her observation of the oral health of women in her community who consumed *halwa* regularly: "I mean like there [are] so many older

people I know that have a gold tooth. Or like uh...a fake tooth because of the sugar that they eat.”

In addition to concerns regarding *halwa*, some participants said the reason for the lack of physical activity among Somali girls/women was gendered. Twenty-three-year-old Ubah, whose mother was diagnosed with T2D just a few weeks prior to the interview, offered possible reasons as to why there was a lack of physical activity among Somali girls/women in her community:

But for girls it's like you can't go to the public gym because it's mixed and awkward cuz there's guys there. And then there's nothing for us.

Ubah's quote illustrates how the lack of physical activity options for Somali women was due to a lack of accessible sex segregated spaces available, as part of Islamic requirements that promote minimal interaction between genders.

In addition to the lack of physical activity options and in light of the environment where they have settled, Ubah has also noticed a trend where girls and women spend their time and energy creating outreach activities for the young Somali boys/men in their community to shield them from negative influences in their neighbourhoods. This tendency frustrated her because it diverted attention away from girls/women's physical activity needs in the community:

Yeah it's all guys it's so shitty cuz it's like. A lot of my friends too...because I knew some girl from [the West end] they were making outreach stuff. And they were only doing it for the guys. And I was like oh what about us? Girls making outreach stuff for the guys and they were like we need to keep the guys off the streets so they don't get into gangs and drugs and all of this stuff. And it's like for

the *gabdās*' (girls)...they think we're all... we're okay. We don't, we don't need anything.

Ubah's statement highlights how female participants in this study took on the role of caretakers of the family and even the community of trees, such as in the following poem about Ambaro's mother and Bishaaro's story of her efforts to manage her mother's T2D. This was the third way in which gender shaped the participants' stories and was evident in many of the narratives of the female family members in this study.

Hooyo

*She is the support system of our family
Doesn't necessarily have time to take care of herself*

*I think our culture kind of promotes eating
It's a way that shows that you care about somebody
You care about yourself
Making sure that you eat*

*I think we look at food as something to be enjoyed
It's not just like for nutrition per se
It is something that is
Something that you do
A part of your life...
that makes you happy*

Ambaro, aged 24

Bishaaro's Story

I met Bishaaro, aged 23, one evening at a university library in downtown Toronto in the Fall of 2018. We began the meeting casually chatting about our day in general and our conversation eventually veered off into various other subjects, such as her favourite music artists at the time. At the time of the interview, she was finishing her first semester in a two-year (compressed) nursing program. Bishaaro's story chronicles her experiences growing up as the daughter of two parents living with T2D, and her role as their main caretaker. It is a story of resilience and love.

A Familiar Forest...

This story takes place in a West end neighbourhood, where Bishaaro was born and raised. Bishaaro grew up with her two older brothers and parents in the same house that she has lived in since she was about three years old. Like Aaliyah, she grew up in a tight knit predominately Somali community

The friends that she had since childhood were still a large part of her life. "It's because we were young, we walked through life together," she explained. Although this was beneficial in some ways since her "friend groups were already made," it also brought on challenges for her because she felt as though she had no one with whom to share her problems. "When stuff happens to you personally and then finally you feel like you don't want to unload on people because they're also going through the same struggles. And like you don't want to seem weird..." she said.

Bishaaro felt like it was selfish to share her experiences in this way with her close group of friends. Her experiences mirrored Aaliyah's in some regards in the last section,

as they both yearned for a space to discuss their feelings. She laughed as she recounted a scenario in one of her classes:

Yeah and also we did this umm, umm group like not group but this final project for our counselling class. Where it's like we paired up with another person that we didn't know in the class and we did like a therapy session. And um I guess it was like, like a hard time in my life like with exams and I was unsure about my future. And I felt like I didn't really have anyone to talk to. Like, like, talking to like my partner who didn't know me at all. It was kind of like this, she was recording too. But like you don't really know the person. And like yeah, I ended up telling her stuff I never told anyone in my life. And I was like woah and I'm like I think I need therapy.

She cherished this memory because it deepened her love for the field of psychology. It was during this time while working in a psychology lab for two years, that she was able to see therapy in a new light. "I used to think like mental health was people who utilized those services and ones who have extreme cases and stuff. But I think like, honestly, I think everybody should go to therapy because we all need someone to talk to."

Despite her passion for psychology, Bishaaro decided against pursuing further study in this field. "I went into nursing because it was more practical and stuff to help my parents and get a job quicker. But I think psychology is where my heart was at," she conveyed. As a second-generation Somali Canadian youth and the only female in the household, she felt pressured to choose a career which would allow her to finish school sooner and provide for her parents, both of whom were living with T2D. In her first semester of a second entry nursing program, Bishaaro admitted that she was not happy

with her program choice but decided to continue with the program nonetheless as she viewed it as a means to support her family in the future.

She mentioned that it was her duty to take care of her parents, even though she had two older siblings. “They’re [referring to her parents] kind of like, they’re getting older, and I like just wanna help them make them retire. Make them like I don’t know. I always have that feeling like I gotta take care of them.” Her eldest brother was married and did not live at home and the middle brother “has a full time job, so I guess like he gets tired and stuff yeah and stuff. And plus, like um me and my mom share a room. So, like it’s just easier for me to uh...check on her.” Beyond the proximity of her mother though, there were other reasons for this relationship of care. She elaborated, “Yeah being the only girl it’s kind of like yeah. It’s a cultural thing...” Thus, for Bishaaro, caring for her parents was a complex weaving together of love and desire to look after them, as well as cultural expectations of a daughter’s duty.

Like Bishaaro, the narratives of several female family members in this study also reflected the expectation that they take on the duty and/or role of caretaker and aide for an individual/family member living with T2D. Many female family members supported their loved ones diagnosed with T2D by attending their parent/s’ doctor’s appointment, obtaining medication, checking blood sugar, cooking healthy meals, and engaging in exercise with them.

Barkhado shared in her interview the roles that she and her sisters took part in as daughters. She discussed how the duty to care for her mother was shared amongst herself and her four sisters, while her father strived to make ends meet for the family working full-time as a taxi driver. Barkhado conveyed, “And I like, the thing is that she

has four...five daughters? Five daughters including myself. And if she needs her pills, she would get it right? Yeah, so we like all kind of help out with that too in terms of like who's gonna help her with certain things." For Barkhado, helping her mother was not a chore. It was a duty that each of her sisters took on proudly.

The males in this study though, did care for their parents in other ways, ways that need to be contextualized within the precarious settlement and spaces outlined in the previous section. Specifically, three of the male participants, Adam aged 21, Hussein aged 21, and Bashiir aged 16, were diligent about reducing their parents' stress (who were living with T2D) and lived their life by "pleasing" their parents, which, as Adam noted, is in accordance with their faith as Muslims. Bashiir recalled the moment that he learned that his father was diagnosed with diabetes and the impact this had on him:

I found out he had diabetes. I did a little bit of research on it and then I found out that it's not really an easy thing to have, you have to constantly check your sugar, your blood pressure...so uh I've been really trying not to give him a hard time, yeah... I didn't know what it was at the time, so I...thought it was...[inaudible]. So I was like let me be something on the side that he doesn't have to worry about so. I didn't take it as a, as a threat to his life. But he has to make a lot of sacrifice when he's eating, you know, praying with us, when he's talking so...So I really have to watch myself when I'm around him.

While there was not an emphasis on daily acts of care in the stories of most male family members in this study (except for Hussein), there was recognition of the role that stress played in their parents' diagnosis. These participants cared deeply about their parent/s' wellbeing. They worked to appease their parents in every way.

Tending to Mother Tree....

Like the other participants in this study, there was love and devotion in the way Bishaaro took care of her mother. Bishaaro's mother was diagnosed with T2D many years ago; she believes it was when her mother was pregnant with her. Unlike her father who was diagnosed with T2D just five years ago, her mother's condition was more serious and required Bishaaro to be more involved in her care throughout the day. In particular, the most critical period for her mother's care was between 2:00-3:00 a.m. when Bishaaro would wake her mother up to check her blood sugar level. "Yeah. I've been doing it since I was a little kid, so I can check on her blood sugar... Yeah cuz the day she's pretty conscious [of her blood sugar levels], she doesn't really take naps and stuff," she said. Over time, Bishaaro got used to staying up late, learning quickly just how fast her mother's blood sugar level would dip at night. This was a scary reminder for her which caused her to remain vigilant to this routine.

At the time of the interview, Bishaaro's father was away on vacation to check up on relatives in Somalia. With him out of the country, this meant that even more responsibility was placed on her shoulders. Bishaaro winced at the thought that something could happen to her mother while she was out during the day; she could not bear the thought. Although this heightened her anxiety, it also made her more proactive to think of solutions of how to keep in touch with her mother when she left the house to go to school or run errands. "I would call to make sure...like, in the morning when I would leave, I would put the phone beside her. And I was like okay I'm going to call you to make sure you check on your blood sugar and what not," she said.

As she said this, she reflected on how her mother's care remained a central focus in her life. She explained that in a way her mother's illness has brought them closer together. It has also made her realize that she is more than just her parent – she was human and just like anyone else, was also susceptible to illness.

This section displayed how T2D was viewed as mainly a woman's disease. Many of the participants provided examples of female relatives who were living with this condition. For those with mothers that were diagnosed with T2D, several could not recall exactly when their parents were diagnosed. Despite the pervasiveness, T2D was rarely ever discussed openly amongst family members. Several of the participants attributed the increased prevalence of T2D in women in their community to an unhealthy diet and/or a lack of physical activity.

This story also illustrated how care for T2D was enacted by female members of the family, thus answering the first research question of this study through CCT which examines the relationship between culture and care. Several female family members supported parents and other family members living with T2D with instrumental acts of care, as described by Bishaaro's story, as she tended to her mother. Although most male family members did not discuss their engagement in daily acts of care within the household, they disclosed their social support for their family member/s diagnosed with T2D and worked to minimize their parent/s' stress (something they realized that could adversely affect their condition). Care in this study, was shown to be gendered, with females engaging in more efforts to maintain the household (which includes members of the diasporic family and their health) and males enacting social support of family

member/s living with T2D. The next section describes the participants' perceptions of T2D, which included bitter-sweet accounts that reflected both negative and positive descriptions of their and/or family member/s condition.

Diabetes as “Bitter-Sweet”

This section introduces the final theme in this study, depicting the bitter-sweet realities of T2D diagnosis and the diverse ways in which the participants described their and/or family members' illness. This theme was most evident to me at the start of this study, during my initial interaction with a health group in the Fall of 2017. Each week, a small group of Somali women would meet on weekday afternoons to learn more about nutrition and health, as they socialized and ate nutritious snacks provided by a settlement agency. There would be women coming into the room throughout the two-hour period. It was a social hub and a place of connection. This meeting room, although small, provided my first glimpse into the many perceptions towards diabetes held by the participants in this study.

The coordinator, Dr. Saleh, led the weekly meetings with this group. Dr. Saleh was a physician in Somalia and a trusted member of this agency. Although she was not practicing medicine in Canada, she was still regarded by many in the community as a doctor. She served as a translator for me at the beginning of this study (when needed) and aided with the initial recruitment of this study. A middle-aged Somali woman, mother, and proud grandmother, Dr. Saleh was able to connect with the women in the group on a deeper level, as she shared many of their lived experiences. Indeed, the members of the group were not only clients of the settlement agency but also included many of her close friends, such as Sophia, aged 63.

Sophia was one of the first participants that Dr. Saleh had suggested for this study. Sophia immigrated to and settled in Canada over 13 years ago. She was now

widowed, unemployed, and living with her son in an apartment complex in a west-end Toronto neighbourhood. She was diagnosed with T2D two years before her arrival to Canada while living in the Middle East with her sister. Sophia and Dr. Saleh shared a special bond and history, as they had both worked in the same hospital in Somalia, prior to their migration to Canada. Dr. Saleh would smile fondly when she remembered the time that they had worked together, their friendship now spanning many years and continents. Reunited here in Canada, they were once again using their medical expertise, but this time in a different capacity and outside of the hospital corridors to help women here in their Toronto community.

Both Dr. Saleh and Sophia were a valuable resource and source of inspiration and support for group members like Ugbad, aged 49, living with T2D. Ugbad had made the difficult decision to not inform her husband and children that she had diabetes for over eight years. She had mentioned to me quietly, the reasons behind her decision to not include her family members in the interview process for this study was because she did not want to share the “bad news” with them. It was only within the confines of the weekly meeting group and through support from other members that she was able to offload, speak about her condition with those she trusted and subsequently find some relief at last. Indeed, members of this group were often the first point of contact for many other women in the group who were newly diagnosed. Sophia in particular was a key source of support:

People call her, everybody gets their diagnosis... when they get diagnosed they call her. She is very good. She is a very good calm person. Some people they

good too, some people when they get the disease, they overwhelmed. (Dr. Saleh)

The hesitation to engage in a family interview expressed by one of the members in Dr. Saleh's health group prompted me to consider moving away from the idea of implementing a family group interview, which I had intended to do at the beginning of this study, and instead interview family members of those living with T2D separately. I found myself remembering this participant often as the study progressed. When I met other participants who also declined to include their family members in this study (see Guleed's story later in this chapter), I wondered again if it was for the same reasons. Indeed, my encounter with this participant was invaluable as it shifted my assumptions of how diabetes was perceived in Toronto's Somali diasporic community, which I had come to learn was quite diverse and varied in views and experiences, depending on whom I was speaking with – a mother, father, daughter, son, niece, and so on. This diversity was also reflected in attitudes towards T2D.

As noted in the methodology chapter, it was during the recruitment for this study that I had witnessed the evocative way in which Jamilah, aged 48, a participant in Dr. Saleh's group, describe T2D using the analogy of a tree and termites. Jamilah described the tree as the body, and termites as T2D, which made its way as an infestation up the roots to outer extremities. I was reminded of the analogy of the tree again in mid-November of 2018, when I met Beydaan, aged 34, a university student and mother of two young boys. Through Beydaan's narrative, I was able to view the other side of the story, that is through the lens of a family member who had come to learn

accidentally of a loved one's diagnosis. Beydaan recalled the emotional roller coaster she went through upon finding out that her father was diagnosed with T2D, following her visit to the Middle East where he worked at the time. She learned about her father's diagnosis by chance upon hearing from his co-worker about a surgery that he was required to have because of diabetes. Stunned by what she had learned, Beydaan decided to confront her father about why he did not tell her and the family about his diagnosis. She recalled painfully, "And I'm like how, how can all these things happen to you, and you never told us? Like um we're family. We can't hide stuff like that."

Beydaan was frustrated by her father's reaction. She indicated that he had just brushed the disease off, as though it was nothing serious. Perhaps her father's response was his attempt to shield her from the implications or burden of his disease, or that he truly believed that diabetes was nothing serious, warranting no further discussion with his family. Still, his reaction made me recall the trees that Jamilah had described so vividly to me the year prior. It made me remember the impact diabetes has on others, on the trees in the surrounding forest, and the parallels with the impact on individuals who care for a loved one living with T2D (and the reverse – on those living with T2D as well).

Beydaan's life and her relationship with her father has changed as a result of diabetes. Her father had to move back to Toronto because of his declining health. Beydaan revealed later that her father had expressed frustration with his loss of independence; complications from his eye surgery has made him dependent on her care. She explained:

Um and then I feel like he gets frustrated at times because he's very independent. He's used to doing his own thing, and now he can't. He has to depend on us for somebody to drive him. So he gets, he gets frustrated sometimes...

Although Beydaan is glad to be able to care for her father, she acknowledged that her own life has irrevocably changed since his diagnosis. Though she was able to draw on the good and bad from his diagnosis, the good being that she was able to care for her father and be close to him, she also has to bear witness to the reality of diabetes – his worsening health and eyesight, the multiple surgeries to correct his vision, loss of independence and subsequent frustration.

This section examines the theme 'diabetes as "bitter-sweet"' and explores the different perspectives of T2D. As Jamilah's analogy indicates, T2D not only impacts the individual living with this disease but it was also collectively experienced by the family and community. The disease was viewed as an infestation, something that damaged roots, and caused issues to the foundation of the tree, requiring support from other trees. As Dr. Saleh's group displayed, bigger trees are valued support systems in the community, and when they fell ill, this meant that little trees were required to support themselves on their own and also the ailing trees around them. Without shade for cover, they learned to grow up fast in order to survive. The following section describes not only the process of disease but also how the system of trees (i.e., individuals in the community) react to illness, the impact on them, and their views of T2D.

These views of T2D are demonstrated by the youngest participant in this study, Bashiir, aged 16 (and his poem on the next page), which included both positive and negative aspects that he referred to as “bitter-sweet”. Bashiir referred to his cousin Hussein to highlight how diabetes brought him and his mother closer, as they co-managed their conditions together. Hussein was diagnosed with type 1 diabetes (T1D) in his teens and while distressed by the diagnosis, was able to rely on his mother for support, who was living with T2D. Despite the adversities they have faced, they found comfort in knowing that they both have each other throughout it all. The participants also discussed positive and negative aspects of living with T2D, relaying the bitter reality of the solitary nature of illness, and the shock, fear, stigma, and denial they experienced. Participants diagnosed with T2D also discussed the positive “sweet” aspects of T2D, of strengthening and relying on their faith to help them make sense of their diagnosis, to feel grateful that they were not diagnosed with something more serious, and that they were able to live yet another day. The story presented in this section is that of Guleed, aged 58, who discussed both bitter and sweet realities of T2D.

“Bitter-Sweet”

*Type 2 diabetes?
It could be a blessing...*

*My cousin, he took it as a blessing
He's made it a way to be closer to his mother...*

*But it can be a curse...
Some people, they don't think they're really healthy
They don't wanna in my definition of healthy
Think like they can be somebody*

It could be bitter-sweet...

Bashiir, aged 16

Guleed's Story

I met Guleed, aged 58, a widow and father to eight children in Spring of 2018. It was in the most unexpected places, a Somali restaurant in Toronto. My colleague, Muhsin, was with me that day to support with recruitment efforts for this study. He had been invaluable to my recruitment efforts from the beginning of this study, serving as a translator for me at times during interviews and helping me reach male participants, as many were reluctant to speak with me alone as a female.

Muhsin had struck a conversation with Guleed while I briefly stepped away from the table. As I returned, he had informed me that Guleed (whom he had just met, I found out later) was interested in being interviewed for this study. Since I still had all of my recruitment items with me from earlier in the day, I was able to conduct the interview at the restaurant.

I thanked Guleed for his time and consideration, and moved over to his table, upon receiving his permission to do so. Guleed had requested that Muhsin remain for the interview, so Muhsin stayed behind. He also asked that I not interview any of his children; Guleed joked that it was because he did not want to scare them. I reassured him that this was fine, and that we could proceed with just his interview.

Thus, we began the interview, as Guleed ate his lunch – a glass of milk, with a side of meat and what appeared to be *soor* (softened cornmeal). As I went over the interview materials, Guleed told me about his educational journey, which included two post-graduate degrees. He mentioned that he had a love for numbers, yet he committed most of his time to writing about Somalia. Guleed proceeded to show us his various articles to date on Somalia, the war, and politics.

Home

It was not long into the interview that I started to notice Guleed's witty humour surface. I had begun the interview by asking Guleed to tell me a little bit about himself and he answered with a smirk on his face: "I'm a man, 58-year-old man, with a beard, mustache... I'm telling you about me..." he said sarcastically. I laughed and then asked another question, this time refining it to be more specific, "So, where did you grow up?"

"I was born in Somalia and grew up in Somalia."

"Where were you born in Somalia?" I asked.

"In Mogadishu."

I told Guleed that I was amazed to hear this because most of the participants were also from this city in Somalia. Guleed responded, "All of us.... All of us. Um so...That is the heart and the root." I asked him to describe what it was like growing up in Mogadishu. Guleed smiled gently at first, recalling that it was "Very beautiful...until we started killing each other," the pain and disappointment in his eyes evident. "Before that from my era, my age, my time, very beautiful..." I slowly repeated his words, "very beautiful yeah..."

"Before," Guleed clarified. He glanced away briefly, staring out the window in front of him. "Neighbours were friends that time. Even my friends, I didn't know their tribes. We grow up together, some of them. I learned their tribe here in Canada. Back then, we never used tribes. This is something new for us."

"So, the tribes you learned here?" I asked.

“It came from nomadic people, not from the cities. The cities. Not in the big cities.” He remembered the moments leading up to the civil war in his country. “The civil war. Something that we don’t know before. I never heard a bullet before that, boom, boom.... But I was 31. I never heard a bullet before I became 31. It was very upsetting, something that nobody knows why. I know that there are too many hidden things that come out from this, but so far nobody knows why we killed each other.”

He sat motionless. “During the war, you keep running 24 hours, hiding. Even you don’t know who is coming to you. Somebody coming to you, you don’t know. Whether he will kill you or he will help you. You can’t tell.”

“You can’t tell?... So that makes you feel insecure?” I asked.

“Yeah, very insecure. It was a nightmare,” he explained. Guleed dabbed the sweat off the side of his face with a napkin and sighed.

“When you came to Canada, how was that?” I inquired.

“Oh, very beautiful.”

“Very beautiful?”

“Yeah, I feel comfortable. Very comfortable, started sleeping again. Deep sleep, deep sleep. Safe...because I feel safe. Safety is the most important to your health. If you feel safe, you sleep like a baby.”

He smiled. “Yeah, I came to Ottawa first. All my kids born in Ottawa except one. Except one. One born here. One is Toronto. He born in uh...what do you call it?... Mount Sinai.” Guleed explained that he decided to move to Toronto in 2002 to ensure that his children were surrounded by other Somalis, so that they would not lose their culture and

language. “So, I took them from Ottawa to Dixon. To Dixon...In two to three months, they were talking Somali. Ninety percent of the kids in Ottawa, Somalis, they don’t know,” he laughed. “When you see a whole school there, Somali people, wow,” he beamed.

Signs

Within the first year of his move to Toronto, Guleed began to notice signs that something was wrong with his body. He did not worry about these signs before his move because he thought that his weight loss was attributed to his night shifts at the post office where he worked in Ottawa. But upon moving to Toronto, and switching jobs and shifts, he noticed that his weight loss did not cease but only continued just as it did before. He explained, “I went to my doctor and said hey I’m just losing weight, what’s wrong with me? He say... your blood test, that was the first time he diagnosed me.”

Guleed was shocked to receive his diagnosis. Other participants in this study had described a similar reaction to being diagnosed with T2D, like Magool, aged 35, mother of two children, and an attendee of Dr. Saleh’s group. However, Magool’s initial feelings of shock subsided over time and were replaced instead with relief because she was finally provided with an answer to her ongoing symptoms (like Guleed and his weight loss), specifically her dizziness and frequent urination.

But for Sarah, aged 28, another participant in this study, her feelings of shock upon diagnosis with T2D, were exacerbated due to factors such as her age and her migration as a refugee. She was just 23 at the time of diagnosis and had come to Canada alone without her husband and family by her side. Her diagnosis came just two

days after she arrived in Canada when she fell ill and sought medical care. She recalled, "That day, I not feel well that's why I need to go home. When I was there, the second day I don't know they tell me like I have sugar, diabetes. I was crying oh I because I don't have family, I don't know everybody here."

Like Sarah and others in the study, Guleed decided initially to keep his diagnosis to himself. He explained, "I never talk about it then. I used to be a smoker. Because what they tell me, they say you don't look you have diabetic. Yeah because you become skinny, you know." Sarah expressed a similar opinion noting that people would often judge her because of her age, shocked to learn that she had T2D at just 23 years old, "Oh why? Still you're young. What happened?" she explained.

Warsame, aged 67, also initially experienced shock upon hearing that he was living with T2D. He was diagnosed after he collapsed in 2010 in public but does not remember the details of that day since he had blacked out and had experienced a stroke. Upon asking how he felt, Warsame indicated:

I didn't get very sick because why it happened. We are Muslim, you cannot say that. Allah will say if something happened, we say *Alhamdulillah* [Praise be to God]. Allah will make you happy and will give you sickness too. So both, we have to give happy whatever place we get. I never become sick.

Warsame thus regards his illness as a normal and accepted part of his life, as predestined by God.

Light...

Indeed, all of the participants used their faith as a source of light in helping them make sense of their diagnosis. For example, Sarah reflected on her diagnosis with gratitude, reaffirming her faith. "I am Muslim I say *Alhamdulillah* [Praise be to God] everything. Still I say I can eat this." She was grateful that she could still eat certain foods and all was not lost with her diagnosis. Similarly, Hibaaq, aged 60, mother of nine children expressed that she was not afraid of her diagnosis with T2D following the birth of her youngest child Tahiiil, aged 20, but rather was at peace knowing that God was in control of her fate, and that whatever happened to her, was truly destined for her. She was grateful to be alive. She mentioned, "One day I don't know when I died. Diabetes to die or the other, other, what's it's... to die. Everything is knows God." What she meant by this is that God knows everything, and nobody knows for certain when and how they will die, and in her case, if she will die as a result of diabetes or not.

Jamilah also noted similar sentiments. She was diagnosed with diabetes in 2013 after seeking medical attention for an excruciating headache while trying to memorize the Quran. Jamilah mentioned that she was grateful that she was diagnosed with T2D instead of cancer, for example, hinting that her experience could have been much worse. Her gratitude in this regard was to God (Allah) to whom she regarded as in control of everything including her health. Likewise, Bilan, aged 43, also expressed gratitude to God that she did not have other illnesses, comparing her reaction to her mother's:

I think my mom took it worse than I did. I was like no, *Alhamdulillah* [Praise be to God], I don't have any of the other diseases, like this is maintainable. So my mom was like oh my gosh, she went into [a] different lane on the road just because she couldn't take it.

It should be noted that drawing on faith alone to cope with and accept T2D was not always viewed in the same light, as told through the narratives of some of the family members. For example, Hibaaq's daughters explained their frustrations over what they regarded as their mother's "blasé" attitude towards diabetes. Ambaro, aged 24, stated:

Uh she'll, she'll be like well if whatever happens is like... it's God's plan. Oh, so it's you know...Yeah I'm going to enjoy my life. You know, whatever happens is meant to happen. It's already written. Um I think she has like a very blasé feeling about diabetes. I think that uh she thinks that it's just something that God has given, like bestowed upon her... so um it's like one of the things just like one her hardships, like 'Okay I have diabetes that's just what God wants for me'.

Hibaaq's other daughter, Hani, aged 26 echoed Ambaro's sentiments pertaining to her mother's attitude towards T2D:

She's like you know when life is come to an end, that's just how your life ends, you know what I mean. Like it's like how *Illahi* or God intended it to be. Um and so...And she'll say things like you know if I walked down the street and got hit [by] a bus. And that's just how I'm meant to go. If I'm meant to go because of this disease...that's how I'm meant to go. And it's disturbing.

It was not so much faith-based coping that was being critiqued by some family members of individuals living with T2D but rather the resultant lack of attention they perceived that their loved ones placed on their personal health. Some family members of those diagnosed with T2D felt that they had stopped taking care of their bodies as a result, forgetting that they too played a role in their own health.

Bishaaro conveyed possible reasons as to why the older generation has relied on faith to cope with T2D in this way:

And I feel like because like, because like back to the immigrant thing, it's kind of like they've been through such a hard situation, and they've always turned to God for solace. And like um sometimes my parents tell me stories about stuff they have experienced in Somalia and coming here and I'm like that's kind of traumatic like you know... I think that's just a way of coping and dealing with stuff... But I feel like with the older generation it's kind of like oh it's happening to me and like there's a certain extent we can do but the rest is in God's hands. And, and I guess that type of mindset has helped them through the most traumatic things like war and stuff like that. So it kind of has a philosophy to their whole life.

Bishaaro connected the older generations' reliance on faith to their migration experience as a whole, indicating that it was a means for them to cope with the uncertainties of life and the trauma that they had experienced due to war. She acknowledged that Somali parents had been through many hardships, and in those difficult times, they have used their faith as light and turned to God for hope to make sense of things outside of their

control. Illness was also viewed in this way by some participants as being outside of their control, something destined by God. They used their faith to help them accept their diagnosis and cope with it, moving from shock to acceptance.

Standing Alone...

Still, while Guleed was grateful his condition was not worse, he felt solitude as a result of his illness – a solitary tree, in a small world of his own. He explained, “I can’t remember the last time I had chocolate,” he laughed. He then pointed to the milk in front of him, “They give me this milk with no sugar. They make people with sugar [he translated in English, the Somali word for T2D is sugar], they give me separate because I don’t want sugar. Somehow, you’re in jail, you know, no ice cream, no cake, no chocolate...nothing,” he said with a laugh. “You’re living in isolation. In another world... So, we are living a world inside a world. We are living together here but we are living in a different...” He elaborated, “...sugar-less world.”

For Guleed, the broader world was not created for individuals living with T2D because sugar was everywhere and in everything. He continued, “Yeah...no chocolate, no cake, no strawberries, you know sugarless.” Like a world without colour, he described it as a difficult world. Guleed explained that it is up to the individual to research and learn for themselves what foods are safe to consume. That is, the onus, was on the individual. He motioned to his plate again, and asked, “See any potatoes here? Is there any potatoes? I can’t tell when was the last time I had potatoes... Potatoes is like the sugar, you know. I don’t use it.” He noted how the restaurant often offered him potatoes but he had to decline because he did not know how much sugar

was in it. It was this awareness that kept him safe because diabetes meant that he had to always be careful. “Medication, testing, you know, not using all kinds of foods you want, sometimes you are cutting [out] your favourite foods....” he said. Furthermore, before consuming any food, Guleed always does a taste test for sugar because he cannot rely on other people’s guarantee of the lack of sugar, especially since it impacts his health. Ultimately, he expressed that he was in control of his health. “I manage on my own. I control myself but everything else is okay.”

At the mention of managing alone, I recalled what Burhaan, aged 47, living with T2D, and father of three children had said about the bitter reality of diabetes, using an analogy provided by his doctor. He described T2D as someone walking alone along a path with dogs on each side. Burhaan noted if the individual were to glance at the dogs, he would agitate them, which would instigate an attack. He connected this analogy back to his own experience. After denying that he had diabetes for a decade, he learned that managing diabetes required self-discipline on his part to avoid temptation, that is, the temptation to glance at the dogs on each side of the path. Burhaan’s analogy displayed his commitment to remain on course. He cautioned in his interview that one must always remain focused on their personal health.

Shamsi, aged 25, whose mother is diagnosed with T2D, also emphasized the importance of discipline in the self-management of T2D. She used the analogy of a beast to describe temptations experienced by a person living with T2D. Like Burhaan, she acknowledged the importance of not succumbing to temptations around which also required self-discipline. She referred to resources and knowledge as being some ways

one could tame temptation and reduce the negative impact of what would result if one continued to indulge the beast. Eventually with time, the beast would become smaller, and so would its impact on one's life. But if one fails to do this, the beast would only grow, eventually consuming a person. Both the narratives of Shamsi and Burhaan reveal the solitude of self-management of T2D, just like Guleed, which required self-discipline and focus.

Fresh perspective & soil...

Indeed, for the participants in this study, T2D diagnosis involved a bitter-sweet journey of self-discovery as they made sense of their illness and evaluated its impacts on their lives. Following their diagnosis, they found themselves landing in a different place – their bodies changed, and their perspectives. This point in their lives served as a marker, which reflected the new site in which they stood and grew as trees. The soil in which they now nestled their roots forced them to forge new networks through sheer survival, faith, and resilience.

Guleed began to discuss his medication. “Because look. If I show you what I have, you won’t believe.” He showed (Muhsin and I) his medication, a bottle of pills. “I have to use when I’m eating,” he explained. “Every time I eat.” Guleed went on to describe what the medication does.

While on the topic of his medication and its vital role in keeping him alive, our conversation meandered towards the positive and his mood began to change, shifting from frustration to gratitude, as he compared T2D to T1D, “Controllable diabetes. You can control Type 2 with no pain because now I am using this pill. I can swallow it

easily.” He explained, “But my friend [referring to his friend with T1D] uses a needle injection...you know. But Type 2, you can control with no pain.”

Like Guleed, Bilan has also accepted her diagnosis. She compared her diagnosis with diabetes with a burn injury that she acquired while cooking.

Yeah it’s like it’s a part of life. It’s like I have burns here right. I have to live with that like I opened a pressure cooker and it flew. I have third degree burns all around this chest area, but like if you see it it’s nothing. Like it's gone.

She used the burn to illustrate how both the burn and diabetes were part of her body and something that she has to live with. The burn, a physical manifestation of injury, was like diabetes in that it was something that she carried with her every day. It was not noticeable *per se* to others and known only if she had told them or revealed this part of herself. “So you are relaxing and talking and you’re telling people you are diabetic but nobody actually sees you as being, yeah it’s so weird,” she said. Bilan acknowledged that she is unaffected by diabetes on the outside – no visible signs of illness or of damaged roots – as she is still a very active mother of two. Nonetheless, her illness is something that is there and that she has accepted as a part of her life.

Guleed ended the interview by expressing, “That’s the only problem that I have. Overall, I am good.” He has learned to accept his condition like Bilan and is doing his best to navigate his everyday life as a Somali father living with T2D – *a single tree in a sugarless world.*

Summary

This section revealed different perspectives of T2D through the theme of ‘diabetes as “bitter-sweet”.’ The participants’ narratives were illustrated using Jamilah’s analogy of a tree, which signified an individual’s experiences with T2D. The experiences of the participants reveal the impact of T2D on not only the individual living with this condition but also the family and community trees, those that share the same soil and are in close proximity to the tree affected – who are susceptible to their pain. T2D was often experienced collectively as discussed in the stories of the family members in this study.

It also evoked a bitter reality, as it impacted one’s sense of community in some cases resulting in solitude as they navigated the illness alone out of fear, denial, stigma, or self-imposed discipline as a means to avoid temptations in society, or as Shamsi referred to it, “beasts.” Indeed, without sugar, life was bitter for some, and felt devoid of people – it was lonely.

The stories in this section reveal the “bitter-sweet” journey of T2D, as participants learned more about the illness, and themselves, and grew to accept it as part of their lives as destined by God. Participants living with T2D found light from their faith, which helped them make sense of the difficulties in their lives. It was their faith that helped them make sense of their past and trauma, inspiring them to stand another day for their children and their futures here - in Canada – in this place they call home. The next chapter discusses the study findings in relation to existing literature and the theoretical framework.

CHAPTER SIX: DISCUSSION AND CONCLUSION

While analysis of diaspora involves three factors, “forcible dispersal, settlement in multiple locations and the idea of a homeland,” the findings of this study highlight that resettlement space occupies most of the focus in the participants’ stories (Wahlbeck, 2002, p. 229). Thus, this chapter is structured to account for the attention placed on diaspora space, given its central emphasis in the participants’ experiences with T2D. That is not to say the participants did not speak about their experiences/perceptions of the homeland and/or with forced migration. Indeed, all of the participants in this study anchored their origins in Somalia as the beginning of their and/or family member/s’ stories.

For example, like Bishaaro, who noted during the interview that her father was away to check up on family back home (see Chapter Five – Bishaaro’s story), some still spoke about the homeland and relatives and family trees situated there. The homeland was a significant part in the participants’ lives for it was a place where they derived their origins and for most of the participants living with T2D, it was where they were raised. Many of these participants recalled a positive upbringing in Somalia. Some remembered their past educational experiences and/or occupations nostalgically (i.e., Dr. Saleh and her experiences as a physician, friendship with fellow healthcare provider, Sophia). While others like Burhaan, aged 47, spoke about dreams lost due to war, such as a law career in Somalia that never came to fruition in his homeland and in Canada. Indeed, the civil war was a significant factor for many of the participants, as it was a key reason for the participants’ and/or family member/s’ departure. The civil war marked the beginning of a transition, a life event which resulted in their and/or their family

member/s' migration. Nonetheless, in referencing the homeland, there was not much discussion of the civil war itself, other than in Guleed's interview. Many participants living with T2D chose to focus on what their lives were like before the war, and what their life is like now in Canada. Regarding this, Idman, aged 58, who grew up in Mogadishu and came to Canada in 1989 articulated:

I remember only the good things that happened in Somalia otherwise if I remember the bombing and the fighting and everything, I say no, it's not worth it so. I remember when I was in university, when I was in college, when I was high school... that's all I remember.

Remembering the positive memories of her homeland helped Idman to push through the resettlement stressors that she had experienced. The fact that there was little discussion on the civil war in Somalia may reflect Aaliyah's interpretation of her parents' silence about their experiences growing up; she attributed their silence to possibly being due to trauma. Indeed, the traumatic impacts of forced migration and war still echoed through this diaspora (Berns-McGown, 2013). For many of the family members in this study, their stories of Somalia were passed down by their parents, since they were too young to remember and/or were born in Canada – and so they did not have much knowledge of what it was like to grow up in Somalia. Their stories of resettlement were often focused on their admiration for their parent/s' and family members' courage to seek a better life.

Given the prominent focus on resettlement/diaspora space, I have structured the chapter in sections, beginning with a discussion of the environmental context or the diaspora/resettlement space. Analysis of resettlement space incorporates dimensions of

the Sunrise Enabler. As noted in the methodology chapter, the Sunrise Enabler acts as “a guide for the researcher to explore multiple influences on care and culture” (McFarland et al., 2012, p. 265), such as: “technological factors; religious and philosophical factors; kinship and social factors; cultural values, beliefs and lifeways; political and legal factors; economic factors; and educational factors” (McFarland et al., 2012, p. 264). In the discussion that follows, I pay particular attention to education, kinship and social factors, and cultural values, beliefs and lifeways on the care/management of T2D in this group given their focus in the participants’ stories. This chapter also describes how the participants built community networks to deal with precarious settlement and subsequent benefits to their health and sense of identity. Indeed, the participants’ religious faith served as a resource and a means for coping with and managing T2D (for participants diagnosed with T2D). Faith was also used to cope with resettlement stressors and offered participants sites of belonging and inclusion. The chapter concludes with a discussion on the strengths and limitations of this research and recommendations, which are informed by the themes in this study.

Resettlement Space: Environmental Context

As the narratives of the participants displayed, the place in which settlement occurs also plays a critical role in the success of integration of refugees in Canada (Agyekum & Newbold, 2019). The participants’ stories described economic factors such as their precarious settlement and unaddressed socioeconomic needs, due to un/underemployment, poverty, proximity to neighbourhood violence, and stigma. The precarious contexts in which many of the participants were situated also became an important part of their stories, since it had an impact on their and/or family members’

care/management of T2D. Consistent with the literature on resettlement of Somali people in Canada, housing was a major concern for many participants and/or their families. The findings of this study, display congruence with refugee health literature on the topic of social determinants of health, given their barriers accessing safe and affordable housing (Hynie, 2018a). Furthermore, the neighbourhood in which their homes were located greatly shaped their lived experiences. Several participants disclosed that their neighbourhoods required them and/or their parents to remain “hyper-vigilant” due to environmental stressors in their daily lives (Mensah & Williams, 2014, p. 451). Some participants also recalled witnessing violence in these contexts. The results of this study are similar to the findings outlined by Bokore (2016a); Fellin (2015a) and Tiilikainen (2020), who illustrated the harmful effects of poverty on Somali families. These “toxic environments” as described by Bokore (2016a) have an impact on not only Somali parents but also their children (p. 133).

The stories in this dissertation contribute to the literature on Somali families in the diaspora, conveying the unique perspectives of family member/s themselves in the resettlement space in which they settled. Due to safety concerns, several participants living within these neighbourhoods described experiences which required them to monitor their children while outside. For parents in these neighbourhoods, this meant that their children experienced a different childhood from the one they had back home (in their homeland), where they were able to play outside freely (Koshen, 2007; Mensah & Williams, 2014). Youth that grew up in these environments recalled memories of a childhood spent mostly indoors or one that was often highly supervised by parents and/or other members of the Somali diaspora.

Impacts on Health

There are potential health consequences for the participants resulting from spending considerable time indoors. For example,

Notwithstanding the reasonableness of these parental efforts to shield their offspring from potentially baleful peer influences, the same neighborhoods where outdoor play is most likely to be restricted are the same ones where indoor play is least enjoyable: low income areas with high concentrations of cramped apartments as well as modest townhouses with undersized backyards. From the perspective of a child, the experience of spending long hours indoors is stifling and from a health perspective it is highly undesirable, given the well-documented links between physical inactivity and childhood obesity. (Mensah & Williams, 2014, p. 451)

While Mensah and Williams (2014) identify childhood obesity specifically, research suggests that environmental risk factors can also play a role in the development of T2D, interacting with biological and behavioural risks factors (Dendup, Feng, Clingan, & Astell-Burt, 2018). Environmental stressors can also increase the likelihood of poor eating habits and other unhealthy coping mechanisms (Dendup et al., 2018). Moreover, there is research available to date that shows connections between stress, health inequalities, and chronic disease (Mikkonen, & Raphael, 2010). Over time, exposure to stressful living conditions may culminate in chronic stress, gradually wearing the body, affecting its ability to fight disease, and increasing susceptibility to chronic illnesses such as T2D (Dendup et al., 2018).

Another health effect of the environmental context was related to gender. In this study, many of the participants mentioned that Somali women were more susceptible to T2D, and even described this chronic disease as a woman's illness, several citing unhealthy diet and lifestyle as causes for increased prevalence of T2D among women in their community. This study cannot confirm if there is indeed a gender component to T2D in this population since this was not the aim of this study. However, there is research available examining health inequalities experienced by Black women in this country, highlighting their increased risk of acquiring T2D compared to White women (Veenstra & Patterson, 2016). It is postulated that the increased prevalence of T2D in Black women may be due to factors related to racism (Veenstra & Patterson, 2016). While the topic of racism was not discussed by the women diagnosed with T2D in this study, research available in the area of Somali resettlement mentions the adverse impacts of racism on Somali women and/or their families (Bokore, 2018; Danso, 2001; Spitzer, 2006).

Many Somali women endured barriers related to their gender, English language fluency, discrimination in the workplace, and the lack of childcare options when they settled in Canada (Affi, 2004; Bokore, 2013). Several have also engaged and/or continue to engage in activism in their communities, advocating for their children and housing, for example (Mohamed, 2016). They have, as Mohamed (2016) states, "...been at the forefront against systematic anti-Black racism and social marginalization" (p. 160). While notable, it should be highlighted that this advocacy and activism may serve as a resettlement stressor for Somali women as they juggle other roles in their lives, shifting attention away from their own health needs. For example, this was a

concern highlighted by Ubah in Chapter 5, when she critiqued the pattern of Somali girls/women creating outreach initiatives for Somali males in her community. Yet, Ubah wondered why there was not a focus on the physical activity needs of girls/women in her community; she reasoned this was because perhaps everyone assumed they were all “okay.” According to Mohamed (2016), “the activism of first generation Somali Canadian women narrates a history of resistance and resilience that has left little space for self-care and healing” (p. 160). Indeed, more research is needed to examine Somali women’s health needs using a gendered lens given their unique migration/resettlement experiences and the lack of research in this area.

However, it should be noted that despite the predominant focus on the female participants in this study because they comprised the majority of participants, the stories of Somali males and fathers also reveal adverse impacts of settlement on health. As Shamsi relayed, the stressors experienced by Somali parents in general, as they formed roots as new Canadians while also running a household, learning a new language, and so on, may have acted as a burden of settlement and had implications for their health. She conveyed that survival of the family came first and health took a “back seat” during the resettlement process. It is within this context of precarious settlement, that many of the participants’ stories are situated. Their narratives, contextualized within the resettlement space, also display in many cases their resilience and survival, as they juggled employment and family duties. For example, like Idman, who was a teacher in Somalia, had to work undocumented general labour jobs upon settling in Toronto to provide for her family both here and in Somalia. Without the

wisdom of elders, the first-generation of Somali newcomers were forced to find their own way within the resettlement process (Berns-McGown, 2013).

Neighbourhood Stigma

The space in which the participants and their families settled had a significant impact on health, particularly in how the neighbourhoods in which they lived were stigmatized. According to Wutich, Ruth, Brewis, and Boone (2014), “stigma is defined as the social process that allows labeling, stereotyping, status loss, and discrimination—and the related personal experience of anticipated or actual judgment—leading to self-devaluation of one’s moral standing” (p. 557). Research shows that neighbourhood stigma can have negative effects in individuals such as stress and mental health issues (Wutich et al., 2014). In the case of the younger participants in the current study, they discussed resettlement stressors related to the sites where they planted their roots and/or were raised. For example, some participants recalled experiences where family members were targeted by police/security in their neighbourhoods, such as Beydaan who described how her brothers were often followed by security in the store in their building and were viewed with suspicion as Black males. Tiilikainen’s (2020) ethnographic research on settlement spaces revealed similar concerns expressed by Somali families who noted how Somali youth were often stopped by police, within the confines of their neighbourhoods. This was similar to Zaami’s (2015) research on the lived experiences of Ghanaian immigrant youth in the Jane and Finch neighbourhood, as they mentioned being profiled by police due to the stigma attached to their neighbourhoods. According to Berns-McGown (2013), this type of criminalization and lack of acknowledgement can create risks for Somali youth, particularly Somali boys.

Furthermore, Zaami's (2015) study illustrates how neighbourhood stigma can limit youth's access to services and resources, such as employment opportunities.

Many participants also described instances where neighbourhood stigma extended to educational institutions. The location of their residence also impacted the services and quality of education their children received (Tiilikainen, 2020). Schools represent settlement sites and are a critical part of the stories of this diaspora due the formative role that they played in belonging for this group, not only within these institutions, but also in greater Canadian society. The Somali diaspora embodies its own "stories of school," ones that are unique to their histories of migration, and settlement within various sites in Toronto (Clandinin, 2020, p. 219). It is integral, as part of research on this diaspora, to include stories of school in the examination of resettlement, given the critical role that educational spaces play within the integration process of refugees.

Education Factors

As a social determinant of health, education is related to better health outcomes due to its relationship with other determinants of health, such as employment and income (Mikkonen, & Raphael, 2010). Limited employment outcomes of youth in the Somali diaspora, particularly for males, is well documented in the Somali resettlement literature and is one of the key concerns for Somali families in Canada (Mohamed, 2018). Likewise, for some of the parents living with T2D in this study, education served as a resettlement stressor, given their realization of the difficulties that their children faced within the education system.

For some of the participants, there is an acknowledgement on their part that their education was not on par with other students living in other areas due to stigmas

attached to their neighbourhoods, and/or as Fowsio noted, due to the racial composition of the student body at her school, which was mostly BIPOC. Some recalled being instructed by educators to lower their standards and expectations and being pushed into the applied stream, which is not as rigorous and has limited access to post-secondary education, instead of the academic stream where students are taught at a more demanding level and expected to attend university. These findings are similar to extant literature that examine the challenges that Somali youth face within the educational system in Canada (e.g., Berns-McGown, 2013; Ilmi, 2009; Mohamed, 2015; Mohamed, 2018). Somali youth in Toronto are sometimes steered to applied courses and not given the appropriate information regarding course selection and the impact/s their decisions have on their future. It is a stressful experience for students who wish to pursue university studies but have gone through high school taking applied courses, thus requiring them to catch-up on missing prerequisites to attend university (Mohamed, 2015). Such exclusion within the education system can have profound impacts for youth and their future potential.

While there was no in-depth discussion of racism in educational spaces in this study, there is mention in the literature of how racism plays a role in the ways in which Somali students are perceived, in relation to low expectations of educators but also how these students are often perceived as a “monolithic group; rather than being recognizing [sic] for their individual differences and needs” (Mohamed, 2015, p. 34). The stereotypes that these students face may contribute to educators’ low expectations regarding the youths’ potential to succeed. Ali (2018), provides an example in her study, of how one of her participants wore glasses as a means to protect herself from the

stereotypes that, "...Black people are not smart enough to go to, and thus do not belong in, higher educational spaces" (p. 51). Similarly, Ilmi (2009), disclosed how he and other Somali students at his school in Toronto became "one Somali student body" (p. 55). They used Somali culture, as means to survive oppressive and degrading encounters and to preserve their sense of self (Ilmi, 2009).

The current study also displays how some of the participants in this study have resisted the lack of support/guidance from educators, and specifically highlights the role that older siblings play in the process of integration within the educational system. It is also further evidence of care being enacted in the diasporic family and resilience as these participants strived to overcome their adversities within educational institutions. For example, Adam, aged 21, noted how his mother approached his guidance school counsellor to request a switch from applied to academic courses. He credits his sisters for paving the way in this regard since they served as a critical source of information on what courses he should pursue, having gone through this educational experience themselves. Fowsio also reflected in her interview on the pivotal role that her sisters played in helping her navigate high school and showing her that she was capable of succeeding in school through her own perseverance and success.

Despite schools being a site of surveillance, source of stress for some, and where access to academic streams was contested, viewing education as a gateway to success and stability was a central part of many of the stories of the family members in this study and occupied much of their attention in their lives. Perhaps for first-, 1.5-, and second-generation Somali Canadians, education was also used as a means to cope with their precarious settlement, for as Gladden (2012) states, "Having hope for the

future, including through education, is a part of the cognitive reframing that takes place for some refugees” (p. 188). Through education, youth may have been able to orient their focus on their futures.

As many participants spoke about their educational experiences, they included in their stories, members of their family too. It was evident in their accounts, how attainment of education was perceived as not only as a personal achievement but also as a collective success. These participants recognized the sacrifices that their parents had made just so they could attend school and achieve their dreams. Indeed, as a social determinant of refugee health, many participants were cognisant of the barriers their parents experienced gaining meaningful employment, as a result of a lack of recognition of their educational credentials, language barriers, and experiences with war and forced migration (Hynie, 2018a). It was this realization that made Marwa, aged 21, for example, tear up during her interview with me, as she spoke about how much her parents sacrificed to raise her and her four siblings in Canada. Similarly, Hussein relayed how his decision to improve his grades in his final year of high school was because of his parents. He explained, “I could have been born back home, but my parents took a chance. They came here so it’s like... if I didn’t do that, I would have let them down and all that, you know. I couldn’t live with that.” These youth were inspired to succeed as diasporic students because of their parents’ migration and resettlement experiences. Here we see how the migration experience of their family impacts their own educational trajectories as diasporic pupils, and even their dreams and aspirations for the future. Indeed, for youth, school was not only a means of becoming a part of Canadian society; it was also a way to provide for the diasporic family. Some female

participants who had family members living with T2D, carefully chose educational pursuits with their parent/s' needs in mind. For example, Aaliyah, Barkhado, Bishaaro, and Ubah discussed their decision to pursue nursing as a career. Barkhado and Bishaaro decided to pursue nursing after their completion of a science degree to attain a position that provided job security and allowed them to support their parent/s living with T2D. Likewise, Marwa, aged 21 explained that nursing was regarded as a lucrative career option for her and her sisters since it provided "a guaranteed job." Since the program did not take too long, it was also viewed as an efficient means to support their parent/s living with T2D sooner. The pursuit of education was regarded as a means for family support and care, one that Bishaaro felt was similar to other immigrant and racialized youth who feel "anxiety" about and carry a "burden" of supporting their parents.

The "interdependence of members in racialized immigrant families" may be telling of not only a cultural commitment to support kin but also the lack of social capital for these youth (Taylor & Krahn, 2013, p. 1017). Somali youth, like their parents, experience difficulties gaining meaningful employment due to racism and a lack of social capital (Jibril, 2011; Mohamed, 2018). In the case of this study, participants were cognisant of the difficulties that their parents had faced due to migration and resettlement and so felt obligated to care for their parents. Unfortunately, there is little information available to date on the role that resettlement plays in the career decisions of racialized refugee and immigrant students. However, Taylor and Krahn's (2013) study on racialized immigrant families reveals how parents' struggles with employment can influence their children's decisions relating to their career and education. While the

current study's participants did not indicate their parents' employment difficulties as central to their decision to pursue nursing, they did discuss their desire to seek a career that afforded them with financial security. Although they did not withdraw from their studies, their decision to pursue nursing, is a means to address "economic challenges" commonly experienced by refugee families, which "can conflict with long-term goals of education" (Hynie, 2018a, p. 216). Such goals must be understood within a context of precarious settlement where participants are negotiating the boundaries of exclusion and inclusion within the diasporic space.

Education was also an important part of the narratives for the male family members in this study. Unlike the female participants in this study, they focused more on doing well in school. For example, Hussein and Bashiir mentioned adversities they experienced during their education, such as falling grades, and the perceived negative impact this had on their parents. Bashiir explained:

[My parents] were so sad when I dropped in my marks. And they didn't like it as well. They didn't punish me or anything but that's when I realized...I said, I'm really going to bring my marks up and get A's and then that's exactly what I did.

These participants remained committed to their educational pursuits despite obstacles that they had experienced related to surveillance on campus, poor grades, and being directed into the applied stream. While some female youth in this study noted being pressured to go into the applied stream, they were able to avoid this outcome through the guidance of older siblings. As noted previously, older siblings (most often older sisters) laid much of the groundwork for their younger siblings to follow. Like their

mothers, they too were involved in building a home here in the diaspora by making space for the community (via education), to ensure that nobody got left behind.

Kinship and Social Factors

The diasporic community was a significant part of the stories of the participants in this study. For Guleed, connection to the diaspora was a means to maintain cultural identity, which is the reason why he decided to relocate from Ottawa to Toronto to an area where there was a large Somali presence, so that his children would not lose their mother tongue. Guleed described language as being an integral part of retaining Somali culture. His view is similar to Somali mothers in Hopkins' (2010) study in Toronto and London, who perceived children's ability to communicate in their mother tongue as fundamental to maintaining Somali culture since it offered a means of connection to the homeland (Hopkins, 2010). The importance of this connection to other Somali people was reflected in the stories of many of the family members in this study who recalled their experiences growing up in neighbourhoods where there were many Somali residents. Aaliyah for example described members of the Somali diaspora in her neighbourhood as one "big family." Sahra, aged 52, explained that she moved from Montreal to Toronto due to the Somali community here. As a single mother, Toronto offered her an inclusive community, and an opportunity for her to be with other Somali women and families. She explained that this made her feel like she was in her country.

Indeed, in many of the participants' narratives, the diasporic community was described as a collective cultural identity. Diaspora offered a way to, as Langellier (2010) states, "submerge clan identities, complying with a communication taboo" (p. 75). In fact, the participants in this study preferred to speak of Somali ethnic identity

and discouraged discussions of differences amongst Somali clans. This seemed to contradict what Guleed noted in his interview, when he mentioned that he only heard of tribes in Canada. There seemed to be a bit of nostalgia in the way he spoke about Somalia previous to the civil war, as it was a time in his life where he did not focus on tribes. So Guleed's discussion of tribes and the other participants ambivalence on this subject is perhaps more of a reflection of their decision to avoid a topic that has caused so much internal divisions in their community. The discussion of tribalism/clannism seemed to be less meaningful within the diaspora, compared to discussions of faith and ethnicity (Berns-McGown, 2013; Langellier, 2010). Family members like Beydaan expressed gratitude for this lack of attention placed on clan differences, since it provided an opportunity for her to grow up in a community where Somali neighbours took care of each other, or what Koshen (2007) refers to as a "communal social safety net" (p. 87) with respect to the benefits of neighbourhoods in which Somali families settled together.

Care

As one of the objectives of this study was to understand how settlement impacts the management of T2D, care, be it for and by the participants individually, their families, or their community, must also be contextualized within the diaspora space. In other words, we must recognize how they navigate the effects of traumatic and forced dispersal, exclusion and othering that characterize their resettlement process, and create a sense of home via their faith and via their relationships with family and community more broadly. Through examining the participants' narratives via the lens of

diaspora theory and CCT, what becomes clear is that care is mainly shaped by the participants' generic understandings of this concept, their faith, and gender.

The findings revealed generic forms of care that were performed by both family and community members. According to McFarland et al. (2012), generic approaches to care include those that are "culturally learned and transmitted," and include traditional and cultural worldviews (p. 263). Ubah, for example, described in her interview how her father was cured from T2D following his consumption of camel milk during his 6-month trip to Somalia. Camel milk is an important part of Somali culture and is believed to possess therapeutic nutrients beneficial for digestion and overall health (Carruth, 2014). Based on her father's experience with camel milk, Ubah remained hopeful and adamant that her mother (who was just diagnosed with T2D weeks before the interview) could also be cured with this substance.

While there was no further discussion of the therapeutic impacts of camel milk by the other participants in this study, most of the generic approaches to T2D in this study were largely informed by the participants' religious beliefs. According to Wehbe-Alamah (2008), "knowledge of generic (folk) care practices that are common among Muslims is critical to providing culturally congruent care to this group" (p. 85). Through emphasis on ethnicity rather than clan differences, participants were able to deal with resettlement stressors as a collective diaspora, one that incorporates both their Somali ethnic identity and their religious faith (Kusow, 1998). Their faith represented a unified identity, a means of coping, and a spiritual home where many sought refuge to deal with environmental stressors during resettlement, such as male family member participants Adam, Hussein, and Bashiir (who belonged to a Muslim sports league and attended

mosque regularly). Several participants in this study created and/or attended spaces that integrated their religious beliefs and their ethnic identity as Somalis, such as religious schools (*dugsi*) or mosque. As the poem about Adam's experience indicates, faith-based institutions offered a "second home" for the participants in this study, especially considering the exclusion they may have faced in school/s and/or in society. The religious communities served as social support systems, and a site for mentorship and guidance for the younger participants.

McMichael's (2002) ethnographic study, which examined the function of Islam in the lives of Somali refugee women in Melbourne, Australia revealed similar results, in that Somali women utilized their faith as an "anchoring home" throughout the process of resettlement (p. 179). Likewise, Berns-McGown (2003) demonstrated how Somali women strived to implement a consciousness of their Muslim and ethnic identity upon settlement in Canada. According to Berns-McGown (2003), this translated into a "religious bent among Diaspora Somalis" as they became more conscious of their Muslim identity and Somali women sought to understand religious texts for themselves (p. 14). Berns-McGown (2013) states,

They began to read the Qur'an and to form study circles to discuss and analyze its meaning for their new lives and its implications for how to live in the diaspora. They did this because it helped them to deal with their own trauma and to figure out how to keep their children's identity strong. In other words, it enabled them to identify what they considered essential as they transformed into a diasporic community and gave them tools to manage their extended reactions to trauma. (p. 7)

This fostering of their religious identity was an important process for the Somali diaspora here in Toronto, as they learned how to practice their faith and apply it readily within this new diasporic context (Berns-McGown, 2003).

Just as the women in Berns-McGown's (2003) study relied on their religion to make sense of their past traumas and strengthen their children's sense of identity, in this study, faith was also an integral part of many of the participants' lives and provided those living with T2D with a means to make sense of and/or cope with the disease. There were many ways that the participants reacted to their diagnosis, such as, acceptance, shock, fear, silence, gratitude, and denial. Despite the various ways in which they reacted to their diagnosis, all participants living with T2D turned to their religious belief systems to cope with T2D. As Bishaaro, aged 23, mentioned the older generation (such as her parent/s who are both diagnosed with T2D) were more inclined to rely on faith as an emotion-focused strategy to cope with T2D since "they've always turned to God for solace." While some participants expressed frustration with this approach, like Bishaaro, they contextualized this within their parents' histories and migration journeys and acknowledged that faith was their way of dealing with trauma and coping with adversities in their lives, and things they felt that was outside of their control.

In addition to faith, the CCT also offers an analysis of gender and its relationship to care (Leininger, 2006). Some female family members in this study highlighted their role as a caretaker for their parents, associating it with their position as daughters. For example, Barkhado explained that her parents had five daughters (including herself) and that each daughter played a role in her mother's care. This was not something that

she was forced to do, rather it was a duty she took upon herself proudly, affirming, “I have an interest in like taking care of my mom personally. She’s my mom.” Many female family members also described themselves in a caregiving role, which included instrumental support, or “observable actions that make it possible or easier for an individual to perform healthy behaviors” (Mayberry & Osborn, 2012, p. 1239). For the participants, these included household chores and/or direct involvement in management of T2D of their loved ones (i.e., attending their parent/s’ doctor’s appointment, obtaining medication, checking blood sugar, engaging in exercise with them, and cooking healthy meals). For Aaliyah and Bishaaro, the responsibility to care for their family members living with T2D, was not something they did occasionally from time to time; it was a role that they engaged in every day. They both expressed that this role was something that they took upon themselves, a duty, like Barkhado, that was rooted in their love for their parents.

This study displays how cultural norms influence how care was expressed in this diaspora, particularly within the family structure. The female participants in this study discussed caregiving duties and duties that were in alignment with traditional gender norms, which centered females as caregivers of the family unit and even the community. This finding was similar to the results in Wolf et al.’s (2016) study, which examined the perceptions of mental health of Somalis residing in Minnesota. Wolf et al. (2016) explained the ways in which care was gendered in this diaspora, explaining that:

Key informants identified that women are the ones designated to show the care and do so by going to an ill person’s house or the hospital and staying with them,

assisting others in need and bringing them food, and reading the Qur'an to anyone suffering. (p. 355)

Indeed, Aaliyah's story describes how her role as caretaker of her family members living with T2D (parents and older sister), was also integrated as part of her identity. In her initial email to me, for example, she expressed her interest to partake in this study, stating, "I'd love to share my insights on lived experiences from the point of view of an individual who is the second oldest and had to take on a maternal role for the rest of the family." She explained in her interview how her younger siblings teased her about being the "second mom." Although she did not directly mention gender in her narrative, her acceptance of the maternal role and title as "the second mom" reflect social constructions related to motherhood, which situate females as natural caregivers of the family. Further, her narrative describes her experience caring for her family, highlighting how this responsibility kind of "fell upon" her shoulders as the second oldest daughter in the family. Usually, the eldest females in their household were responsible for the care of the family. In Aaliyah's case, birth order (since the eldest sibling was diagnosed with T2D and could not provide care in the same way) and gender expectations played a role in her enactment as the second mother in her family.

Some of the participants in this current study also expressed their acknowledgment that their role in their household was different from that of their brothers. Canab, aged 32, noted that "girls are always there for their mothers." From an early age, she became aware that it was her responsibility to take care of her parents. These findings were similar to Ali's (2018) research on second generation Somali women in Toronto, where participants also performed household duties and were

expected to take care of the family unlike their male siblings. The participants in this study therefore juggled duties at home and outside (through pursuit of career/education). While these social expectations were sometimes an additional challenge for Somali women in this study, it is also important to acknowledge their resilience as they carried these responsibilities without the support of female relatives who aided with childcare, as is traditionally the case in Somalia (Abdi, 2014; Affi, 2004).

That is not to say that males did not care for family members living with T2D; rather, care was expressed and shown in different ways. As mentioned in the findings chapter, Hussein described that he and his mother act as a team to co-manage their diabetes together (he was diagnosed with T1D and she was diagnosed with T2D). He was proud of his role in supporting his mother and also relayed how beneficial it was for him to have her support with his condition. The other males in this study also engaged in forms of social support, offering care but focusing more on the awareness of how their behaviour impacted their parent/s health. The male participants were motivated to do better, not only for themselves but also for their parent/s living with T2D. They did not want their parents to worry about them and were concerned about how stress affected their wellbeing.

Summary and Recommendations

This section examines the recommendations outlined in this study. It is structured according to macro (policy, structural, and legal), meso (community and interpersonal), and micro (individual) factors related to the participants care/management of T2D and are informed by the theoretical frameworks implemented in this study.

Macro

Macro level recommendations are focused on the precarious settlement of the participants in this study. Several participants described their experiences living on low income. The impact of poverty on their lives was far reaching; as it created barriers for care and/or for self-management of T2D, via environmental stressors that they encountered within the resettlement space. Many participants experienced barriers accessing determinants of health, such as safe and affordable housing, employment, and education.

Precarious settlement impacted the family as a whole, and the ways in which they integrated and navigated the diaspora space. Further research is needed to examine effective approaches at the federal, municipal, and local levels, to address structural inequalities experienced by this group. Regarding this, Colic-Peisker and Tilbury (2003) state that “at a structural level it is easier for the government to individualize and personalize difficulties rather than to deal with structural constraints to successful resettlement, such as the lack of jobs and discrimination in the labour market, which are much more difficult to address” (p. 82). Attention should be directed towards the creation of programs and services aimed at reducing poverty and socioeconomic disadvantage throughout resettlement, such as employment, mentorship opportunities, as well as recognition of foreign credentials and funding for community-based health and education programs for Somali youth and adults (Bokore, 2013; Pilkington et al., 2010; Stewart et al., 2008).

The findings of this study are consistent with previous research, which highlight the negative impacts of poverty on self-management of T2D, as several participants disclosed fulfillment of basic needs often taking precedence over diabetes self-

management and care (Pilkington et al., 2010). Therefore, understanding resettlement stressors experienced by this population is integral in the provision of care for Somali immigrants and refugees living with T2D and their family member/s. Further research is needed examining the role of income in T2D prevalence, care, and self-management in this population, in light of the precarious settlement and employment barriers experienced by many Somalis during their resettlement in Canada (i.e., Bokore, 2016a; Fellin, 2015a; Spitzer, 2006). This study did not include household income in the demographic questionnaire, so inclusion of income and/or employment would be beneficial to assess in future studies given the integral role of this social determinant of health as a risk factor for T2D.

Furthermore, longitudinal studies implementing an intersectional approach are necessary to better understand the health outcomes of different members of the Somali diaspora in Canada (Dendup et al., 2018; Patil et al., 2011). Longitudinal studies can offer more in-depth analysis regarding the health outcomes experienced by Somali immigrants and refugees throughout resettlement compared to retrospective chart reviews, for example, which often only include medical information at a particular period of time (Kumar et al., 2021). More research using longitudinal research approaches are needed to determine the prevalence and risk factors associated with T2D in this population. This knowledge may be particularly useful to healthcare practitioners, since it can be used to provide a more targeted approach for diabetes health promotion in this population (Gele et al., 2016).

Meso

At the meso or community level, the narratives in this study revealed the weight of T2D on community members, namely families dealing with this chronic disease. As the stories revealed, T2D resulted in life changes and the participants felt the weight of these burdens, like snow piling a top and encasing tree branches in the winter's cold. They were dealing with life, while also raising and nurturing a family of trees. However, symbiotic relationships were present not only in the family trees but also throughout the Somali diaspora, which included community networks that were also used to care for and support individuals living with T2D.

As a diaspora, this group incorporates social frameworks, which influence the ways in which members of this diaspora operate and integrate in society. Diasporas are built on relationships, so understanding these networks can also reveal further clues and/or insights into how care is experienced, and/or accessed in this group. In light of the central role of community, this study recommends funding and support of community-based organizations/programs that attend to the resettlement needs of Somali immigrants and refugees living with chronic disease and their families in Toronto, programs that are inclusive of their cultural and religious worldviews, such as Dr. Saleh's health group and the Hooyo Initiative Fund, for example. The Hooyo Innovative Hub (iHub) is a community-based initiative led by Somali-women in the Greater Toronto Area (GTA) that primarily works to address the social and the economic needs of Somali women and their families in this city. Created in 2018, this organization has led several projects in Toronto, such as the Hooyo Project which offers educational, skills-based learning opportunities, and mentorship for Somali women in Toronto. More resources and funding are needed to support community-based Somali

organizations, such as iHub with community outreach and health promotion programs to address the needs of Somali immigrants and refugees diagnosed with T2D and their families in Toronto.

Community-based mental health programs, in particular, are recommended. The stories of the participants in this study revealed multiple stressors experienced by this group as they navigated their everyday lives and the care of their and/or loved one's condition within this resettlement context. Caregivers in this study (such as Aaliyah and Bishaaro) articulated the need for mental health services, such as individual and group counselling. Mental health supports that strive to understand the diverse migration histories, resettlement stressors and needs of Somali student caregivers should also be incorporated within postsecondary institutions counselling, medical, and health promotion services. Cultivating a space and community for Somali caregivers to address mental health needs may be helpful for those caring for a loved one living with T2D. It may be used to access social capital or the benefits one receives from "their participation in cohesive groups or social networks" (Cockerham et al., 2017, p. S8). Individuals living with T2D may also find comfort in individual and community-based support and mental health services for the same reasons noted above.

In this study, community-based supports such as Dr. Saleh's group, offered those who were reluctant to disclose their condition an alternate space to talk with those that they trusted. The women in Dr. Saleh's group were able to receive objective forms of social capital as they accessed information on health, settlement, advice, and assistance with personal matters (Cockerham et al., 2017). Dr. Saleh's group was not only a source of social support and counsel, but it was also a means for the participants

to embark on collective forms of health promotion that were more aligned with their cultural frameworks. According to CCT, both care and culture are intertwined, and are “embedded in each other” (Leininger, 2006, p. 4). Cultural preferences for group counselling are also akin to what Bokore (2013) described as a “gender-based support system” to address the trauma and resettlement challenges faced by Somali women in Toronto (p. 105).

Indeed, more research is needed to examine the mental health needs and benefits to individuals living with T2D who may wish to access similar community support, including gendered forms of social support as was demonstrated by many of the participants in this study. Research on social support highlights that women are more likely to provide and acquire social support compared to men (Taylor, 2011). As a social determinant of health, social networks can offer benefits to refugees mental and physical health (Hynie, 2018a). In particular, Hynie (2018a) notes that, “Co-ethnic communities can be a tremendous source of social support for refugees, providing information, emotional support, and material support that help them navigate their new environment and buffer the negative impacts of migration” (p. 217).

Community-based initiatives should also focus on stress management/coping for individuals living with T2D (Agyemang et al., 2012; Goosen et al., 2014; Kelly & Ismail, 2015; Yaribeygi et al., 2017). More research is needed examining culturally appropriate forms of stress management approaches in this population. Stress management offers potential benefits to individuals diagnosed with T2D, such as sustained improvement in glycemic control (Agyemang et al., 2012). According to Goosen et al. (2014), “Interventions aimed at increasing physical activity may have large effects as this would

contribute to stress reduction, a risk factor for diabetes that is highly prevalent among asylum seekers” (p. 1539). As mentioned earlier in this section, more funding is needed to support community-based health initiatives (i.e., such as physical activity interventions or spaces, etc.), inclusive of the participants’ personal, social, health, cultural, economic, and religious needs.

In addition, healthcare providers and diabetes educators should nurture trusting relationships with and integrate themselves into these existing community structures, as they offer a valuable site for health promotion and diabetes awareness. Mosques as religious institutions can also be particularly powerful media of health education, as was demonstrated during the recruitment period of this study and also in other health promotion interventions (Abdulwasi et al., 2018). Cultural-religious institutions may help bridge trust between the community and healthcare providers. These relationships should include a focus on partnerships that are collaborative and strive to understand and incorporate the lived experiences of this group in health programs and services (Henderson et al., 2014; Pilkington et al., 2010).

Micro

Through a micro level analysis, we see how the participants’ stories showed the complexity of the impacts of T2D on their lives, reflecting the third theme in this study. Despite the burden of both the disease and its management, the participants described both positive and negative aspects of T2D, the bitter-sweet reality of this condition. Their reactions to T2D ranged from acceptance, shock, fear, gratitude, and denial. While the participants exhibited diverse reactions to their condition, all of the participants turned to their faith to cope with management of T2D. Their religious beliefs

offered not only comfort but also strength to move forward and a means to deal with resettlement stressors in diaspora. Understanding impact/s of faith in this diaspora (a care factor in the Sunrise Enabler) is imperative, as doing so would incorporate the worldviews of the participants and their diverse, complex, and sometimes contradictory perceptions of this illness. The next section offers more in-depth recommendations through a discussion of culturally congruent care.

Culturally Congruent Care

Culturally congruent care requires that healthcare providers work to not only understand cultural knowledges of individuals and groups, but also implement care that includes the worldviews of individuals and groups (McFarland et al., 2012). In this study, the participants' faith was viewed as a means of coping with illness, and as a collective resource for the participants during unsettling periods in their lives, such as diagnosis with T2D. All the participants living with T2D referred to their faith as a means of making sense of their illness. Bishaaro commented that it was this reliance on faith that was also used to help her parents (who were both diagnosed with T2D) to deal with the most traumatic experiences in their lives. *Allah* (God) is regarded by Muslims as the "ultimate healer" of all illnesses (Koenig & Shohaib, 2014; Wehbe-Alamah, 2008, p. 88). The findings in this study are similar to Wolf et al.'s (2016) research on Somali immigrants in Minnesota, as faith was also demonstrated to be an important part of the participants' approach to mental health. Rather than dismissing faith-based approaches to illness, health care providers should include Somali patients' faith within care if it is requested by patients. Including this discussion in the care/treatment of T2D, also demonstrates a recognition on the part of the healthcare professional of the importance of the patients'

worldviews surrounding health and healing. This would be in alignment with culturally congruent care, since conventional and faith-based approaches can be integrated at the request of the patient.

Strengths of the Study

A major strength of this study is that it offered a unique insight into the experiences of Somali immigrants and refugees living with T2D and their family members. This group presents many risk factors for this condition, such as marginal status in Canada, ethnicity, and/or refugee status. This study's inclusion of family members affords additional new insights into the experience of this illness within this resettlement context. Importantly, this approach is also congruent with the cultural worldviews of the participants in this study, which reflect a preference for support from family networks (Stewart et al., 2008). Analysis of the participants' individual experiences with T2D and that of the family member/s with this illness, revealed different illness narratives and perspectives for this population and knowledge on the ways in which Somali immigrants and refugees and/or their family member/s manage/care for this illness.

A second strength is, as a qualitative study, this study explored the participants' experiences with T2D using their own perspectives. It addresses a void in the health literature, where the voices of individuals of African descent living with T2D are limited. Much of the research on T2D amongst African refugees and immigrants incorporates quantitative approaches, which tend to focus on the prevalence of illness. In contrast, the participants in this study answered questions in their own words and relayed their

experiences and stories in detail, which provided especially insightful and rich forms of knowledge.

Third, this study also included multiple approaches to understand the experiences of the participants in this study. The first involved narrative research methods where participant's experiences were conveyed as stories. Three stories were included in this study, which were representative of the themes present across participant narratives. Data analysis in this study included various approaches, such as analysis of narratives, narrative analysis, and found poetry. The addition of poetry offers another means of knowledge dissemination that includes the participants' words and offers a compact and more accessible form of knowledge dissemination (Furman, 2007).

Another strength is my positionality as an East African Muslim woman researcher. I was able to relate to the participants on a personal level as I understood many of their experiences as a diasporic East African Muslim, which offered a degree of insider positionality on my part. Participants did not have to explain religious references since I understood these words/phrases as well, being of the same religious faith. I was fortunate to attend and support initiatives that the participants were conducting, such as Warsan, aged 53, who became a dear friend over the course of this study. This participant was also in the process of creating an event for Somali women in Toronto, which unfortunately was put on hold due to COVID-19. I believe that my engagement in the community has helped me understand the needs of the participants more clearly and build relationships that were respectful, reciprocal, and ethical.

Another strength of this study is that it can be used as a medium of “social action” (Chase, 2013, p. 57). Narrative research using storytelling offers a promising approach for community research initiatives, since it strives to centre the narrator’s voice (Riley & Hawe, 2005). Therefore, the stories in this thesis, I believe, can be used to gain more understanding of the ways the participants are marginalized (for example, via neighbourhood stigma and racism) that have implications for their sense of belonging and navigating health issues. The participants’ stories also draw attention to their resilience and agency in response to these adversities.

To mobilize the stories produced in this study and engage in social action, I plan to continue to use oral methodologies, such as poetry and stories, as a method of health promotion in the future for diabetes education in this community and broader East African diaspora, given its alignment with cultural worldviews (Njeru et al., 2015; Wieland et al., 2017). As part of community-based health promotion initiatives, I also plan to create illness narratives in the future, compiling the stories of East African families navigating T2D across Canada. These stories can offer a useful and meaningful way to understand chronic disease and the factors related to the progression and impact of illness in this group (Bleakley, 2005; Lee et al., 2016; Stephens, 2011). Ultimately, I hope that this thesis can be used to improve the social conditions and quality of life of the participants (Chase, 2013).

Limitations of the Study

This study also presented limitations related to the design of the study and recruitment challenges experienced. The first limitation is the manner in which interviews were conducted. This study used a semi-structured interview guide, which

included questions or probes related to the theoretical framework and research questions explored in this study. While there was flexibility in the way/s questions were asked and/or approached, this method is not as effective in producing stories compared to unstructured interviews (McCance, McKenna, & Boore, 2001; Thomas, 2010). In unstructured interviews, the interviewer only follows a rough sketch of topics, which allows for the participant to lead the interview (McCance, McKenna, & Boore, 2001). This freedom provides for optimal conditions for the production of stories, since there is less rigidity and focus on answering all the questions (McCance, McKenna, & Boore, 2001). Further, given the large number of participants in this study (37) and recruitment challenges experienced during this study, I was unable to re-interview individuals to request for more information regarding their narratives. However, I did explicitly ask participants upon meeting them to share their stories, memories, and details of their lives to provide rich sources of data for this study. While the interviews in this study did not produce “big stories” or “grand narratives” of an individual’s life which require more in-depth engagement with participants, the interviews still offer valuable insights regarding participants’ experiences (Sools, 2012; Stephens, 2011, p. 73). The stories in this thesis are more reflective of “small stories” of the participants’ everyday experiences (Sools, 2012; Stephens, 2011, p. 73).

Another limitation experienced in this study is related to some of the participants’ reluctance to disclose illness, such as T2D to their family member/s. The idea of a family interview was not appealing to many participants in this study, which required me to interview family members and individuals living with T2D separately. By interviewing

each of these groups separately, I was not able to obtain a full picture of a family's experience with T2D.

Further, this study also presented limitations regarding the recruitment of participants. The participants in this study are predominantly female. Of the participants identifying as family members, only 4 males were recruited. In addition, only 6 males diagnosed with T2D were recruited. Due to this limitation, the results are only reflective of the participants' experiences and cannot be used to draw conclusions related to care and/or gendered expressions of care. The interviews conducted with the male participants in this study were in group setting/s (with other individuals or participants), often at the request of the participants. In this case, my gender as a female served as a limitation, since it limited my ability to recruit males and required me to navigate research processes with a male participant using a male gatekeeper.

Lastly, I experienced barriers related to language mainly when conducting interviews with participants. While there were many participants that spoke English fluently, there were some that required a translator. My lack of fluency in the Somali language served as a limitation since I had to rely on translators for further insight and translation (two translators were affiliated with settlement agencies, serving as gatekeepers, and one was a neighbour of the participants). Further, translators were not used for member checking of these interviews (but participants were encouraged to contact me where I would connect them with translators if they required any clarification). To resolve this issue, future studies can provide translation of all interview materials (including transcriptions).

Conclusion

This study used the metaphor of a tree and termites to describe the process through which T2D made its way up the roots of a tree and impacted the participants living with T2D and the family trees. T2D as a chronic disease was a part of their stories, but not their identity. The participants' stories relayed their strength in light of adversities and resilience. Older trees provided much wisdom to the younger trees, shading them from the harms of precarious life – and praying for them. In many cases, younger trees also grew up around and supported older trees.

Through reflexivity, researchers analyze their own stories by examining how their “personal beliefs, values, and biases” may have influenced the research process (Creswell & Miller, 2000, p. 127). I end this thesis with a reflection of my connection to this dissertation. My experiences with diabetes are indeed personal as they include my father who was diagnosed with this condition shortly after my families' migration to Canada. The memories and accounts of the participants living with T2D and/or family members brought up memories of my father and his experiences living with T2D. In many ways, this experience has made me return to the beginning of my life story and has in the process strengthened my own identity.

In addition, I could see parallels between the participants, many of whom were mothers, and my own mother and her resilience working multiple jobs, just to provide for our family. This further solidified my sense of identifying with my participants. These feelings were perhaps reciprocated, as many of the participants welcomed me into their community and homes, some even telling me how proud they were to see me continue

with my education, encouraging me to finish, and even requesting that I invite them to my graduation.

Although I am an insider in many ways, I cannot ignore the fact that I was also an outsider too. This presented itself as a barrier in some cases, as I did not have the cultural understanding to capture the richness of what was being conveyed in the moment and during the interview process. I missed the meanings and understandings of what it meant to be Somali as an insider. I leave as a member of this forest, despite being at the periphery, I cannot deny my connections to the participants through their stories and faith, and experiences with this chronic disease as an East African diasporic Canadian. For these connections have brought me back to my story too. I end this thesis, full circle back to my roots. I will never forget about the forest of trees that supported me, their care, and light. These are the memories that I will carry with me forever.

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Appendices

Appendix A: Recruitment Poster

**Ma waxaa tahay qof qaxooti Somaali ah oo ka weyn 12 jir
qabtana sonkorowga nooca 2 (Type 2 Diabetes)**

**Ama qof Qoyskaaga ah oo 16 jir ka weyn oo ah qaxooti qaba
Sonkorowga?**



**Cilmi baaris ay wadaan baarayaal ka socda jaamacadda York
oo la wado ayaa lagu doonayaa in dhegeysto xaal nololeedka
adiga iyo qoyskaaga ee la xiriira waaya aragtidiina
sonkorowga.**

**Taladaada la xiriirta cilmi baaristan aad ayey u fiicnaan
lahayd.**

Wixii faahfaahin dheeraada kala soo xiriir Munira Cabdiwasi :



ama emailka :



Appendix B: Interview Guide

Tell me a little bit about yourself?

Probe a: Where did you grow up?

Probe b: Why did you and/or your parents/family leave Somalia?

Probe c: How were your educational experiences? - *Educational factors*

Probe d: What is your relationship like with your family? - *Kinship & Social factors*

When did you first come/arrive to Canada? (Or when did your parents/family come to Canada?)

Probe a: When did you (or family member/s) first come/arrive to Toronto?

Probe b: What were your (or family member/s) initial experiences like in Canada?

Probe c: What were your initial experiences like as refugees/immigrants obtaining housing and employment? (Or family) - *Political/Legal/Economic factors*

Questions on health:

1. How would you describe your health overall? (Additional question for family: How would you describe your loved ones' health?)
2. What does being healthy mean to you? - *Cultural values, Beliefs, & Lifeway factors*
3. When were you first diagnosed with type 2 diabetes? (For family, when was your loved one diagnosed? How did you find out?)
4. How does diabetes impact your day-to-day life?
5. What do you do to manage/care for your/family members type 2 diabetes?
Technological factors

Attitudes and Beliefs of Type 2 Diabetes:

6. How would you describe type 2 diabetes? - *Religious & Philosophical factors*
7. What does type 2 diabetes mean to you?

Impact of type 2 diabetes on self/others:

8. How has type 2 diabetes impacted your family, friends, and/or significant others?
9. How has type 2 diabetes impacted your life as a whole?

Conclusion:

10. Is there anything that you would like to add?
11. Do you have any questions or comments?

Thank you for your time.

Appendix C: Demographic Questionnaire

Please answer the following questions below. The following information will only be made accessible to the research team.

- 1) First and last name _____
- 2) Age _____
- 3) What is your gender? _____
- 4) Marital status _____
- 5) Number of children _____
- 6) Number of years in Canada _____
- 7) Immigration status _____
- 8) Are you managing and/or receiving healthcare for type 2 diabetes? _____

Appendix D: Informed Consent

Project Title: A Critical Examination of the Lived Experiences of Somali Refugees and Immigrants Diagnosed with Type 2 Diabetes and their Family

The intent of this letter is to provide you with the necessary information you need to make an informed decision regarding your participation in this study. This letter is yours to keep.

Researcher: Munira Abdulwasi, PhD Candidate (York University), email: [REDACTED]

Supervisor: Dr. Yuka Nakamura, PhD (York University), email: [REDACTED]

Purpose of the Research: The purpose of this qualitative study is to examine how adult Somali refugees and immigrants diagnosed with type 2 diabetes over the age of 16 and their immediate family members over the age of 16 manage and come to terms with type 2 diabetes. Through this study, we aim to gain a better understanding of how Somali refugees and immigrants diagnosed with type 2 diabetes and their families experience type 2 diabetes.

What you will be asked to do in the research: If you agree to participate in this study, you will participate in an in-depth open-ended individual interview lasting approximately 60 to 90 minutes in length which will be audio-recorded by the primary researcher.

Demographic information will be collected in the form of a questionnaire. The purpose of the questionnaire is to gather information of the composition and background of the participants involved in this study. This information may be useful to aid the researcher(s) in their analysis of who the research findings can be generalized to.

Risks and/or Compensation: This study may pose potential risks for you such as emotional distress during and after the individual interview as you disclose your lived experiences. You may discontinue your participation in this study at any time if you experience any discomfort or pain.

At the completion of the individual interview, you will be provided with a list of community resources to qualified professionals, Somali cultural centres, and Diabetes Education Programs. If you experience any adverse effects due to your participation in this study, we will do our best to connect you with the appropriate resources to assist you.

All participants are eligible to receive the full \$20 for their participation in this study. Participants will be compensated with \$10 for the first 45 minutes of the individual interview, and \$10 for the second 45 minutes of the individual interview. Participants are eligible to receive the monetary amount for each portion of the research even if they withdraw from the study.

Benefits of the Research: Participants may derive benefits from their participation in this study in disclosing their lived experiences. The information derived in this study may lead to benefits to the participants as it may lead to policy development and/or services tailored to meet the needs of the participants of this study.

Voluntary Participation: Your participation in the research is completely voluntary and you may choose to stop participating at any time. Your decision to stop participating, or to refuse to

answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event that you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

Confidentiality: Confidentiality will be provided to the fullest extent possible by law. All interviews will be audio-recorded and transcribed by the researcher of this study and will only be accessible by the researcher of this study. The transcribed data from the interviews will be stored on a pass-word protected laptop with no personal identifying details. Audio-recordings of the interviews will be deleted from recording devices and laptop. Transcripts and interview materials will be stored in a locked secure office where they will be stored for two years after which they will be destroyed.

Questions about the research? Please review the letter carefully and feel free to ask the researcher and/or her primary supervisor Dr. Yuka Nakamura [REDACTED] questions if anything is unclear to you and/or if you need further clarification regarding the research process and/or your role as a participant. You may also contact York University's Graduate Program office at 416-736-5728. This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and will conform to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, you may contact the Senior Manager and Policy Advisor for the Office of Research Ethics, 5th Floor, York Research Tower, York University, telephone 416-736-5914 or e-mail ore@yorku.ca.

Legal Rights and Signatures:

I _____ consent to participate in "A Critical Examination of the Lived Experiences of Somali Refugees and Immigrants Diagnosed with Type 2 Diabetes and their Family" conducted by Munira Abdulwasi and Dr. Yuka Nakamura in the School of Kinesiology and Health Sciences at York University. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

I give the researcher permission to use direct quotations for use in this study. All quotations will remain anonymous.

I give the researcher permission to audio-record both the individual and group interview process of this study.

Participant's Signature: _____ Date: _____

Investigator's Signature: _____ Date _____