

RUNNING HEAD: T2DM in Belize

**Informing Services through Patient Perspectives of
Living with Type 2 Diabetes Mellitus in Belize**

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A Thesis submitted to the Faculty of Graduate Studies of
The University of Manitoba
in partial fulfilment of the requirements of the degree of

MASTER OF SCIENCE

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Abstract

Type 2 diabetes mellitus (T2DM) is the leading cause of death in Belize, and its prevalence is rapidly increasing. The purpose of this study is to understand the everyday realities of people living with T2DM in Belize (e.g., barriers to care, strengths, health practices), how these affect diabetes self-management (DSM), and implications for health care. Data generation methods include interviews with T2DM patients, discussions with key informants, field notes, and participatory observation which took place in February and March of 2020.

Principal findings were categorized into three main themes. The first is that patients experience numerous difficulties, including a tiered health care system privileging those with more resources, communication barriers with health care providers, and major gaps in prevention, education, and social supports. Secondly, many Belizeans with T2DM engage in spiritual practices that provide for mental strength, stress relief, lifestyle guidance, overcoming addictions, overcoming denial, and building determination toward health promoting, life-affirming attitudes and actions. Further, geographies can empower DSM. Home is a domain where personal power is most focused. A community domain that is conducive to active living is crucial. People use a plethora of local plant medicines instead of, alongside of, or to complement pharmaceuticals for DSM without disclosure to HCPs.

Plant medicine usage and cultural-spiritual healing is pervasive in this population; therefore, health care can optimize T2DM outcomes through open dialogue and collaboration with patients, herbal doctors, traditional Indigenous medicine practitioners, community leaders, and faith leaders. Integrating these understandings will be key for moving forward to improve DSM education and support, as well as culturally safe care.

Chapter 1: Introduction

This study originated from a multi-organization collaboration¹ with the purpose to learn about how to prevent Type 2 Diabetes Mellitus² (T2DM) prevalence from worsening in Belize. Diabetes is a major concern in Belize where the prevalence for adults (20 to 79 years of age) is 17.1% of the population, up from 9.8% in 2010 (CEIC, 2019). Belize ranks fifth poorest in the world and the poorest in amalgamated Central America and South America for diabetes prevalence (WHR, 2019). The proportional mortality attributable to diabetes has increased from 5.6% in 2001 to 11.95% of total deaths in 2019, and it is considered the leading cause of death in Belize alongside coronary heart disease (MoH et al., 2018; WHO, 2016a; WHR, 2019). There is high prevalence of diabetes risk factors, such as being overweight and obese, at 50.5% and 20.6%, respectively (WHO, 2016a). In a 2018 study of a random sample of Belizeans, 33.1% were found to be in a prediabetes range while 8.5% of those were undiagnosed (Isabel, 2018). Hospitalization rates for diabetes-related complications such as heart attacks, strokes, renal failure, and amputations are also rising in Belize, a country considered among the ‘least developed’ in Latin America (MoH et al., 2018; UNDP, 2018).

There is an intricate latticework of intermingling ethnicities and cultures in Belize with a population that self-identified in the 2010 Census as 53% Mestizo, 26% Afro-descendant Creole, 11% Mayan (including three distinct groups, namely, Yucatec, Mopan, and Q’eqchi’), 6% Garifuna, as well as Mennonite, Middle Eastern, Indian, and Asian. Indigenous Belizeans is a term inclusive of the distinct communities of the Mayan, the Mestizo (Spanish-Mayan), and the Garifuna (African-Indigenous Guyana). As such the country is not only a notable place to study

¹ In collaboration with local research coordinator Wuri Lucia Ellis, health educators (HEs), community health workers (CHWs), the Belize Diabetes Association (BDA), the Ministry of Health Belize (MoH), the National Health Insurance Office (NHI), and the World Diabetes Foundation (WDF) which all have representation on the project’s Steering Committee, and in partnership with the University of Manitoba (UM), Canada.

² Type 2 Diabetes Mellitus accounts for the vast majority of diabetes in Belize and will be referred to interchangeably with the shorter terms “diabetes” or “T2DM” for the purposes of this paper.

diabetes (due to prevalence), but also to study the implications of chronic disease management in a context of cultural multiplicity (OYE, 2017; SIB, 2013). Living with chronic illness is challenging in any country, but chronicity takes on meaning distinctive to Belize, as does resilience. An important pillar of resilience for people living with diabetes in Belize was found in spiritual or religious³ attitudes and practices. Diabetes prevention, education, and treatment interventions that are designed to be culturally appropriate and take into account patient spirituality/religiosity in self-management strategies have been shown to positively affect health outcomes. (George et al., 2013; Koenig, 2014; MoH et al., 2018; Rivera-Hernandez, 2016; Roger & Hatala, 2018; Sridhar, 2013; WHO, 2018). This care is not consistently available in Belize, however, it could represent an important overlooked resource (Balboni et al., 2015; Koenig, 2004, 2014).

Health care providers and planners can benefit from hearing directly from service users to understand how their day-to-day realities, struggles, and barriers to care impact their health and could be alleviated. Understanding how patients' strengths and coping (including their spirituality or religiosity, as well as their plant medicine usage) affects their compliance to care plans, their health behaviours, their coping with chronicity, their mental health, their wellness goals, their social supports, their physical functioning, and their overall health is key to delivering health care that best serves the people who utilize it. When health services are

³ "Spirituality" is used as a term to describe a "search for the sacred" that encompasses traditional religiosity, but also positive states of mind, meaning to life, interconnectedness, peacefulness, and wellbeing for those who do not identify as religious (Koenig, 2008, p.350). Elaborating on the many intricacies of definitions of the terms "spiritual" and "religious" are beyond the scope of this paper. For a more in-depth discussion on how these terms are used in research contexts, please refer to (Koenig, 2008). I use "spiritual" and "spiritual/religious" throughout this paper because I am referring to both regardless of which I use, applying the definition that the former encompasses the latter.

incongruent with the beliefs and cultural practices of the people they are meant to serve, patient uptake of care and adherence to care plans are negatively impacted (ICS, 2019; MoH et al., 2019; Waldram, 2008), and this is often heightened among Indigenous contexts and cultures. With Belize's health system's efforts to curb the growing rates of diabetes and its complications, it is crucial to understand the perspectives of patients themselves regarding what works in diabetes care and self-management (Anderson & McGibbon, 2017; MoH et al., 2018).

In this thesis, I explore some of the main challenges faced by people living with T2DM in Belize, such as inequitable access to care, communication barriers with Health Care Providers (HCPs), setbacks experienced in diagnosis and complications, lack of knowledge for prevention and management, and lack of social support. I explore how the spiritual practices of people living with diabetes in Belize affect their commitment to self-management, their psycho-social health, and their ability to transcend the difficulties of living with chronicity. I also delve into how certain geographies can empower self-management, including local plant medicine usage, land-based cultural-spiritual⁴ practices, and health-promotion built into the landscape.

1.1 Significance

Belize has at least 22,193 people living with diabetes (approximately six percent of the total population), according to the Ministry of Health 2012-2016 data, though this number does

⁴ Throughout this thesis, the term “cultural-spiritual” refers to socially-embedded and enacted ideas, customs, norms, protocols, standards, traditions, and behaviours, that relate to the realms of the sacred, the spirit, or the soul, inclusive of the interactions between these components.

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not include a sub-population of people not accessing public services (approximately 25% of the total population), people diagnosed since 2016, people who have not yet been diagnosed, nor people receiving suboptimal care, therefore the number of existing cases is underrepresented (MoH et al., 2018). The president of the Belize Diabetes Association counts the number of cases (Type 1 and Type 2 combined) at 50,000 people, approximately fourteen percent of the total population (personal communication, Lynette Valerio, August 20, 2020). This study holds significance for the abovementioned populations, their communities, policy decision-makers, and program planners who can influence diabetes care in Belize. It contributes to the academic literature in the areas of patients' lived experiences of diabetes, health, and health care in Belize, as well as culturally specific diabetes care.

Adequate nutrition and exercise play key roles in T2DM prevention and management, and these can be fostered through developing culturally appropriate health-promotion, education, and policies (WHO, 2015, 2016a, 2018). When diabetes is not controlled, health deteriorates (e.g., fatigue, vision loss, nerve damage, restricted blood circulation leading to limb amputation, mortality), and T2DM is associated with kidney disease, cancer, amputation, and depression, all of which represent significant economic burden (Cheng, 2013; Dekker et al., 2017; MoH et al., 2018). If the people of Belize, HCPs, Health Educators, Community Health Workers, the Ministry of Health, the Belize Diabetes Association, and the other stakeholders can more deeply understand how to help prevent T2DM, how to care for T2DM patients, and how to overcome existing barriers to care, then many burdens could be relieved (MoH et al., 2018). This study is significant for people currently living with the disease, and those who will be so in the future.

This study can inform international health organizations, administrators, researchers, planners, and providers.

1.2 Background & Context

This section reviews three major areas of literature. The first is the current state of literature to apply Chronicity Theory to understanding which populations suffer from T2DM, narrowing in on economic-based distributions across nations in general, and on Belize in particular. The second delves into literature that cross-sections spirituality (or religiosity) with diabetes around the world and in Central and South America (CASA), including some global scoping and systemic reviews. The third literature area reviews the state of academic knowledge on CASA plant medicine usage and cultural-spiritual practices for treating diabetes and its related ailments.

1.2.1 Chronicity theory: Who in Belize suffers with diabetes?

Rates of diabetes (and other chronic illnesses) are swiftly rising around the world (MoH et al., 2018; WHO, 2016a, 2018). In their volume on chronicity and experiences of illness, Manderson and Smith-Morris (2010: 6) described causes of obesity and diabetes as “a result of economic transition: from agricultural subsistence to one of industrial wage labor...” and “the resulting decrease in physical activity and overconsumption of high-fat, nutritionally poor foods consistently and reliably produce poor metabolic health.” These authors outlined the varying emergence of diabetes chronicity burdens across low, middle, and high income countries, then state that populations are now affected worldwide (Manderson and Smith-Morris 2010:10).

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While its swelling prevalence is universal, diabetes is exacerbated by conditions of poverty, disparity, and structural violence; patients, for example, cannot take medications they cannot afford (Weaver & Mendenhall, 2014).

A common feeling in Belize is that regardless of class, race, ethnicity, age, sex, or gender is that “Everyone has diabetes” (Key informant, 2020). Despite this feeling, there is scant statistical evidence stratified across categories. Literature specific to Belize agrees with the wider assertion that diabetes places a disproportional burden on Low-Middle Income Countries (LMICs), and within the country, there may be pockets of lower than average incomes and higher diabetes prevalence (Dekker et al., 2017; WHO, 2016b). A mixed-methods study by Dekker (2017) found that the village of Elderidge, near Punta Gorda in southern Belize, had 79 percent of its population living below the poverty line and that diabetes was poorly controlled in 74 percent of patients. Physicians were concerned regarding prescribing insulin for patients without refrigeration, with low levels of health literacy, and with limited education on disease process and self-management strategies (Dekker et al., 2017). The study revealed a need for more lifestyle counseling for diabetes patients including nutritional advice; however, “We eat what we can afford,” is how one participant framed the issue (Dekker et al. 2017:8). Nutritional advice must be locally relevant and consider accessibility issues to be of any use. Further, the underlying socio-economic reality, as well as the status of food sovereignty, must be addressed simultaneously with education efforts around diabetes nutrition.

In 2014, Gulley studied an occupational diabetes screening program at a major corporation in Belize and found that half of the employees had elevated glycemic levels, most of whom had previously been unaware. They cited economic constraints in purchasing diabetes-

friendly food products (e.g., quality protein, complex-carbohydrates, multigrain) as a major issue for employees (Gulley et al., 2014). Similarly, for the employees who did know they had diabetes, it was difficult to afford glucometers, testing strips, and oral medication, resulting in inadequate glycemic control (Gulley et al., 2014). While this article shows potential in the areas of corporate social responsibility and worker productivity-driven research, and demonstrates a high hidden prevalence, it also highlights the need to address the accessibility of nutritious food and medical supplies.

A group from the University of Boston (United States) carried out an education and screening program with the general public in Punta Gorda (Belize) and six of its surrounding villages in 2011 (Brown et al., 2013). Although less than 5% of participants reported experiencing diabetes symptoms, they found that 52.6% of participants had elevated blood glucose. Further, while Body Mass Index (BMI) is a globally accepted risk factor for diabetes, this data set showed no relationship, leading authors to question what kind of variation was underlying the difference that is manifesting in this part of Belize. Thus, while using patient BMI as a risk factor is tempting⁵, it is inadequate on its own, making blood glucose testing even more important⁶. Regardless of the lack of prevalence data by income category, there are economic factors to overcome in stretching diabetes prevention and treatment planning across Belize.

As institutions are an important part of the interplay of forces exacerbating the condition, interdisciplinary cooperation is needed for solution-focused research and development across

⁵ BMI is inexpensive to calculate and more “visible” than other risk factors.

⁶ Glucose testing and supplies are expensive and in short supply in Belize.

silos; chronicity requires innovation from system planners. Manderson and Smith-Morris (2010) pointed out that health care systems privilege acute care needs over those of chronic disease management, and that this is detrimental to preventing an exacerbation of the increasing pervasiveness of chronic illness. Further, it ignores the way chronicity perpetuates itself in society (Manderson & Smith-Morris, 2010). While systems shift to stress diabetes self-management strategies, there must be consideration that these strategies are undeniably linked to the patient's economic control over their lifestyle (Manderson & Smith-Morris, 2010).

Through the movement toward promoting self-management, a substantial burden of chronicity homework is placed on patients involved in diabetes care (Roger & Hatala, 2018). Self-management assumes patients can afford nutritious food, clean water, glucometers, testing strips, and to live in a peaceful place; it assumes resources for caregivers for elderly people, those living with amputations, those visually impaired, or other people with complications. Many people in Belize cannot afford these things, and rely on a patchwork of volunteer efforts, government, and private systems (Bowser et al., 2013; Gulley et al., 2014). While intentionally gender-based analysis is often missing in the literature, there are studies that note that chronicity homework falls more often on the shoulders of women than those of men (Arifin et al., 2020). Indonesian women with diabetes, for example, were found to have both more caregiving duties and more stress than their male counterparts (Arifin et al., 2020). The women in the study managed their own diabetes without additional support despite compounding stresses of paid work, housework, kin work, and chronicity homework. The men in the study, however, felt their diabetes did not contribute to their stress because the women in their lives looked after them (Arifin et al., 2020). This type of inequity itself contributes to increased stress and is not because

of “females potentially being more sensitive to their illness” as is commonly stated in the literature (Arifin et al., 2020).

Though most Belizean participants reported not experiencing much stress, those who did were working mothers, as well as those who could not afford what they needed. There are implications for physicians and health planners regarding providing care for women; women are more likely than men to experience poverty, depression, and diabetes (NWC, 2013; WHO, 2015). More research is needed to understand categorically who is most affected by diabetes in Belize, and how this chronicity interacts with common struggles, barriers to care, and self-management practices.

1.2.2 Religion, spirituality, and diabetes

A 2018 systematic review found a positive relationship between patient spirituality or religiosity and improved management of T2DM (Darvyri et al., 2018). Spiritual practices, such as regular prayer, scripture reading or communal worship, improved patient emotional adjustments to diagnosis, psychological endurance with chronic disease, mental health (including reduced depression and anxiety), glycemic control, and quality of life (QoL) (Darvyri et al., 2018; Heidari et al., 2017). A structured review of articles from five continents between the years of 1970 to 2012 also found that practicing spirituality or religiosity was beneficial to patients’ health self-responsibility, self-management, mental health, coping strength, and social support systems (Permana, 2018). In another literature review, religious practices, such as mosque and religious ceremonies attendance, religious support provided and received, and subjective

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religiosity, were linked to the abovementioned factors, as well as reducing alcohol, nicotine, and drug use while improving physical exercise and diet (Heidari et al., 2017).

There is also literature particular to African American, Native American, Latino, Hmong, Adventist people (in the United States), and Indigenous peoples (in Canada) with T2DM that describes a lack of confidence in the medical system, and the need to shift into more holistic approaches with great importance placed on spirituality and local cultural practices (Devlin et al., 2006; Jacklin et al., 2017; Koenig, 2014). Spirituality was described as a central patient strength found in underserved communities in the eastern region of the United States (both urban and rural), and strength-based care was found to be essential to optimizing outcomes (Aamar et al., 2015; Gupta & Anandarajah, 2014). A study in Qom City, Iran, observed significant positive correlations between religious practices and diabetes self-management, including regularly testing blood sugars, performing foot care, sticking to a specific diet, and not smoking. Studies with Thai Muslim women, Thai Buddhist women, and Malaysians outlined similar findings (Heidari et al., 2017; Lundberg & Thrakul, 2013; Saidi et al., 2018). Other studies similarly showed significant relationships between T2DM patients' spirituality (or religiosity), reduced emotional and mental problems, and increased quality of life (QoL) scores (Yazla et al., 2018). Most evidence in these areas recommends embracing cultural, religious, and spiritual care, and collaborating with faith leaders for optimal health outcomes and support (Darvyri et al., 2018). Indeed, a faith-based intervention for Hispanic Catholic church-goers found improvements at six, nine, and twelve months on glycated hemoglobin (HbA1C), waist circumference, QoL, and self-efficiency measurements (Wilmoth et al., 2019). Another study in Nicaragua found best practices to include interdisciplinary teams with church-based diabetes care (Newlin Lew et al., 2016).

While there is an abundance of literature on spirituality, religiosity, and faith-based practices positively affecting health and wellbeing, Roger and Hatala (2017) discussed the need for more specific understanding of how medicine can become responsive to the needs of patients from an increasing plurality of faiths. The purpose of examining spiritual and religious practices is to understand how they affect clinical practice (e.g., lifestyle counseling, behavior changes, adherence to care-plans, patient-provider relationships, communicating diagnosis) for treatment to be efficacious.

Certainly, providers are right to be concerned as not all spiritual practices are easily compatible with medical protocols, and some even detract from them and their compliance. Indeed, some authors found that diabetes patients seeking out spiritual healing in Ghana, in Kuwait, and in the United States, for example, would not consistently take their medications, which exacerbated complications (De-Graft Aikins, 2005; Jeragh-Alhaddad et al., 2015; Koenig, 2004). Critics have argued that the literature has too vaguely defined spiritual practices as positive and health promoting without enough nuanced discussion on which specific practices have which specific effects (Roger & Hatala, 2018.)

To address this criticism, one needs to look closer and to carefully define how particular spiritual/religious practices interact with outcomes (Roger & Hatala, 2018). This territory is now beginning to get mapped out (Roger & Hatala, 2018). For example, studies on Muslim T2DM patients who participate in fasting during Ramadan now provide HCPs with clinical management advice such as doing pre-Ramadan patient assessments and Ramadan-specific education (Lee et al. 2017). Knowing how Muslim patients tend to modify their pharmaceutical schedule around fasting, for example, helps HCPs to work more effectively with them, much better than ignoring

the religious practice and its implications on treatment (Al-Arouj et al., 2010; Lee et al., 2017).

Fasting is not unique to Muslim observers but is a common spiritual/religious practice of many of the world's faith and cultural traditions and requires understanding and a collaborative approach between Health Care Providers, patients, and spiritual/religious leaders. A 2017 study in Ethiopia found that some Orthodox Christians, Protestant Christians, and Muslims who practiced religious fasting were modifying the timing and amount of dosages for diabetes around fasting rites (Habte et al., 2017). Taking their insulin while fasting resulted in hypoglycaemic episodes which could be better managed with medical advice (Habte et al., 2017). The study also found that Orthodox Christians sometimes used holy water in place of pharmaceutical prescriptions, particularly when visiting holy water sites, and that they omitted their insulin and oral medications at other times for religious reasons (Habte et al., 2017).

There are many gaps in knowledge on how HCPs can provide optimal care for T2DM patients practicing spiritual/religious rites and fasting. Another example is found in First Nations spiritual healing traditions in Canada. While Anishnaabeg people have practiced four days of fasting incorporated into sacred ceremonies (e.g., Sundance, Vision Quest) thousands of years, and Anishnaabeg Medicine People have been managing diabetes in observers for decades since the emergence of the disease in their communities, there have been no studies on biomedical implications for diabetes management. This is an important area for more research considering the high and growing prevalence of diabetes in Indigenous communities, as well as the gaining resurgence of these ceremonies which survived decades of systematic political oppression (TRC, 2015). A spiritually-centered, culturally appropriate, Indigenous-led approach is key to Anishnaabeg diabetes care (Allen et al., 2020; TRC, 2015). While there is no formal

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reconciliation process in Belize, the unique needs of Indigenous Maya, Mestizo, Garifuna, and other communities, each with their own spiritual practices, needs to be addressed to mobilize diabetes self-management strategies effectively.

Diabetes is exacerbated by psychological stress; stress adversely affects health behaviours such as exercise levels, dietary choices, and compliance to medication schedules (Hackett & Steptoe, 2017). T2DM and depression are associated with poor glycemic control and cardiovascular complications (Hackett & Steptoe, 2017). Evidence has shown Eastern-based spiritual practices such as yoga and meditation to reduce stress and depression (Ferguson et al., 2010). Prayer has not been studied as much in this way, and there are concerns that must be considered when studying spiritual/religious practices, yet there are studies that suggest prayer has an alleviating affect on stress (Ferguson et al., 2010; Koenig, 2008). For example, a mixed-methods study with Roman Catholic participants showed that an intervention of two private prayers per day and one two-hour group session per week for ten weeks decreased participants' overall self-reported stress (Ferguson et al., 2010). Another quantitative study found prayer and encouraging self-talk to decrease stress levels in university students (Belding et al., 2010). Despite these studies, there is no consensus on which spiritual practices (e.g., yoga, meditation, prayer) affect T2DM-specific outcomes and in which ways. Studies from Mexico and Peru also highlight how social and spiritual support are beneficial to T2DM patients, but there is otherwise a dearth of literature regarding spirituality and diabetes in CASA (Krederdt-Araujo et al., 2019; Rivera-Hernandez, 2016).

1.2.3 Tropical plant medicines and cultural-spiritual treatment approaches

In the tropical forests of Central and South America, there are hundreds of plants used for treating diabetes and diabetes-related complications and symptoms (Ferrier et al., 2018; Giovannini et al., 2016). These culturally significant traditional Indigenous medicines prevent and delay “progression of diabetic related AGE⁷ formation which contribute to the development of retinopathy, cataracts, atherosclerosis, neuropathy, nephropathy, diabetic embryopathy and impaired wound healing” (Ferrier et al. 2018, p. 505).

Belize enjoys a relatively good track record for protecting and preserving their forested areas, culturally significant sacred sites, and plant medicines (Chanecka, 1998; Ferrier et al., 2018). In a country where twenty-five percent of the population does not have access to health care, traditional Indigenous healers are important, and this is especially the case in the more remote villages (Bowser et al., 2013; Chanecka, 1998; Hatala et al., 2015). Traditional Indigenous healers specialize in an array of areas such as birth, forest-derived medicines, herbalism, women’s medicines, bone setting, toxicology, and spiritual healing (Bowser et al., 2013; Chanecka, 1998; Ellis, 2010b; A. Hatala et al., 2015).

Belizeans draw on these cultural-spiritual healing traditions to manage many diseases including T2DM (Ferrier et al., 2018). Mayan healers, for example, have diabetes-specific prayers, rituals, and herbal medicines (Hatala et al., 2015). Garifuna healers conduct ancestral prayers to help people with diabetes and, understanding the disease as passed down through families, call on the help of ancestor spirits to help their kin (Ellis, 2010a). Through ceremony,

⁷ AGE stands for advanced glycation end-products.

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ancestor spirits can direct the patient on which plant medicines to take, as well as initiate behavioural changes (Ellis, 2010a). In the Black community of the African diaspora, there is a spiritual society based in roots and ties to ancestral homeland, though Christianity is the most practiced religion in Belize of which there are numerous forms, including Roman Catholic, Pentecostal, Seventh-day Adventist, Anglican, Methodist, New Covenant, and Mennonite, as well as Indigenous-Christian and Garifuna-Christian synergies (Ellis, 2010a; OYE, 2017).

Despite the strength and prevalence of these spiritual communities, there is little found in the literature about faith-based diabetes interventions (proven to work elsewhere) applied in this context. While it is known that Belizeans practice a rich array of spiritual, religious, and faith-based practices, that cultural-spiritual healers provide care for their communities, and that faith-based missions mobilize international medical volunteers, it is not yet clear how to bridge health care and spiritual care efforts toward better outcomes for people living with diabetes in Belize. There is scarce literature on detailing Central and South American cultural-spiritual healing for diabetes, on best practices in ethnomedicinal research with local cultures and plant medicines, and on how biomedicine systems can interact most effectively with the abovementioned for the best interests of the patients. There are gaps in the literature where there could be more understanding of Belizeans' cultural relationships with land, ideations of nature, and experiences of plant medicines. Further research could lend insight into interactions between T2DM and sacred healing sites, as well as with environments built for active living.

In summary, more research is needed on T2DM in Belize to understand: 1) Prevalence trends across socio-demographic categories to identify key populations for prevention and education programs; 2) The role of corporate social responsibility in transformative research; 3)

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How to enhance self-management of material and medical resources for those living with chronic poverty; 4) Which specific spiritual, cultural, and plant medicine practices are being used and how they affect self-management and T2DM outcomes; 5) Potential guidelines for Health Care Providers regarding how to support their patients' cultural-spiritual and plant medicine resources for best results; 6) How faith-based organizations, cultural-spiritual healers, herbalists, and other stakeholders can collaborate in health-promotion efforts, 7) Interactions between T2DM and environment. This exploratory qualitative study was a first step to address several of these gaps and provide direction for future research priorities and clinical practice.

Chapter 2: Methodology

This chapter outlines the methodology used in the study including discussion on the steps and stages of its development for the purposes of transparency, openness to critique, repeatability, usability by the research team of the larger research program, and usefulness to stakeholders. It includes a brief description on the project's origins, history, and process of community engagement. It outlines the research paradigm, design, methods, ontology, epistemology, theoretical framework, and approach. It lays out the data generation and analysis phases, provides commentary on ethical considerations, and briefly outlines the researcher's role and positionality.

2.1 Project History and Community Engagement

This project builds on relationships between Dr. Andrew Hatala and Belizean community partners which were formally established in 2011, and from the collaborative investigators evaluating the Belize National Diabetes Self-Management Programme. My study was carved out of this larger study, just as my research proposal was informed by the Programme's locally developed research protocol. I worked closely with guidance from the project's qualitative research expert Dr. Hatala, the research coordinator Wuri Lucia Ellis, local health administrators, and members of the Steering Committee to strategically engage the community and to prioritize relationships as central to the project. I had the honour to get to know Wuri Lucia Ellis since her visit to Canada in May 2018 through a series of lectures, health centre tours, and meetings.

My relationship-building efforts with the project stakeholders were facilitated by 1) Traveling to Belize to meet stakeholders, interview participants, and engage with Belizeans in

home, community, and health settings and everyday context, 2) Online communications and workshops; 3) Checking back with stakeholders as the academic work of transcribing, analyzing, synthesizing, and writing evolved. Throughout all phases of this study, the local research coordinator and other local stakeholders were consulted through in-person meetings, written reporting, email check-ins, and virtual meetings. As a member of the University of Manitoba (U of M), I assisted in offering mentorship and capacity building opportunities in qualitative research methods for members of the Belize Diabetes Association (BDA) and others helping with the project in response to local interest.

2.2 Paradigm, Design, and Methodology

The study arose from a pragmatist research paradigm in that it prefers to transcend the quantitative-qualitative paradigm binary, to be skillful with all the tools in the research toolbox, to have the ability to discern the correct tool for any given job in order to be purposeful and useful research (Creswell & Poth, 2018; Feilzer, 2010). My design was qualitative (while attached to the larger quantitative study though functionally independent) as it sought to understand peoples' perspectives and experiences of diabetes and health services (Creswell & Poth, 2018). The study methodology was primarily *Constructivist Grounded Theory* while seeking to also apply an *Interpretive Phenomenology* lens for increased depth and supplementary understanding.

Charmaz (2011) described Constructivist Grounded Theory as using a critical lens to examine how power works within and through societal constructions, institutions, and processes, and applying that understanding to social justice issues such as barriers to care, health inequity,

and poverty-induced disease with the intention of addressing the sequelae, namely, the imbalanced distribution of suffering across the populations in focus (Charmaz, 2011). This methodology required me to ask about, rather than make assumptions about, the meanings people make of their experiences, to embrace a multiplicity of perspectives, and to remain diligently aware of nuance while continuously reconsidering concepts that emerged from the data (Charmaz, 2011). It allowed for local people to inform and construct the theory of what is happening in their lives with their collective lived experiences (Charmaz, 2011). The research questions about barriers to care and everyday struggles of living with T2DM matched best with Constructivist Grounded Theory given its interest in equitable services while the research question about spiritual practices for coping and overcoming difficulties fit best with IP given its interest in human experiences of disease.

Interpretive Phenomenology is interested in consciousness and the ways in which humans experience it day-to-day, directing it with intentionality (Hesse-Biber, 2017). The questions of how people experience their health conditions, perceive different health care settings, and make meaning of interactions with health care professionals were all phenomenological in nature, requiring attention at the level of awareness of embodied sensations, cognition, and interpretation (Hesse-Biber, 2017).

The initial Constructivist Grounded Theory-related questions about structures as helpful or as barriers led to the Interpretive Phenomenology -related questions, such as about the psychology of acceptance of chronicity, or the power of building determination to follow health-affirming practices through prayer, or what rebuking negativity in interpersonal conflict feels like. Using Interpretive Phenomenology necessitated going further than being descriptive, as it

elicits lived experiences as a mindfulness practice, as a philosophy, and as a research method inclusive of consciousness within the interviewer-interviewee interaction in moment-to-moment detail (Wimpenny & Gass, 2000). As the interviewer, remaining present and connected to the respondent throughout the interview process was essential, as was active listening, reflective clarifying, and following up on dropped conversational threads led to a greater depth of understanding the phenomena (Hesse-Biber, 2017).

Constructivist Grounded Theory and Interpretive Phenomenology are often used together without the recognition that this is the case through *mudding*, *slurring*, or *blurring* (Wimpenny & Gass, 2000). Mudding refers to when the two methodologies are mixed without any acknowledgement this is happening, slurring refers to an explicitly pragmatist approach that requires a variety of tools, and blurring refers to when there is no one defined methodological approach clearly identified (Wimpenny & Gass, 2000). This study was pragmatist and sought to be explicit about using primarily Constructivist Grounded Theory yet including philosophical underpinnings and methodological understandings from Interpretive Phenomenology (particularly for the understanding of spiritual practices). While the distinction is relevant in philosophical discussion and to academic texts, it is less so in practice (Wimpenny & Gass, 2000). The core work is similar, and in practice, both Constructivist Grounded Theory and Interpretive Phenomenology use interviews as a primary data collection method, requiring the same techniques of reflection, clarification, request examples, request descriptions, conveying interest, and active listening (Wimpenny & Gass, 2000). Constructivist Grounded Theory uses all types of interviews (formal, informal, structured, unstructured) while Interpretive Phenomenology tends to use structured, in-depth interviews, but there is a lot of cross-over in the

literature (Lin, 2013; Wimpenny & Gass, 2000). I used semi-structured in-depth interviews which were matched with both Constructivist Grounded Theory and Interpretive Phenomenology theoretical understandings. Phenomenology tends to borrow its system of organization in data analysis from Grounded Theory (Lin, 2013). I used Constructivist Grounded Theory in the data analysis phase.

While my research proposal included a second visit to Belize with a second iteration of questions as per Constructivist Grounded Theory methodology, the covid-19-related travel restrictions made this international travel impossible. If a follow-up trip would have been possible, I would have used more Interpretive Phenomenology in the next series of questions. I will provide here an example where this theory would have been an excellent guide. In most of my interviews when people acknowledged using spiritual practices for coping with T2DM and for better health, I asked about those practices (e.g., prayer, meditation, referring to sacred texts). In a second iteration of questions, I may have asked more deeply Interpretive Phenomenology questions, such as: How do you feel when you are praying? Do you feel close to God? When do you feel God's presence? What sensations arise when you feel that way? Can you express how this affects your body, your wellness, or your health? This line of questioning draws not only from Interpretive Phenomenology theory but also from reflections on encountering the sacred in psychotherapy and interviewing skills (Griffith & Griffith, 2002). While not all interviewees were articulate in these areas, there were certain participants and key informants who were leaders in their spiritual communities (e.g., Garifuna, Methodist, Roman Catholic) whom I feel would have been receptive to this. Therefore, under different circumstances, returning to Belize with a second, deeper iteration of questions would have been excellent, to honour the potential of

a more fulsome Interpretive Phenomenology exploration.

2.3 Ontology, Epistemology, and Theoretical Framework

According to Charmaz, the Constructivist Grounded Theory ontology upholds that there is one ultimate, objective truth while also validating that human experiences and interpretations of reality happen in relative, complex, and continuously changing ways (Charmaz, 2011).

Epistemologically, this theory understands knowledge and ideas to emerge directly from the data that participants provide to the researcher, and it is unique compared to other research frameworks by requiring the data to lead and precede the literature review (Hesse-Biber, 2017).

The researcher conducts the literature review after the data collection and data analysis phases, fitting the study into a broader academic context at its near-completion stages rather than its beginning stages (Hesse-Biber, 2017). This helps to avoid over-emphasizing the verification of pre-existing theories and to bring an open, unassuming mind to the project (Charmaz, 2011).

However, it is justifiable in Constructivist Grounded Theory (and in Interpretive Phenomenology) to have read relevant literature prior to commencing the data collection as long as, when interviewing, one practices mindfulness, unknowing assumptions, bracketing, the suspension of preconceptions and presuppositions, and other appropriate techniques to the greatest degree of qualified naiveté possible (Hesse-Biber, 2017; Kvale, 1996; Wimpenny & Gass, 2000). Guided by my chosen paradigm and methodology, I acknowledged my previous experiences and learning in relation to the research topic, I proceeded with reflexivity, and I conducted the literature review iteratively with the cycles of data collection and analysis.

Theoretical sampling is a term that refers to Grounded Theory's approach to inviting and recruiting people into the research, allowing space for the story that respondents want to tell to emerge, and using this to directly inform new theoretical constructions (Charmaz, 2011, 2014; Hesse-Biber, 2017). While as a researcher I consider Critical Race Theory, Feminist Theory, Queer Theory, Anti-Colonial Theory, and other anti-oppression theories to be potentially very relevant and important to eliciting minority knowledges in this study, my task was to remain as open-minded as possible to what theories the participants themselves are constructing (Charmaz, 2011, 2014; Hesse-Biber, 2017). My personal preference for an anti-oppressive theoretical framework was not entirely absent considering the intention to recruit participants for the fullest expression of diversity as possible (including diversity of race, class, gender, age, sexual orientation, etc.); however, the recruitment was completed by the local research coordinator and local stakeholders through word-of-mouth, thus resembling snowball sampling more than theoretical sampling as was intended. This fact influenced who participated in the study and therefore the data generated. Further, the theoretical framework of Constructivist Grounded Theory includes constructivist philosophy, accepting that human knowledge is born of how we interact with the world and our reflections on our experiences (Charmaz, 2011; Hesse-Biber, 2017). My role as a researcher, my positionality, and my process of reflexivity were thus also important which is why these elements are discussed in the subsection 2.9 Researcher's Role, Positionality, and Reflexivity.

2.4 Approach

The approach to this study and its larger program was community-minded with the desire

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to be useful and of service to the people and communities involved. Dr. Hatala and I offered an optional capacity-building component to local stakeholders (such as members of the Belize Diabetes Association, Health Educators, and the Toledo institute for Development and Environment (TIDE)). People interested in developing their skills for qualitative research were invited to a three-session online training in August 2020. These workshops acted to build the vision, relevancy, and capacity for qualitative research in Belize.

The sessions introduced people to the principles, purposes, concepts, and technicalities of qualitative research, as well as interviewing skills, ethical considerations, and cultural safety. The interview guide and its questions were discussed and reviewed with the Belizean trainees for relevancy and cultural appropriateness. These workshops helped me to solidify my learning through sharing the research process and findings, to continue my learning through dialogue with trainees, to maintain my relationships with local stakeholders, and to establish new relationships. The sense of building a research team was an exciting step toward engaging communities to amplify the voices of Belizeans to inform policy domestically and to communicate with the global community on learnings toward slowing the spread of T2DM.

Dr Hatala and I have offered the local stakeholders additional trainings in future on topics including transcription, analysis, creating knowledge-products, and knowledge translation. We have continued to provide qualitative research training support on an ongoing basis throughout this process as the Belize Diabetes Association, the Ministry of Health, and other stakeholders look to increasing their research capabilities. We are planning for future opportunities for trainees to be involved knowledge translation and dissemination of findings through conferences, reports, publications, community gatherings, and any other informal and formal venues of information

sharing generated through the larger mixed-methods project.

2.5 Participants

The intended population of focus was originally decided by the Steering Committee for the Belize National Diabetes Self-Management Programme. They wanted to focus on adult Belizeans with T2DM who are not suffering from major complications (e.g., blindness, amputation, renal failure) between the ages of 18 to 60 who were diagnosed within the past 5 years. I did not restrict my study's eligibility criteria exactly to that of the Programme's research protocol. I justified this in many ways. Firstly, the research coordinator and I decided that it was important that I pilot the interview question guide with as diverse a population as possible. This contributed to significant additions and amendments to the original interview question guide, making it more relevant, comprehensive, and culturally safe for future use.

Secondly, the Programme had originally intended it to reach across the entire country. Later, the Programme's Steering Committee had to change that decision to include only patients registered in the National Health Insurance (NHI). This was because these patients would already be monitored for their A1C blood glucose test, and the project could access that existing data rather than pay for expensive blood tests or run into data gaps. The limitation of this decision was that unregistered patients who were more likely to not be receiving adequate care were no longer included, despite that they may have been in worse condition than NHI patients. With the decision to use only NHI patients, the Programme could no longer be touted as a national study⁸.

⁸ This is because NHI does not cover 25% of the population of Belize (MoH et al., 2018).

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On the other hand, it enabled the Programme to proceed. I, however, did not exclude anyone who did not have NHI, enabling me to hear from underserved areas.

Thirdly, while excluding Type 1 Diabetes is an acceptable criterion because it is a distinct disease, using the criterion “without co-morbidities” was too vaguely defined. We discussed this issue at a meeting at the NHI office. Identifying as “without co-morbidities” did not necessarily mean a participant did not have any organ damage (e.g., participants may not necessarily know their statuses at the point of study enrolment, doctors may not have up-to-date test results). Further, there was ambiguity around how co-morbidities was being defined. Therefore, I did not exclude anyone based on this criterion.

Fourthly, the Programme’s age inclusion criterion was too narrow because many diabetes patients are over sixty years old, and they have valid and important insights to share. The Programme’s stated purpose for the age criterion was to focus on those young enough to prevent complications and exacerbations through the educational intervention component of the research. Their theory of change was that those younger and more recently diagnosed were more likely to uptake the education and make behavioural changes needed for successful self-management. With the Programme’s capacity reduced due to covid-19 restrictions, the education component was no longer be possible, thus the criterion was no longer useful. I did not exclude anyone by age or years since diagnosis.

During a meeting at Ministry of Health, I became aware that they understood the purpose of the qualitative part of the larger mixed-methods study to be evaluating the impact of the educational component of the Programme. My study provided exploratory context to inform the

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Programme, rather than an impact evaluation of an education intervention that has yet to happen. The covid-19 restrictions shifted but did not negate my study's purpose and sample. Further, the Belizean qualitative research trainees are continuing to expand the sample for the larger study. Thus, the rationale for my eligibility criteria was discretionary, as I did not want to exclude people, especially if they were motivated to participate. Qualitative studies tend to use the concept of data saturation more than have a pre-set sample size. The latter is a more of a quantitative research concept, though more important to qualitative researchers in mixed-methods studies. The Programme had pre-set a sample size and eligibility criteria, but these enrolment goals were a work in process.

Snowball sampling (Hesse-Biber, 2017) was used, starting with the local research coordinator, health care administrators, Health Care Providers and Belize Diabetes Association offices. The research coordinator arranged for five interviews with people in their own homes. With the facilitation of the NHI office and Punta Gorda Polyclinic personnel, I conducted two interviews in that clinic. The Belize Diabetes Association arranged for three interviews in their Belize City office, and another interview occurred after a Belize Diabetes Association meeting in Dangriga at the Red Cross building. There were more interested potential interviewees, but my study was limited in its sample size due to numerous cancellations under covid-19 restrictions including travel into Belize for follow-ups and a second round of interviews.

Our trainees have conducted another eight interviews for the larger project. My final sample was eleven people (8 women, 3 men) between the ages of 30 to 90 including one person with partial blindness due to an occupational injury whose wound-healing has been complicated by diabetes. Participants were from four of the six districts of Belize, namely Toledo, Stann

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Creek, Cayo, and Belize City, representing people of Creole, Garifuna, and East Indian heritage. The sample was lacking Mayans, Mestizos, minorities, and people from the Corozal and Orange Walk districts, which is further discussed in the section on limitations. For a breakdown of participants by pseudonym, town, district, ethnicity, gender, age, and occupation, see Table 2.5 below as well as in the *Summary of Participants* in Appendix 1.

Table 2.5

Summary of interviewees

	Pseudonym	Town, District	Ethnicity	Gender	Age	Occupation
1.	Isabella	San Ignacio, Cayo	Garifuna	W	80s	Retired teacher
2.	Felicia	Mount Hope, Cayo	Creole	W	50s	Wife/Mother
3.	Rosa	Punta Gorda, Toledo	Garifuna	W	60s	Shopkeeper/Minister
4.	Cynthia	Punta Gorda, Toledo	Creole	W	60s	Retired Nurse
5.	Henry	Elridgeville, Toledo	East Indian	M	50s	Labourer
6.	Meera	Elridgeville, Toledo	East Indian	W	40s	Housekeeper
7.	Josefina	Dandriga, Stann Creek	Garifuna	W	60s	Grandmother
8.	Maurice	Dandriga, Stann Creek	Garifuna	M	40s	Retired military, Barkeeper
9.	George	Belize City, Bz	Garifuna	M	60s	Surveyor
10.	Yvonne	Belize City, Bz	Creole	W	50s	Retired supervisor
11.	Natalia	Belize City, Bz	Garifuna	W	30s	Legal secretary

The key informants who were consulted in person included personnel at the National Institute of Culture and Heritage (NICH), the Ministry of Health (MoH), the National Health Insurance (NHI) office, the Belize Diabetes Association (BDA) (in its Punta Gorda, Dangriga, and Belize City offices), the Punta Gorda Polyclinic, the Independence Health Authority, the San Antonio Clinic, and the University of Belize (U of B, Punta Gorda campus). Key informants

during my trip included doctors, nurses, home care workers, Community Health Workers, Health Educators, health directors, health administrators, the research coordinator, the data entry specialist, friends of informants, neighbours of informants, restaurant owners, and community elders. I met with additional informants through online meetings, including more Belize Diabetes Association personnel, qualitative research trainees, and representatives of Indigenous health organizations.

2.6 Data Generation

A primary qualitative method was interviewing people with diabetes, though site visits⁹, discussions with key informants (in person and online), participant observation, and field notes were also used. The interview questions were based on the Diabetes Quality of Life Questionnaire, although I modified it to include feedback and additional questions from the Steering Committee, stakeholders, and study participants. It was used as a conversation guide in semi-structured interviews (Hewitt, 2007; Liamputtong, 2007). See amended *Qualitative Interview Guide* in Appendix 2. All participants' first language was English, which, as a former British colony, is the national language of Belize. Most Belizeans are bilingual, speaking a diversity of maternal languages at home. The Belizean Kriol and the Garifuna¹⁰ dialects influence the language, apparent in the interview excerpts I included in this thesis.

⁹ Site visits included meetings at the offices of National Institute of Cultural Heritage, Ministry of Health, National Health Insurance office, Belize Diabetes Association (Punta Gorda, Dangriga, Belize City locations), Punta Gorda Polyclinic, San Antonio Clinic, administration offices (Punta Gorda, Dangriga, Independence, Belmopan), University of Belize, and in community.

¹⁰ The Garifuna language was officially esteemed as a treasure of the intangible heritage of humanity by the United Nations in 2001 (Ellis, 2010a).

Interviews took place during my 14-day research visit to Belize in February and March of the year 2020 in clinics, community buildings, and homes. No participants had to travel for the interview. I drove myself, the research coordinator, and the data entry specialist to numerous relevant locations across Belize for project meetings and study interviews. Informed consent discussions were performed prior to each interview and consent forms were signed each time. Interviews lasted between 20 and 60 minutes depending on how much the person was inclined to share and talk. The entire research process was explained to participants to the detail required by the University of Manitoba Ethics Review Board including data usage, decline and withdrawal, data storage, privacy, and confidentiality measures. The interviews were audio-recorded with prior participant permission.

I generated eleven interviews in my first trip before covid-19 travel restrictions disrupted plans for a second visit. Through discussions with my advisor and the research coordinator, it was decided that the data from the trip was rich enough to proceed into analysis, and that by going ahead, my study would facilitate the larger project to also continue moving forward. Despite the challenges around the pandemic and mobility restrictions to protect public health, this decision acknowledged the importance of continuing to address diabetes and other chronic diseases. While it was sometimes tricky, for example, to meet with key informants who were busy with all the work of pandemic prevention planning, tracking, and response, both data generation and analysis phases of the study were facilitated by the fact that stakeholders became more accustomed than ever to having meetings through online forums rather than in person. Through ongoing virtual meetings, key informants and stakeholders have continued the discussions surrounding this work with myself and the rest of the research team. I have drawn on

information shared in the online meetings between March and October 2020 to further inform my study.

2.7 Data Analysis

I transcribed the 11 interviews using verbatim oral-to-text word processing, incorporating any relevant body language and emotional responses noted by the interviewers and facilitators in the memos, as per Hesse-Biber (2017) and Liamputtong (2007). One shortcoming of transcription to text was the inability to fully capture how much people smiled, laughed, and seemed to shine as they told their stories. Though I offered the option to keep their names with their stories during the informed consent discussion prior to interviewing, there were no participants who indicated this preference. All participant information was de-identified.

All recordings and computer files were kept in a secure and confidential manner. I entered interview transcripts, corresponding memos, and field notes into the computer software program entitled Dedoose, then I coded the data into themes and subthemes as these emerged. I checked with my supervisor (Hatala) and the research coordinator (Ellis) as these themes developed into a foundation for this work¹¹. Data was analyzed line-by-line and paragraph-by-paragraph, attending to all the possible underlying meanings of what was said, portrayed, and assumed, (Hesse-Biber, 2017). Literal codes, focused codes, and analytic categories were used in a systematized order, analyzed for emerging themes, descriptions, meanings, patterns,

¹¹ We wrote a book chapter together that helped to solidify the direction of the thesis.

comparisons, interesting ideas, and assertions through the Constructivist Grounded Theory framework, keeping the human story central to the work of analysis, in accordance with Charmaz (2011). I applied code names derived from verbatim expressions, verbs, actions, and processes rather than descriptors or nouns to enhance and prime the analysis work (Charmaz, 2011, Hesse-Biber, 2017). I used verbatim expressions and phrases to name the codes and main sections of the results whenever they emerged as of primary importance (Charmaz, 2011).

Throughout the coding phase, memo-writing was used to help me to connect, percolate, and set down ideas so that I could be free to move forward through the discovery without staying attached to holding one idea, as per Charmaz (2011). I engaged in vigilant self-questioning throughout to be sure to honour the essence of the participants and their stories and not stray far from their words. I engaged with the sense of actively listening to the data in the analysis phase, just as I had actively listened in the participants in the data gathering phase, consistent with Hesse-Biber (2017).

All the gathered experiences and perspectives were considered valid (Charmaz, 2011). I understood the differences between people's experiences as important and looked for potential interpretations. Constructivist Grounded Theory and Interpretive Phenomenology were appropriate methodological foundations because they center people as experts of their own lives, so I was able to learn directly from those living with diabetes. The trustworthiness of the analysis was ensured through: 1) Discussion with Belizean stakeholders; 2) Reflexivity and integrity as continuous practice; 3) Asking how does each part of the decision trail impact participants; 4) Asking if the emerging theory and story makes sense in context; and 5) Looking for the negative cases that disprove or alter emerging theories, as per Charmaz, (2011) and Hesse-Biber (2017).

2.8 Ethical Considerations

The study occurred within a context of community engagement and research relationships since 2011 for my advisor Dr. Andrew Hatala, and since 2000 for research coordinator Wuri Lucia Ellis. The study included engagement with numerous partners in Belize, and this helped to ensure that the spirit and intent of the research project were aligned with community well-being and that it will not result in any harm or rejection. All interviewees were fully informed about the purpose and scope of the research, as well as the nature of their potential involvement including all the features that might reasonably influence their willingness to participate. They were informed that they could decline the study and/or stop their involvement at any time without penalty, that they could decline any question they were uncomfortable with or did not wish to answer, and that data would be kept strictly confidential. Participants were given the option to have their real names stay with their contributions as this can transmit a powerful sense of their ownership over their stories; however, no one chose this option, so participants were randomly assigned pseudonyms from a list of the one hundred most popular names in Belize. The consent forms that were used to guide the informed consent discussions can be viewed in Appendix 3.

Full prior informed consent of participants was given for data to be used only for the purpose explicitly given consent for. Data was kept on one password-encoded laptop in a locked office. There were no anticipated risks associated with participation. Participants understood there was no monetary compensation for them despite that being the original intention. The issue

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of compensation was discussed with the local research coordinator who was concerned that paying people to participate would jeopardize future local research initiatives, creating an expectation where it currently did not exist. The concern was that it would be hard to sustain similar compensation in the future, and this would privilege international researchers over local researchers. There was also some concern over personal safety issues in distributing monetary compensation, so this intention was abandoned. There was no cost to the participants to be in the study. They were given small tokens of appreciation, namely each person was given a magnet with Indigenous art from Canada. The benefits for participants included the opportunity to explore their thoughts and feelings on living with diabetes, and to tell their stories. Interviewees often communicated their strong desire to participate and their enjoyment in discussing these impactful aspects of their lives.

The University of Manitoba Human Research Ethics Board (HREB) approved the larger study, with my name listed as a researcher and interviewer along with Dr. Hatala, in the months prior to it proceeding under the name *Belize Diabetes Self-Care Management Program; A Qualitative Exploration* (HS23313 (H2019:406)), and the program director confirmed permission to have me pursue the study at that time. I had to also submit another application to the HREB as a master's student. This was officially approved in May under the name *Informing Diabetes Services Through Patient Perspectives in Belize* (HS23931 (H2020:229)), linked to the above but specific to my master's student status. Developments for a research ethics board in Belize are underway, however there is no such organizational body at the time of publication. The decisions of the Steering Committee and collaboration with numerous local stakeholders helped to ensure the study was ethical and appropriate in the context of Belize.

While I intended to send each participant a version of their transcript to provide the opportunity to make deletions, additions, and/or revisions, most interviewees did not have access to a computer and internet. I could no longer hand deliver them, given the covid-19-related travel restrictions. Therefore, I consulted with my advisor and the research coordinator so that we could consider the transcriptions together to ensure their quality and the meaning of culturally specific concepts. I regret not getting people their copies of their transcripts. This was difficult because I realized when I was already in process that most of my interviewees did not have email addresses. Many did not have phone numbers either. I could have thought to ask for mailing addresses, but the feasibility of that possible course of action was low too, considering that mail delivery was made especially unreliable with covid-19 restrictions. Canada Post suspended delivery to Belize. Belizean airports and shipping ports were closed, and shipping port workers went on strike when reopening was planned, so there was concern that I would be waiting for a response for a long time to no avail. For some people, I believe the review and editing of documents would have been difficult, particularly those with limited computer access, poor eyesight, and/or lower levels of education. Though not without personal consternation, with the support of my research team, the decision was made to carry on with the research process into the coding phase and not to wait for an opportunity to distribute and retrieve the transcripts. I believed this pathway to be more ethical than excluding people from the study who do not have access to email or choosing to not use interviews from people without email addresses.

2.9 Researcher's Role, Positionality, and Reflexivity

It is important for any researcher to situate themselves in the research, to identify their role as researcher, and to examine their influence in the research process (Hesse-Biber, 2017). I used persistent self-reflection throughout all study phases to find insights into how my positionality may have affected things like what knowledge was shared with me, how I interpreted it at the time of sharing, how I analyzed it later (Hesse-Biber, 2017; Hewitt, 2007; Liamputtong, 2007). I kept a highly detailed reflexive journal throughout the project. I included only a few of the most pertinent details here.

I am a non-Belizean, experienced by participants as an outsider and foreigner. I am aware that community members sometimes perceive outsiders as less trust-worthy because they do not understand the realities of living in the place; however, people sometimes see outsiders as safer to talk to because they are not embroiled in local politics and interpersonal conflicts (Hesse-Biber, 2017). To mitigate my status as an outsider from Canada, I worked closely with the Belizean research coordinator and community liaisons to continuously check in about all aspects of my work and the project developments. I felt accepted by participants because I was aligned with the local research team members. I was transparent about my positionality, purpose, and methodology as I built rapport with participants, and I gave them time and space to decide whether they wanted to participate or not. I deliberately sat beside or below the participants during interviews, without a desk between us whenever possible, to position them as experts in their own lives, and to disrupt the perceived and/or real power imbalances between us.

In some cases, my outsider status may have been an advantage, as I asked questions that a local researcher may have not felt they needed to, about subjects local researchers may have felt is common knowledge. During the capacity building workshops, we compared the text of different interview transcriptions, and Lucia commented that I asked more questions than Belizean interviewers. That said, I am also aware that there are tiers of knowledge (e.g., spiritual rituals particular to belonging the Black community, trauma related to anti-BIPOC¹² racism, etc.) beyond what it was appropriate for me to ask about. A Black or Indigenous researcher would have different access to these topic areas and communities.

I am a white Canadian woman with European settler ancestry, working to become an always-improving ally to the BIPOC community. Working to dismantle the destructive constructs of white supremacy is essential to overcoming racialized forms of oppression and realizing social justice goals such as health equity (DiAngelo & Dyson, 2018). I persisted in diligently practicing mindfulness so as to not contribute to perpetuating what I seek to change. I deferred to my Belizean counterparts for decision-making matters throughout the study, I made myself of service whenever possible, and I prioritized participant safety, comfort, and empowerment in the interviews. I acknowledge that it remains an enormous privilege to be earning a university education and that I have benefited from white privilege in these endeavors. I sought to use the power available to me to amplify the voices of BIPOC people in this work.

¹² The term BIPOC refers to Black, Indigenous, and People of Colour as a collective.

I do not have diabetes myself. In my professional life, I worked as a midwife-apprentice to screen, test, diagnose, and treat gestational diabetes, in consultation with obstetricians and endocrinologists. Personally, my grandmother (and namesake) lost two siblings to insulin-dependent diabetes. Her sister died of diabetes complications in childbirth as a young woman. Her brother died of the compounded co-morbidities of alcoholism and diabetes, passing the latter on to his children and grandchildren. Through knowing these family stories, knowing that diabetes is in my bloodline, and as a mother and community caregiver, I have become invested in disallowing this preventable disease.

Religion and Spirituality emerged as a major theme in this work. I grew up in a non-religious Protestant household. I do not consider myself Christian; my own spirituality draws on several sources, including Vipassana (Buddhism), Anishnaabeg ceremonies (Indigenous to where I live in Manitoba), and Judaism (through marrying into a religious Jewish family). When I discuss religious beliefs and spiritual practices relayed to me by participants, it is for the purpose of informing the effect on their health and health care. I do my best to relay what was shared with me without having to agree/disagree, promote or dispute anyone's spiritual beliefs.

As research with marginalized groups is a privilege that requires sensitive and thoughtful navigation of inclusion, validation, and celebration of voices, I strove to honour this principle in my work through practicing very careful listening. I listened attentively to underlying emotions, to body language, and to what was spoken or perhaps unsaid in interviews. I listened, during the slow and cautious transcription and analysis phases, to what was at the heart of each person's story, and to the meaning of stories held collectively (Hesse-Biber, 2017; Hewitt, 2007; Liamputtong, 2007). I consider it an honour and a privilege to do this work of listening to the

voices of the participants in this study. I am grateful for the diverse, honest, and soulful words they shared with me.

Chapter 3: Results

Asking people questions about living with T2DM in Belize led to many answers, as well as to more questions; these are outlined in the areas for future research in the discussion chapter. The key informants and interview participants provided a wealth of data. Once their words were transcribed, coded, categorized, and analyzed, major themes emerged. Subthemes were organized within the major themes. When a subtheme arose only rarely and/or outside of a major theme, it was not explored as deeply as those which were most common. For the sake of the purposes and parameters of this thesis, I am therefore focusing on three main themes. These themes are: A) Daily struggles and health barriers faced by those living with T2DM, B) Spiritual practices for overcoming the struggles of living with T2DM, and C) Plant medicines and geographies that promote health and empower T2DM self-management. See Table 3.0 for a summary of the main themes and subthemes of the results.

Table 3.0

Summary of results

	Subthemes				
Theme A Struggles & Barriers	A tiered health care system	Difficulty communicating with HCPs	Diagnosis & complications	Need for education & prevention	Need for social support
Theme B	Building determination	Spiritual stress relief		Prayer as a way of life	

Spiritual/ Religious Practices that Help			
Theme C Plant Medicines & Geographies that Empower Self- Management	Home as a domain of personal power	Sacred sites and healing relationship to land	Pervasive usage of local plant medicine

Under Theme A, the struggles and barriers that were discussed by participants included health equity issues arising from a health care system that is tiered; Difficulties in communicating with Health Care Providers; Psychological and emotional setbacks that come with diagnosis and complications; The need for increased education and prevention efforts; and, The need for social support for those living with T2DM. Theme B emerged from participants sharing a central strength, namely, their spiritual practices. These included fasting, observing Lent, and praying to help build determination and commitment to healthy lifestyle choices for T2DM self-management; Referring to sacred texts, praying, and meditating to provide relief for both inner tensions and external stressors which could otherwise exacerbate the condition; and, Numerous types of prayers are regularly employed to help with T2DM and chronicity. Under Theme C, participants discussed their relationships with power domains found in geographies that stimulate self-management. These subthemes include how people engage in spiritual practices daily at home where they are in the domain of their own personal power; How neighbourhoods can be constructed to promote health within the power domain of the

community; and how using the local plant medicines is a culturally-embedded way of engaging with the land that also keeps the the power domain in the community.¹³

3.1 Daily Struggles and Health Barriers

The first theme describes some of the difficulties faced by people living with diabetes in Belize. These barriers acted as frustrating obstacles and oppressions that deter people from seeking medical help and weigh people down, exacerbating the disease. People had difficulty reliably accessing affordable care and treatment. They often experienced poor communication with physicians and have difficulty getting adequate information. Things got worse for people when they received a diagnosis they were not expecting or could not accept, and when their diabetes led to debilitating complications. Participants were passionate that more prevention and education needs to be done across the country so that people know how to protect their health before it deteriorates. Further, they wanted social support for those struggling with T2DM. Though there was at first some hesitation on the part of some participants to be perceived as complaining and some reluctance to perceive things critically or negatively, when asked in a few different ways, people would come to describe their challenges with clarity, insight, and valuable analysis. See Table 3.1 for a summary of the daily struggles and health barriers.

¹³ Past tense is used throughout these chapters to acknowledge that I met participants at a certain point in time and their views may have changed since then.

Table 3.1

Summary of daily struggles and health barriers

Tiered health care system	Difficulty communicating with Health Care Providers	Diagnosis & complications	The need for education & prevention	The need for social support
<p>NHI does not cover everyone</p> <p><i>"The Ministry should have more NHI that people can go. Because a lot of people want NHI, and they cannot."</i></p>	<p>Fear of asking questions</p> <p><i>"I always want to ask her [why she touches my feet], but she's so delicate, you have to think what you asking her. Yeah, but always she put her hand here But she doesn't tell me anything, she just do it"</i></p>	<p>Diagnosis as life-changing, physically & socially</p> <p><i>"I think back to the way I used to before. Now my body change, my lifestyle change, everything change."</i></p>	<p>Need for education on self-management strategies beyond increasing dosages of pharmaceuticals</p> <p><i>"They're taking this insulin, and next month they're taking another dose, and next month they're taken another. ...There are a lot of things they could do for themselves."</i></p>	<p>Sense of belonging to one's culture linked to unhealthy food choices</p> <p><i>"I slow down from a lot of the food in my culture... in our culture there's a lot of white rice."</i></p>
<p>Public clinics have long wait times & medication shortages</p> <p><i>"Because sometimes I go and it's a lot of patients to wait for...sometimes they don't have the medication too."</i></p>	<p>Deterred by HCP anger</p> <p><i>"She's so mad, and whoo! And I think that is wrong for people who are sick. Especially diabetics cause sometimes, I don't want to go."</i></p>	<p>Experiencing frailty & vulnerability</p> <p><i>"Diabetes is not a good feeling. When I first felt it, I thought it would be the end of me cause I started feeling bad. I'd get dizzy. A lot of negative things come my way."</i></p>	<p>Need for nutrition, fitness, & educational programs</p> <p><i>"That would be good if we had more support groups and different programs toward this diabetic thing, no? So, we could learn more about it."</i></p>	<p>Need for friends & family to support & engage in healthy food choices & exercise in solidarity</p> <p><i>"I think that is my problem because my buddy, she has abandoned me... Her and I used to go walk. We used to do everything...Exercise isn't easy. It's a commitment."</i></p>

<p>Many cannot afford dentistry, foot care, eye care, dialysis, medications, or surgery</p> <p><i>“No, that doesn’t come under the NHI. I would have to like, personally go. I know with the diabetes it affect your teeth and your gum.”</i></p>	<p>Need for HCP active listening & clear explanations</p> <p><i>“They don’t listen to the patient. Or explain what exactly is the problem.”</i></p>	<p>Experiencing shock & denial</p> <p><i>“I was in denial for almost six months before I accepted this.”</i></p>	<p>Need for prevention to reach youth & remote villages</p> <p><i>“It hurt me bad. I could have done better back then. Nobody educate you, so I wish they would educate people now...The people in the villages, when they sick bad, some of them don’t have access to come out...[Health care should] take time, spend all the money, go to meet the people in the rural villages, meet the old people, the young people. Go to the schools.”</i></p>	<p>Social life impacted as person becomes default educator</p> <p><i>“When I talk to them, I tell them about my situation because some of them look at me and say, Man! You’re looking different. You reduce your weight and all these things. So, I tell them my sickness, I have diabetes. I had to lose weight to help my health.”</i></p>
<p>Private clinics expect direct payment from patients</p> <p><i>“They told me to wait for the next three months or something like that, that they will call me... I suspect that they wanted a bribe, for me to pay personally...They never did call me up.”</i></p>	<p>Need for medical information upfront</p> <p><i>“I actually went back to the hospital and asked for an appointment with a regular doctor...And I sat with him (while he was on the phone), and at the end of the conversation, he went, Oh, here’s a paper, this is good. And it</i></p>	<p>Complications as loss of vitality & self-worth</p> <p><i>“We have people, diabetics, who are confined to their homes, maybe they are amputees... Looking at themselves, it’s very hard. Sometimes they go depressed. Very bad, depressed.”</i></p>	<p>Need to counter myths & stigma to increase knowledge & testing, especially in men</p> <p><i>“In Belize, the first thing come from people, oh, you have AIDS! ... No, diabetic. Sometime the men, you see them. They think hard, and they know they are diabetic, but ...you know (they don’t get tested).”</i></p>	<p>Mothers self-sacrificing & prioritizing children</p> <p><i>“My youngest child was four at the time, so it was hard. I had four, seven, and fourteen-year-olds, and it was difficult. So, because of that, I think in the early years, I did not keep the diet as I was supposed to.”</i></p>

	<p><i>actually told you what you could have, what you should avoid, and what you should have. But if I did not go back, how would I have known that?"</i></p>			
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3.1.1 “People who can afford it”: A tiered health care system

One of the subthemes that emerged from the study was the issue of affordability and accessibility of health care. Participants were differently equipped to access T2DM management and treatment, depending largely on their economic status. Those with the resources to do so often chose to pay directly for private clinics, brand name prescriptions, herbal doctors, home care, massage therapy, gym memberships, and other wellness supports. Those who could not afford these items suffered more long, drawn-out complications. This is in part due to the way that the health care landscape in Belize is a tiered composition of private, semi-private, and public clinics, supplemented by random injections of international volunteer projects and supports from relatives who live abroad (typically the United States). Further, there is also the important presence of the Belize Diabetes Association (BDA) providing medical supplies at reduced costs in certain locations.

The National Health Insurance (NHI) system (the public system in other words), has been rolled out since 2003 (Bowser et al., 2013). The NHI covers 75% of Belizeans for their health care delivery through primary, secondary, and tertiary institutions (MoH et al., 2018). However, Belize still faces several limitations in the provision of clinical services; for example, the NHI primary care responsible for diabetes screening and management only covers the south side of

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Belize City, the two southern districts (Toledo and Stann Creek), and Corozal Town (MoH et al., 2018). This leaves the other four districts (Cayo, Orange Walk, most of Corozal, and most of Belize District) and a lot of Belize City without NHI (MoH et al., 2018). Belize City is the most densely populated part of the country with the highest prevalence of T2DM, and this leaves numerous geographical gaps in the public system (MoH et al., 2018) Further, the demand for laboratory services, human resources, infrastructure, pharmaceutical supplies, and equipment has increased significantly over the past two decades, yet the system has failed to keep pace with this growing need (MoH et al., 2018).

Participants shared that even in the places that do have NHI clinics, there are waiting lists to get into the public system. Some interviewees shared their experience that a T2DM patient can lose their place in the public system if they miss their appointments or if they move to a place without coverage. Key informants suggested that people do not report their changes in address for this reason. Natalia, a working mother living in Belize City, said: “The Ministry should have more NHI that people can go. Because a lot of people want NHI, and they cannot. It’s hard. Cause not everyone has the finance to. They pay more attention to the cancer than the diabetes.”

Three of eleven participants felt they had all the care they needed. While some participants were happy just to be in the public system, others were willing to pay for private clinics. One reason is because the wait times to see the doctor are longer in the public rather than the private clinics. Josefina, a woman living in a 20’ by 10’ house with five other family members, preferred the private clinic because there were lower wait times and more reliable availability for medications. She responded: “Because sometimes I go here [the public clinic], and it’s a lot of patients to wait for. And sometimes they don’t have the medication too.” Some

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participants described going to the public clinic and finding it too busy to sit in the waiting room, and others complained about not finding any doctors present when they went to the clinic. One respondent, Maurice made a point of analyzing patterns of patient flow to avoid the public clinic's busy times. Another, Yvonne was not keen on going to any clinic. She said: "I haven't been there for a long time... anything else except them!" (laughing). When she absolutely needed to be seen, she preferred to go to a private clinic. Yvonne described the public clinic:

You wait long... Well, people who can afford [to go to the private clinics]. I'm not saying that the public system isn't good, it's good primary care. Apart from the wait. [At the private clinics] you get better medication than the public clinics. And you don't have to wait that long time. ... Like any public place, it's impersonal. You don't get that treatment of course, like if you pay money to the private doctor. It's okay. If you have to use it, you have to use... Do what you have to do.

There were negative perceptions about the quality and availability of T2DM medications through the public system. Felisha declared they simply did not work for her at all, reporting that this is a widespread experience, that brand name medications from the United States were superior to those made in Mexico or Guatemala, and that people who could not afford them preferred to use herbs or nothing at all having lost confidence in the pills. Felisha expressed:

I stopped take some of the medication, and I am taking my own herb... Cause they giving us some Metformin, and the Metformin have different colours in the medication, but they say only for the NHI. Well, people complain about it because it doesn't work. And for me it doesn't work either. I think they say they get it from Mexico or Guatemala or

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somewhere. Cause we used to get from America, the original. They don't want to give us the original... I have insulin at home, that is okay. The pill they give us, like three different pill, the colour is different. They are not working. They are not working... A lot of people complain about it... I go to the drugstore down the boulevard, and I get the one that I want. But the people who can't do that, they have to go with the same one that don't work. It don't work none at all!

Whether or not randomized controlled trials have been performed to confirm efficacy of the generic T2DM medications available to Belizeans, popular belief was that they do not work, and this impacted patient adherence to the drug schedule, thus further inquiry to address this issue is merited. Further, some people reported taking their medication less often than prescribed to save money. Similarly, people did not test their blood glucose levels regularly because the testing strips cost money.

Diabetes can have devastating impacts on multiple bodily systems leading to loss of eyesight, loss of sensation in the extremities leading to amputations, and deteriorating oral health, and this necessitates check-ups with specialists. Yet, many people do not have adequate access to optometry, ophthalmology, podiatry, or dentistry. Participants in most places mentioned having a hard time accessing dental care. In Belize City, for example, Natalia reported it was hard to access the dentist, "No, that [dentistry] doesn't come under the NHI. I would have to like, personally go. I know with the diabetes it affect your teeth and your gum." Josefina in Stann Creek indicated she really needed help with her eyes and her feet, but had not seen an optometrist in three years, nor had she ever seen a podiatrist, a diabetes foot care specialist, or dedicated foot care nurse. Most participants had never heard of specialized foot care in Belize

except Cynthia, a retired nurse. She stressed the importance of monitoring feet. She told of her experience nursing people with diabetes, “You told them, wear comfortable shoes, then they’re going out with slippers, and there’s no sensation. Something will hurt, and they don’t even know. By the time they found, it’s gangrene. So, they stress out.” Injuries, gangrene, and amputations could be avoided with monitoring the status of patients’ feet, so improving foot care is worthy direction to pursue across the country. Participants in Punta Gorda, in the south of Belize, typically reported no trouble getting T2DM-related optometry because the polyclinic had various types of clinical offices under one roof including an eye doctor. People reported satisfaction and appreciation of the polyclinic model in Punta Gorda. It is unclear how many people can access ophthalmology in Belize, but key informants indicated this is an issue in several places.

One participant had a distinctly challenging experience of the structural barriers around adequate eye care. George described undergoing a series of exams with a series of doctors with conflicting opinions, until eventually a visiting doctor from New York checked his eyes in Belmopan, the capital city of Belize, and asked him to go for surgery in Belize City the very next day. When he presented at the office the next day, he was turned away by the reception staff. He speculated that he was turned away because he did not offer a bribe.

He told me to come for surgery in Belize City the following day, so I could get my surgery here immediately. So, I went to the eye clinic, and when I went there, the pushing around started.... They told me my file wasn’t there... they told me that they weren’t going to operate on me because they didn’t have any file. They told me to wait for the next three months or something like that, that they will call me. ... I suspect is that they wanted a bribe, for me to pay personally...I explain to them, I do have a file here. I did

everything here. For years, I have a file here, and if they need information, they should be able to get it from Belmopan. They have the information, and they could do fax it. They could do whatever you want. They said no. Sometime in the next three months, they will call me. They never did call me up to now. And this was in 2011. Well, I didn't see the doctor from the U.S., the surgeon. I didn't see him...I hear somebody say it's about \$800 [to bribe them]. That's what I heard. If they do it, I don't know. I just, you know...I was waiting, then my eyes started to see worse.

George did not find the care he needed within Belize, and one doctor's opinion sent him to the neighbouring country of Guatemala to get the eye surgery he needed. He experienced complications through this process which exacerbated his vision loss. George relayed:

I ended up in an eye surgery in Guatemala, I did a follow-up here. I don't know what happened. My understanding is that the procedure here might have left a lot of dust or stuff in my eyes, and that's why it couldn't heal...The surgery went okay, but for like two years, 2013, it had some kinda stuff that the doctor here told me... It got worse... Yeah, I have to get another surgery. My eye didn't heal...They don't listen to the patient. Or explain what exactly is the problem.”

George's story speaks to the ways that there are direct, immediate, and serious impacts of being under-resourced while living with T2DM. People with more personal financial resources or perhaps social connections could have accessed better care domestically or abroad to avoid partial blindness. George continued to have difficulty accessing eye care and manages his life around his partial and increasing blindness. Felisha, on the other hand, had no problems with her

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vision but was worried about the sequelae that T2DM might have on her kidneys. She declared:

“I no rich already. If you no rich, you take care of yourself so you don’t lose your kidneys.

Because dialysis, look how much it costs for dialysis! You spend all your money, and you’re still dead.” Similarly, Maurice was concerned with the lack of dialysis machines in Belize. He answered: “I believe Dangriga needs proper dialysis machines. Well before I have this (diabetes diagnosis), I was working with that group that was trying to get a dialysis machine, and there’s been all kinds of problems.” Thus, the need for more optometry, ophthalmology, dentistry, foot care, and kidney dialysis machines are on people’s minds. Even the machines for monitoring T2DM blood glucose levels (glucometers) and their corresponding glucose strips, are difficult for many to afford. Cynthia, who volunteers for the BDA, expressed:

We have the Belize Diabetes Association, it has taken us a long way. For people to learn their condition and the availability of supplies which the hospital sometimes don’t have to offer. ...Because they [hospitals, clinics, NHI] usually don’t have the monitors to give or to sell. They don’t have the strips to give people. There are times they don’t even have the syringes to give insulin. But with the Diabetes Association, you get the syringes.

There are small BDA offices in Corozal Town and Belize City with satellites in Dangriga and Punta Gorda where a limited number of staff and volunteers see many people with T2DM each day who come to purchase glucometers, strips, and medications at prices subsidized for their membership. The BDA depends almost entirely on international donors. They are an important organization in the landscape of supporting T2DM self-management in Belize and are working hard to meet demand with limited resources.

The NHI clinics are much reduced in capacity for conducting regular appointments during the covid-19 response, leaving people with diabetes even more vulnerable. People in general are discouraged from using the clinics and hospitals, and those with diabetes felt especially uncomfortable accessing care due to exceptionally long waits and increased susceptibility to covid-19 complications. There are shortages in medical supplies and pharmaceuticals, exacerbated by border and port closures. For those with the resources they need, they can succeed in T2DM self-management, but for those with less, “self-managing” can mean being completely on their own without check-ups or medications, self-testing supplies or adequate nutrition. Thus, there are serious health equity issues arising from the tiered structure of the system and its failure to address poverty and economic inequality.

3.1.2 “They don’t really listen”: Communicating with Health Care Providers

Another subtheme that emerged within the broader theme of struggles and challenges for those living with T2DM was that of communicating with HCPs. Participants described difficulties such as not feeling comfortable asking their HCP questions, having to manage HCP irritability, not feeling listened to, not having time or space for talking to their HCP, and wishing for more lifestyle counselling and medical advice pertaining to living with T2DM.

Three of eleven participants felt satisfied with their providers’ communication, though one of the three made a point never to go to the clinic in a poor mood to maintain relations. Several participants discussed having difficulty talking to their doctor about their condition and wanted to be more able to ask questions. Felisha, for example, had always wanted to know why

her doctor touched her feet during appointments, but she felt apprehensive about asking her doctor. She described her doctor as having unpredictable moods and being sometimes angry, so she felt she needed to be cautious when trying to talk to her. Felisha described her dilemma:

I always want to ask her [why she is touching my feet], but she's so delicate, you have to think what you asking her. Yeah, but always she put her hand here whenever she check my feet. She do it like this. But she doesn't tell me anything, she just do it.

Felisha would have liked more explanation about what the HCP was doing so she could understand her own condition more thoroughly and to improve and facilitate her daily self-management routines. She went to her doctor with some trepidation, having experienced relational uncertainty and unpleasantness, so she only continued to go because it was a mandatory step to get her prescriptions filled. When she was asked to say more about her relationship with her doctor, Felisha answered:

I see that she wants to help, but I don't know what's her problem. Why she have an attitude sometime. Because I met this man, and he went there, and she give up on him, she didn't want to touch his feet. Well, I don't have that problem with her. The problem that I have is that sometimes she's unpleasant. And you can't be like that because she have problem, I have problem too. That's why I go to the doctor. And then if you not pleasant, how am I gonna communicate and tell you what's my problem... every time people they complain about her... I'm not too happy, but she's the only person who do it there. Someday they gonna move her. It's not me alone, but she have problem with other people who go to her. They always want to fight with her, and different things. Cause

they don't like her attitude. One time when I go to her, she'd be so nice and smiling, and next time, she's so mad, and whoo! And I think that is wrong for people who are sick. Especially diabetics cause sometimes, I don't want to go. I go because I want my medication. Cause she does the referral, and then you go for the medication. That's the reason why I go. But if I could just get the medication like that, I wouldn't go back.

For Felisha and other T2DM patients, talking to their HCP was difficult. Key informants who were physicians described the strain they experienced when they sought to care for patients without adequate human resources, supplies, medicines, and equipment. HCPs are dealing with short intervals of time per patient, and between patients, in an under-resourced setting. This contributes to the tension that exists between patients and providers due to (often the case) differences in class and education levels, and cultural and ethnic backgrounds.

Most participants wanted to be empowered to improve their conditions through self-management, seeing HCP appointments as an opportunity to do so, if only they could more safely ask questions of their HCPs, be asked more questions by their HCPs, and see that their HCPs were really open to listening. For example, George, who lived in Belize City, recounted: "Most of the doctors...they don't really listen to the patient. And it's not only for diabetes but other patients." He described longing for a process that suggested the practice of active listening. He went on: "They don't listen to the patient. Or explain what exactly is the problem. So, if I tell you something, and you tell me back, then it's okay. That's what I think." Further to listening and reflecting back to be sure of HCP understanding their patients, George wanted doctors to spend more time with their patients to more completely address their concerns. Maurice, Henry, Felisha, and others offered similar sentiments. Maurice made a point of booking numerous

appointments back to back to be able to have the time for asking his questions, sometimes on the same day, sometimes for a few days in a row. If his HCP seemed busy or preoccupied in his appointment, he waited in the office until he could ask questions.

Participants also described the need for more open dialogue for things such as self-management routines, rationale for drug schedules, and comprehension of multiple prescriptions. George described an issue he had when he asked about a new prescription. He had read about the drug's potential side effects (online), and he was concerned when he learned that his medication would weaken his immune system. His physician responded to his question with anger. George explained: "That's why I decided not to use it. When I explain to her, she get very mad...[so] I just told her I would use it, but I never use it." He described another incident where more open communication with his HCP would have made a difference to his health. When he tried another anti-diabetic prescription, the effects were extreme. George relayed:

No, not insulin. I don't remember the name, but within a month I gained twenty-one pounds... My blood sugar went extremely low. Then what I did, I went to half. But my sugar was still too low. Then I cut it to one third. Then I use it every few days, I cut down one third, but it still stayed too low. So I stopped using it.

He initiated a conversation about it with his doctor, but no response followed. The doctor did not ask him any questions, explain what may have happened or why, nor try to dialogue in any manner, so he left the experience confused and disillusioned with the process.

Adding to situations noted above, several participants described having enormous difficulty getting consistent and accurate information on how best to manage their T2DM,

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reporting a lot of misconceptions and myths circulating in Belize both via word-of-mouth and the internet. Participants heard many conflicting messages from the internet and other diabetes patients. They often needed medically sound physicians' advice to curb the misinformation they were frequently exposed to. For others, confusion arose from conflicting medical professionals' opinions and difficulty navigating contradictory diagnoses. Maurice described his quest for accurate T2DM information, including developing his health care system literacy, patient self-advocacy, and the need to make multiple appointments:

I believe we need doctors who have time to tell you what you are venturing into. When I still felt bad, I went back to the hospital. Then I found out, from the tests that they have run, that's when I found out my cholesterol was bad. I have creatinine. I have something in my kidney. But the doctor didn't tell me that, the one that took care of me. He focused on the diabetes, tried to get me out of the hospital. He only asked me if I have a glucometer. Now, with my sugar going up and down, I can only wonder how other people feel, who do not have a glucometer, and have these strange feelings in their body. The system here is probably in its baby stage... [Doctors need to have more time] to sit down and talk to you and counsel you into what you are going into. The difference with (this town) is that it is a small community, and people will tell you stuff. But also, some of them will tell you stuff that is not true! ...People will tell you, this work, that work. There are people who tell me that they consume a lot of coconut milk. As their treatment for diabetes....and he already lost a toe. The other guy who was at the other ward, he was like, the only thing saving me is whiskey. But he was about to get a couple toes cut off. So, you have to be constantly filtering what you are hearing.

Maurice was very motivated to learn more about how he could help himself. He persisted in returning to medical professionals to seek out advice despite having the sense that they wanted to dismiss him. He mentioned that he made a point of waiting for a HCP to finish chatting on the phone with a relative, hoping the HCP would be relaxed enough to talk with him after the call. After he hung up on his personal call, the HCP happened to remember that he had a relevant pamphlet on diabetes which he gave to Maurice. One simple but accurate and informative pamphlet made a huge difference to Maurice. He felt he could finally understand the physiology of T2DM and discern medically-sound advice from popular myth in terms of what to eat. He shared: “I actually went back to the hospital and asked ... But if I did not go back, how would I have known that?... Yeah. And that [pamphlet] was an afterthought for him.”

While Maurice demonstrated health literacy, patient self-advocacy, and system analysis, not all patients understand how to maximize their care. It is the role of the HCPs and other health care workers and administrators to translate knowledge into helping people. When asked about his relationship with his doctor, Henry expressed gratitude for those HCPs who have studied health for years and share what they know to help people. He went on to say, “I just would like them to keep on advising us. Especially people with diabetes. How to go on living this life.”

3.1.3 “I had a bad feeling”: Diagnoses and complications

Within the challenges described by those living with T2DM in Belize, the subtheme of facing diagnosis and dealing with complications also arose. The event of receiving a diagnosis of an incurable chronic disease can often be monumental and life changing for patients and their

identities. This is especially true of those who were not expecting a diagnosis. Three participants had family members with previous T2DM diagnoses and were less surprised by their own diagnosis, as were two participants who had been warned by their physician when they were found to be in a prediabetic phase. It was considered “a mercy” to have been warned of T2DM by a doctor before diagnosis, such as in a prediabetic phase. For example, when asked about experiencing diagnosis George responded: “The doctor was kind enough to tell me about it earlier. It was prediabetic, yes, I knew. He told me I was prediabetic.” Yvonne said it was very difficult when she was first diagnosed even though she knew she had a family history of T2DM. She stated: “I manage to handle it better over the years, but at first it was very difficult cause I was set on the type of food I ate.”

When participants experienced more surprise with diagnosis, there was more grief and difficulty accepting the required behaviour changes they had to make in their lives. When Henry learned of his T2DM diagnosis, he had not known much about the disease previously, and he went through a period of sadness, grieving aspects of his life that he used to take for granted. He described experiencing loss in having to give up large aspects of his social life, and the changing meaning of his physiological reality. Pre-diagnosis he had related to his body as a vehicle of enjoyment and festivities, and post-diagnosis he had to prioritize exercise and discipline. This required him to find new ways of feeling joy. He reflected: “Yeah, sometimes I think back to the way I used to be before. Now my body change, my lifestyle change, everything change.” Physically as well as emotionally, T2DM is not pleasant to experience. Maurice had received his diagnosis only days prior to participating in the study. He had been accustomed to depending on his body to be strong throughout his years of serious military training. When he retired, he purchased a bar

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and spent most nights partying, and this had changed his relationship to his body. He was baffled by the loss of his strength. He described what it felt like to have the disease,

I feel a bit frail. It's a strange feeling. The way I describe it, it's like you tie a person's hands and feet behind him, hang him upside down, throw him and probably punch him a couple of times, you feel a big - a little bit of roughing up.

Josefina was a mother and grandmother, who was living in chronic poverty, and who listed alcohol as one of her main diabetes medicines. She remembered her process toward diagnosis as starting with a bad feeling that brought her to the hospital. She experienced a slow and gradual dawning of what it would mean to have T2DM, having little information prior to diagnosis. Josefina described:

I was in Cayo, and I had a bad feeling... I came here two days to come to be in that check-up with the doctor. I found out my pressure was high. I went home the evening. I came back an hour later, sent me for emergency. I was admitted for five days. After that, not every month, but regular, ...I used to go into the hospital, three days, four days. It quieted down, but slowly, slowly. I try to control it.

George similarly described the negative feelings around living pre-diagnosis and the journey toward understanding and controlling it. While receiving the diagnosis was devastating, it made an important difference to know what was happening to his body, the name of the disease, and medical advice going forward. He had lost a sense of his own body, an intimate connection and control that required pathophysiological knowledge and medical advice to be regained. He relayed his story:

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I was diagnosed with diabetes about five years ago. Diabetes is not a good feeling. When I first felt it, I thought it would be the end of me cause I started feeling bad. I'd get dizzy. A lot of negative things come my way. So, I came over one day to the hospital, and they do a test on me, and I had got diabetes. It was diabetes. Then the doctors started treating me for that sickness, for that diabetes. I started on this Glimepiride and Metformin. And I see it works out. They asked me to do a diet, go on a diet eating mostly vegetables, leave out salt, sugar, all these things. Yes, I started to do these things, I noticed I started to lose weight. I feel more comfortable.

Felisha had no information about T2DM prior to being diagnosed. She was in shock after hearing the news because she did not think that a young person such as herself could get diabetes. Felisha shared her story of diagnosis, coupled with her regret for the complete lack of T2DM preventative education in Belize at the time. She reflected:

After giving birth to my son, I was diagnosed with diabetes... when I was 25 years... I used to see symptoms, but in Belize at that time, they didn't used to educate us. So, I look at the chart, and I said: but that can't be me because I'm so young. I know the diabetes is for the older people. No one was educating us... I believe that back then, if they was educating us, I wouldn't reach this stage. I would do things different.

Lucy received her diagnosis after years of working with people with diabetes. Even though she did have previous knowledge of T2DM, her own diagnosis was a shock that she had difficulty accepting. She declared: "I was in denial for almost six months before I accepted this." Lucy also described how some of her patients had difficulty with T2DM-related complications

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such as mobility issues. She empathized: “We have people, diabetics, who are confined to their homes, maybe they are amputees.” Lucy went on to describe complications that lead to stress and depression, one of the only examples of these phenomena given by any participants. Lucy elaborated on some of the issues that compound T2DM for people who have had the disease for longer. She explained:

We do have people who are stressed. Especially when they are in the hospital...It's very hard. Looking at themselves, it's very hard. Sometimes they go depressed. Very bad, depressed. Sometimes it takes them two, three months before they could accept their condition. But it's very hard to deal with them. Especially looking at themselves like that.

It is difficult to come to terms with the meaning diagnosis carries for one's life, the changes in self-perception, and the loss in strength and abilities. Depression has been linked to long term chronic diseases such as T2DM in studies in other countries. Mental health issues carried substantial social stigma in some parts of Belize, and there is work to be done in addressing these issues.

3.1.4 “I wish they would educate people now”: The need for education

Another major subtheme that arose among participants' reflections on the challenges they faced was that of the dire need for more prevention and education around T2DM. This harkens back to the need for more opportunity to have open dialogue with HCPs to obtain accurate and medically-sound advice. It also includes how all the participants were passionate about telling their friends, families, and communities how to prevent diabetes; they deeply wanted there to be a diabetes education program rolled-out countrywide. They wanted to be sure to include youth

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because they are less likely to know about the disease, as well as to include men because they often dismiss their own health issues. Participants were busy educating themselves and had learned a lot they wanted to share with others. In this sense, people with T2DM represented an underused resource as community outreach and educators. This power was still locked within the domain of community power, requiring some resources, organization, and momentum.

All participants communicated a strong desire for T2DM education for themselves and their fellow Belizeans. When asked what they would most like to tell policymakers, many participants repeated that citizens need more prevention and education. Rosa, for example, thought that what was most needed was: “Education, because some people really don’t understand. And they seem to think that they can’t get rid of – I have to eat this.” Expanding the commonly known repertoire on locally available diabetes-friendly food would help, and one participant forwarded her vision of creating a special Belizean cookbook for this purpose. George prioritized proper nutrition and wanted education for people who suffered from years of T2DM-related problems built up into increased dependence on medications alone. He felt the answers to T2DM management needed to be much more than simply increasing doses of insulin. He asserted:

I think that we should listen to one another more. Sit down and discuss our challenges...Cause there’s a lot of people, they could do better. Cause for some reason or another, they’re taking this insulin, and next month they’re taking another dose, and next month they’re taken another. Right there, there’s people, there are a lot of things they could do for themselves.

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George felt that if people knew more about T2DM and if they had the proper resources to improve their self-management, then their conditions would improve instead of deteriorating. His theory of change implied that more funding for education would result in less strain on the health care system. If applied to a larger scale, his instinct toward food-as-medicine could keep power in a more local domain, rather than increasingly depending on foreign pharmaceutical companies. Most participants had taught themselves the best market days for accessing fresh produce nearby.

Henry desired T2DM educational opportunities, as well as fitness programs, saying, “That would be good if we had more support groups and different programs toward this diabetic thing, no? So, we could learn more about it.” His first and only source of T2DM information was the doctor who diagnosed him and provided his annual check-ups. Had he grown up surrounded by consistent educational messaging from home, school, community, and media, he may never have gotten to the point he did with the disease. Yvonne wanted to tell her fellow Belizeans, especially the youth, about nutrition, so they could prevent diabetes in the first place. She communicated that,

It is never too early to start to eat healthy. Don't wait until you're diagnosed with diabetes. There's nothing wrong with healthy food. Cause they're - it doesn't taste good, it doesn't taste good. But you could fix it in such a way. And if you feel in your mind that it will help you in the future, it will. So, it's never too early to begin. I want to tell the young people that. Start to eat healthy from the young age.

Yvonne believed that given the proper information, people could harness their

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determination to avoid ever getting T2DM, thus the lack of education is any injury to their agency as well as their health. Henry similarly wanted the youth to know more about nutrition, saying, “I would tell them to stay off...all this type of food I was eating before, all these sweets, all these different type of things. Just stay off and keep on a diet.” Felisha was passionate about educating the youth for T2DM prevention because she was diagnosed at a young age with no prior about what the disease was or how to get it. She shared:

I always talk about it. Cause it hurt me bad. I could have done better back then. Nobody educate you, so I wish they would educate people now. Like go to the schools and the rural villages and check on the people there.

Felisha wanted to see education and prevention efforts cover the entire country, not just spotty discontinuous efforts. “Every time there’s any program, they don’t go all about. Do it every time and go ALL about. There’s a lot of people can’t come out, a lot of people that suffer with diabetes.” She went on,

I just want to try and help the people with diabetes in our country. And look after them more. The people in the villages, when they sick bad, some of them don’t have access to come out. A whole lot of things. I wish they would take time out, spend all the money, go to meet the people in the rural villages, meet the old people. The young people. Go to the schools. Cause the people who are young have diabetes. But they don’t educate them, so they don’t worry about nothing. They just live, you know? Encourage people to take their check-up even if they don’t have symptoms, take a check-up every time. So, if you have something you can work on it right away, so you can save yourself. Nobody care about

diabetes people.

Cynthia, a retired nurse, agreed with the consensus that education is an urgent need, saying “I would like to see happen is constant education because it’s limited.” When asked what works best for education, Cynthia described workshops that educate people on T2DM, nutrition, implications for medical management, such as, “Talking about their condition, talking about what to eat, the importance of taking their medication, the importance of going for their blood test in order for them to be controlled, monitored correctly”. She envisioned a program with the ability to do both individual level counselling and community workshops with educational resources and tools for people to take home, such as glucose testing schedules, logbooks, and recipes. Beyond telling people what to eat, she wanted to see family-oriented cooking classes that supply people with a few meals. As a diabetes nurse she made it a point to also be an educator, but she found it frustratingly limiting to not have more tools like pamphlets to give patients. Further, there was no space for educational sessions in the clinic. She shared:

We used to find at the clinic is that there is no privacy for health education. Everybody sits in one. You’ve been there this morning, right? The waiting room is for everybody.

You don’t have a special area to take your group to talk to them about health education.

She expressed that patients were less likely to ask questions about their health concerns when there is no privacy. They were distracted by the random activities of the waiting room, and it would be more effective to conduct educational workshops in spaces dedicated for such. Cynthia also wished for more nursing staff dedicated to diabetes and diabetes education, including foot care. Participants agreed that there was no special consideration for foot care, an enormous gap

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in care and education.

Participants wanted education for those already living with diabetes, for those who were in prediabetic stages, for the youth, and for men, who tended to think themselves unlikely to get sick. They expressed the need for widespread, consistent efforts for societal awareness to be raised. As Natalia stated:

To me, I would want more people to check, especially the men. On a personal, to me, they're in denial and ashamed. For example, when I first found out I had sugar, I had 260 pounds. It just dropped, it just dropped. In Belize, the first thing come from people, oh, you have AIDS! ...I remember when I would first take my paper, people would say, you get small. I said: I'm diabetic. Cause at first, they think AIDS. No, diabetic. Sometime the men, you see them. They think hard, and they know they are diabetic, but ...you know (they don't get tested).

Considering that social stigma around AIDS and other communicable diseases was severe enough that it impacted upon help-seeking behaviour, and that T2DM was commonly misunderstood as such, the lack of education could have had devastating unknown consequences. There were unfounded theories and myths circulating about both sexually transmitted infections and diabetes in Belize, with difference across sex and gender. Men, for example, were sometimes convinced that it was unnecessary to be as careful with their health as women, that wearing condoms caused erectile dysfunction, and that drinking sweet beverages built their muscle mass and enhanced their sexual prowess. In fact, erectile dysfunction affects over half of men who have diabetes, and prevalence odds show erectile dysfunction to be 3.5 times more prevalent in

the former than in study control subjects (Kouidrat et al., 2017; Malavige & Levy, 2009).

Women, on the other hand, sometimes reported that cleaning their house was all the exercise they needed, with no distinction, for example, between cardiovascular aerobics, muscle-building, and/or endurance training activities. People were often not able to articulate the pathogenesis or pathophysiology of diabetes, or strategies to prevent its onset or complications.

3.1.5 “I don’t see anybody support each other”: The need for social support

The final subtheme of difficulties and challenges is that of the need for social support. People needed a lot more social support to make the major lifestyle changes required by successful self-management, especially around what food they ate and how often. Participants who felt that they had good social supports in place tended to be from families with more than one person with diabetes. Many people listed social support among the most important aspects of their ability to cope with the disease, but not all the participants had that.

While there is diversity and cultural variation of diet, Belizean staples include white rice, white flour, fry jacks, fried plantains, and corn tortillas, all of which are high in simple sugars and thus not ideal for preventing and/or managing T2DM which requires more proteins, fresh produce, and complex carbohydrates (Gulley et al., 2014). People would not necessarily eat fresh vegetables from the market even if they themselves were producers. Fish, a traditional Belizean food, was considered healthy and delicious but too expensive. Country foods were increasingly abandoned for convenience store foods with higher glycemic indexes, and Indigenous youth were particularly disenfranchised from their traditional foods, preferring foods that were faster to

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prepare like white rice. Further, there was more social status imparted to those who purchased store foods such as potato chips and soda pop than those who ate traditional foods from the land and drank water.

Participants explained that their family members' food preferences highly influenced what they ate. It was especially hard to stick to a diabetes-friendly diet when those loved ones surrounding them were eating the types of cakes, cookies, and sodas they themselves had previously enjoyed since childhood. As Henry reflected: "I slow down from a lot of the food in my culture. I slow down. Can't eat as much as I want like before because I'm diabetic..., in our culture there's a lot of white rice." Many participants equated white rice and sweets with their sense of belonging to a culture, though simultaneously recognized that their newfound choice of eating mostly healthy foods did not disenfranchise them. They gained new self-esteem and personal power through their new lifestyle disciplines which was further validated by the attention other people gave them. In fact, they expressed joy when their community members commented at their losing weight and looking healthier while they enjoyed feeling stronger. Yvonne laughed: "Well, they told me that! I met an old principal that I had in school say, You look strong! I said: What?! I think it's the stretch band, I'm not sure (laughing)." They still enjoyed socializing but no longer equated it with partaking in alcohol and rich foods at parties, having gained awareness of their younger selves' illusions of invincibility. Instead, they visited with friends and family who were also becoming increasingly aware and respectful of their earned wisdom of health conscience boundaries. Almost inevitably, people living with diabetes become educators in their social circles. Henry explained:

When I talk to them, I tell them about my situation because some of them look at me and

say, Man! You're looking different. You reduce your weight and all these things. So, I tell them my sickness, I have diabetes. I had to lose weight to help my health.

Henry expressed that the positive reinforcement from his social contacts helped him stick to his diabetes diet and exercise regime that led him to lose almost one hundred pounds. He felt substantially better physically, proud of his accomplishment, and committed to perseverance. In these ways, he became a positive role model, inspiration, and success story among his people, and this was more profound than if he had not endured and transcended his disease experience to return to a state of, albeit carefully managed, health and wellbeing.

There were some sex and gender differences across social roles and social supports that arose in the interviews. While male participants did not mention how fatherhood affected their ability to follow diabetes self-management protocols, women often discussed the impacts that motherhood had on them. Women would embody self-sacrifice in their mothering, an influence that often narrowed the range of their lifestyle choices. For example, mothers often had difficulty in preparing diabetes-friendly food that their children like and eat reliably, so they ended up deferring to their children's influence and the need for quick meals rather than meet their own dietary requirements. When asked about family support, Yvonne responded:

That is still an issue (laughing) because my food has to be without fat, salt, sugar, and all these things. My youngest child was four at the time, so it was hard. I had four, seven, and fourteen-year-olds, and it was difficult. So, because of that, I think in the early years, I did not keep the diet as I was supposed to. But now they have gotten bigger and older now, and I cook my food, but it was a challenge.

Men were not socialized to do the cooking for the family or to self-sacrifice their physical health for their children to the same extent as women. The men all shared stories about their work lives. Their professional and social statuses were more central to their identities than fatherhood. While the status of a father was linked to being a provider effecting work external to the home, it was not an expectation that the men maintain the family by performing health care duties for others within the home. The men were therefore a step removed from both the chronicity homework of diabetes and the physical and psychological impacts of providing for the needs of others through daily domestic chores, cleaning, and cooking. Most of the women were also employed outside the home, lending to feeling too exhausted to exercise. This can be significant if the mother continues to forfeit her own nutritional and exercise needs throughout several years of childrearing by prioritizing her children over herself. While children may grow up and leave home eventually, the impact can affect mothers of adult children as well. Despite knowing she feels ill with sugary food, Felisha felt she should be courteous when visiting her adult daughter. She relayed:

The day before yesterday, I went to my daughter, at her cousin house, and the lady give me some Kool-Aid to drink. She give me some food. It was white rice ... I feel the difference. I told her, the Kool-Aid was made with white sugar? And she said: yes. I don't use white sugar. I don't even drink Kool-Aid. But she offered me, so I just take it, and I drink it.

Women have been socialized from a young age to be polite and agreeable, and it was hard for Felisha to decline the sugar beverage out of courtesy. She would not have consumed the problematic simple sugars if her social contacts were more aware. When asked how she typically

coped with this type of interaction, Felisha replied: “Yeah, staying home. I don’t move a lot, moving here and there because irritate me. I can’t go to lots of people house.” This contributed to her feeling that people did not care about those living with diabetes and her sense of isolation.

While Felisha was one of the participants who experienced a scarcity of external social supports, by staying home most of the time she also resisted negative social pressures to indulge in eating sugary foods and other common activities of her community that can exacerbate diabetes, such as going to parties or clubs with alcohol and smoking which, if indulged in, can exacerbate the condition. Indeed, three participants (two of the three men, one of the eight women) had struggled to overcome alcoholism post-diagnosis. This required major changes, sacrifices, and reprioritizations such as removing themselves from their friend groups, seeking new social venues, and even changing occupations. As some cultural celebrations obliged attendees to drink alcohol, this represented another layer of the experience of loss.

Clearly, not all social influences were negative. Some were positive; for example, participants expressed great appreciation for food they could eat, and for when other people cared enough to offer diabetes-friendly food. They liked when people exchanged health information with them, shared herbal medicines, and made a point of checking on them. Some social influences were a mixture of positive and negative. Occasionally, family members took on the role of policing their habits. This was well-received by participants when offered in balance with understanding rather than guilt or judgement. Rosa occasionally ate a little off her diet, for example, when baking birthday cakes for the family. When asked if her family understood her dietary needs, she responded:

They respect the fact that I eat certain things. My children – whoo! They get after me when I start, what is this? You are making the cake, and you’re tasting it!? (laughing)

They understand, and they make sure and say, Gramma, why are you eating that? And the little ones ask, and I say, every once in awhile I will (laughing).

Her family showed that they cared about her by remarking what they witnessed of her choices, yet they did not scrutinize her or give her grief. A handful of participants felt defensive against the social stigma that can arise when others comment on what they are eating or try to break their poor dietary habits for them. They described how people set up situations to stay in denial as long as possible in order to eat the food they like and the sugar they crave, allowing them to carry on feeling “normal” or just like everybody else around them. They feel there is no use resisting the power that such foods have over their lives, and social pressure to change only drives them into hiding their disease and/or their eating habits. They then become more dependant on pharmaceutical interventions to manage their diabetes.

Along with diet, another important aspect of diabetes self-management is regular exercise. Getting regular exercise requires commitment, and participants wished for more social support to commit to a daily or weekly regimen. Other people had a fair amount of power to propel or dampen their exercise efforts. One participant described having had an easier time exercising when she was accountable to her daily workout buddy, and that when her friend dropped off, she lost her momentum. Yvonne reflected:

I think that is my problem because my buddy, she has abandoned me (laughing). She has diabetes too. She used to go. Her and I used to go walk. We used to do

everything...Exercise isn't easy. It's a commitment. (laughing) So, yes, I do [struggle] sometimes.

George found the motivation to go running, despite dealing with diabetes-related sleep disturbances and subsequent fatigue. When asked about social support, George replied: "Yeah, well if I had a [workout] buddy it would be okay. It would be okay for me." A related issue that harkens back to the first subtheme is that there are not many easily affordable and readily accessible gyms and exercise programs where people can meet other people, learn new skills, develop fitness training routines, and be accountable to a larger community. Natalia expounded:

I am motivated by my kids because I have to get up for them and for work. My kids make sure I get up in the morning. My son challenges me to work-out with him. I would like to try weightlifting, but I'm not sure where I could go.

There was a need to improve social supports available for those living with T2DM through promoting a more health conscious society. Many participants sought out social support at the BDA meetings, spiritual gatherings, and/or through friends, family, and neighbours, yet many also still wished for more such opportunities. Some participants felt quite alienated and isolated from diabetes-friendly social supports when, for example, their families did not live nearby or acknowledge the difficulties of living with this chronic disease, or when there were no organizations like the BDA in their communities. As Felisha explained:

I see that nobody worry about diabetes. You know, if you have it, well, you just have to fight yourself. But nobody done worry, and come and talk and say, that this happen and that happen, and what we could do different. I don't see people do that in Belize here.

When you get it, they say, huh, well it's hard for her. But I don't see anybody support each other when it comes to diabetes.

The need for social support worsened significantly under Belize's covid-19 public health restrictions which required people to endure such psychologically difficult things as maintaining physical distance from other people, wearing a mask over one's mouth, limiting social contacts, isolating oneself with household members, shutting down public transportation, and instating checkpoints to scrutinize vehicle travel. People with diabetes were hit harder with isolation and loneliness than those without pre-existing conditions that made them more vulnerable to the virus, and they suffered more from the subsequent reduction in regular services and hours of operation offered at clinics and hospitals across the country during the pandemic.

3.2 Spiritual /Religious Practices for Enduring and Overcoming the Struggles

After discussing their daily struggles and barriers to health, participants shared about what helps them to cope, lifts them up, and brings them through those difficulties. The second major theme emerged from how people draw strength from spiritual and religious practices to endure the challenges of living with diabetes. While modern and clinical definitions of the terms "spiritual" and "religious" differ in ways that matter to quantitative studies measuring effects of specific practices, for the sake of this essay, they are not defined exclusively; spiritual practices are defined more broadly than and may include religious practices (Koenig, 2008). People typically prayed, meditated, and referred to sacred texts without necessarily considering themselves religious. Most participants could name a church or faith they were aligned with at

some point in their lives, but they did not tend to limit their explorations to only one way of practicing spirituality.

Ten of the eleven participants in this study reported that they had a strong faith in God, ascribing many health benefits to this. Being a person of faith helped them in their daily lives when coping with diabetes and enduring chronicity. It gave them more ability to commit to regularly eat well, exercise, and perform glucose self-monitoring tasks by endorsing self-responsibility to respect the physical human body in a sacred contract for the gift of life. Spiritual practices, such as meditation, prayer and referring to sacred texts, also provided people with significant stress relief by allowing for some aspects of health to be controlled by a higher power and by guiding participants to live without malice toward other people thus reducing their inner tensions. Participants utilized prayer for many reasons and in many ways; for example, they prayed for strength to stick with healthy behaviours and overcome addictions, they prayed for grace and acceptance of their chronic disease and its impact on their daily lives, they prayed for guidance on lifestyle choices, they prayed for protection from harm in surgery, they prayed for help in hard times, and they prayed with gratitude for life and all its blessings. Thus, the use of spiritual practices for enduring and overcoming the hardships of living with T2DM became a central theme, as explored in the following subsections. See Table 3.2 for a summary of participants' spiritual/religious practices.

Table 3.2

Summary of spiritual/religious practices

Spiritual practices that help to build determination and commitment to healthy lifestyles	Spiritual practices that provide stress relief	Prayer as a way of life
<p>Fasting</p> <p><i>“We need to do more. We need to get to the root of the problem... I call for fasting, or intermittent fasting. Because if you don’t eat, your sugar won’t go up. I could tell anybody that.”</i></p>	<p>Referring to sacred texts for job stress</p> <p><i>“The Bible tells you not to worry about anything...Make your concerns known to God. ...I had a supervisor position, and it was very stressful. And I realize that stress makes you ill...That is my foundation. You don’t worry about anything. You tell Him what you need, and He’ll provide it. And He has. So, it has improved my mental health and my physical health of my body. It is a connection. And my health has improved because of that.”</i></p>	<p>Prayers for guidance & help meeting needs</p> <p><i>“I believe in God, you know. I believe in God. I know that once you pray, a lot of things get done easy... I’m sure it helps. A lot, lot, lot. When your situation is not going forward, not getting there, that’s when I pray.”</i></p>

<p>Observing Lent</p> <p><i>“(The hardest part of having T2DM is) the carbs and the crave for sugar...This is Lent, it’s the Lent season. And that is what I said I am going to give up for this, and if I survive, I know I’m good.”</i></p>	<p>Prayer & meditation for interpersonal relationships</p> <p><i>“I meditate to myself. I pray at home...When having diabetes, you don’t want to be frustrated... I don’t hold malice and say, I am vexed with this one and I won’t - No, no, no! That’s the way how I live my life. And it’s good for everybody who have diabetes. Don’t wanna have nothing holding over their shoulder. Diabetes is enough...cause can’t hold malice at people when you’re sick too.”</i></p>	<p>Prayers for protection in surgery and medical matters</p> <p><i>“Recently, about a year now, ...I get a surgery on like Tuesday, and Wednesday, I was home, praise God. Just like I didn’t get a surgery. And I was worried because they say, I am a diabetic and could get hard to heal. But no.”</i></p>
<p>Prayer & church</p> <p><i>“Church... Yeah, it helps! Because before, man, I used to be out there drinking a beer, drinking all these things that don’t agree with this diabetes thing... It’s helped me a lot.”</i></p>	<p>Prayer & meditation for self-regulation</p> <p><i>“I pray a lot. I rebuke any negative thoughts.”</i></p> <p><i>“I pray about it, pray for healing. Over all these years, all the time, it used to be, oh, 200, but it never affected my sight or anything. So, I said: probably God takes care of it. Praying and making sure that I meditate, and I watch it isn’t getting any worse.”</i></p>	<p>Prayers for acceptance of T2DM & gratitude</p> <p><i>“I was in denial for almost six months before I accepted this; I am one of them [diabetic patients] now... I think when you give thanks and pray, it alleviates most of your problems and feel healthy. That’s the way I see it.”</i></p>

3.2.1 “All you need to do is do the right thing”: Building determination

Central to diabetes self-management is eating a diet of fresh fruits and vegetables,

quality proteins, and complex carbohydrates while avoiding addictive simple sugars (Franz and Evert 2012; Ahmed, Guillem, and Vandaele 2013). Participants used spiritual fasting practices to strengthen their determination to abstain from problematic foods that exacerbated diabetes symptoms. Inspired by his Garifunaduau spiritual¹⁴ outlook and practices, George, for example, controlled his blood glucose levels through daily fasting, eating only one small meal each day. Rather than dabble in moderating his consumption of desserts and sweet beverages, he abstained from sugar altogether and focused on eating fresh local produce. He disliked the trend he had seen of people with diabetes needing increasing anti-diabetic drug dosages without changing their lifestyle choices, an important consideration in a country where medications are not always available and/or affordable. George asserted: “We need to do more. We need to get to the root of the problem... I call for fasting, or intermittent fasting. Because if you don’t eat, your sugar won’t go up. I could tell anybody that.”

Cleansing and purification rituals are used in Garifunaduau spiritual healing traditions. George was a proud Garifuna man who found personal power in fasting and exercise, having tried and abandoned numerous T2DM-related prescriptions which he found ineffective and misaligned with his values. Practicing his regime positively reinforced his dedication to his health and to God while his faith reciprocated in strengthening his resolve; he experienced these elements coming together to improve his chronic condition and make life consistently more

¹⁴ “Garifunaduau” refers to the Garifuna people who are descendants of Africans and Indigenous peoples of South America. Garifunaduau spirituality includes rituals for healing individuals involving their friends and community members in shared responsibility to address crisis, to mark stages of life, and to seek guidance from one’s ancestors (Ellis, 2010a). Rituals involve collective spiritual synchronization through the rhythm of drumming and dancing, creating sacred space to express emotions for release and healing (Ellis, 2010a). There are cultural protocols that must be respected in preparation for, during, and after the rituals specific to discipline and food (Ellis, 2010a).

manageable without the use of pharmaceuticals.

Cynthia was also a Garifuna woman and a retired nurse. She went through months of binge-eating after she was diagnosed with T2DM, disbelieving, and struggling with her shift in identity from being a health care provider to becoming a patient of the health care system with chronic disease. While she was in denial, her blood glucose levels were high and increasing. She needed a remedy to the denial that was triggered by her diagnosis before she could move into the mentality of self-responsibility required for her to shift into behaviours of healthy self-management. As Cynthia explained,

I was in denial. Because when I checked my sugar level, it will be 300, 400¹⁵, but I don't care, I'm going to take my coke [Coca-Cola], eat whatever I want. And it took me about six months to accept the condition I was in. I was in denial. I said: no, because maybe I had a lot of coke, maybe because I eat a lot of sweet things. I was in denial for almost six months before I accepted this; I am one of them [diabetes patients] now.

As she gained membership to those labelled by diagnosis, she lost membership to a social status considered “normal”, “not diseased”, or “healthy”, requiring a process of grieving and letting go of who she was before. Cynthia came to accept her new limitations through perseverance, prayer, and faith in God, settling into a clear fortitude: “Having diabetes is a condition that you have to live with, and all you need to do, is do the right thing and have

¹⁵ These numbers refer to the blood sugar test called Fasting Plasma Glucose (FPG). For someone without diabetes, the range of normal includes 70 to 99 milligrams of glucose per decilitre of blood. For someone with diabetes, the recommended range for management is 80 to 130 mg/dl. The level that confirms diagnosis is 126 mg/dl (ADA, 2020).

control.” Cynthia accepted the new rules of engagement with her body after it became clear that denial would not help her and that ultimately, she had to take control over her own destiny, resisting the temptation to submit to cravings for sweets and external determinants of health. With her surrender to the need to change and the acceptance of her condition, a key element fell into place for her to be able to follow self-management guidelines, which she was now firm with herself about and disciplined about.

Other participants shared this sentiment of strong determination and attitude of self-responsibility, although it was also tempered by an understanding of life and death as of the ultimate domain of power. Felisha, a Creole woman, shared:

I hope that in the future, I live many more years and that diabetes don't bother me that much. I believe it's up to me to take care of myself. When God says it's time, I understand that part, but without that, just taking care of myself.

Study participants talked about God as someone or a force that helps them in their day-to-day life with “heavy lifting” that may be too overwhelming to do on their own, and as a persuasive, consistent, and clear voice of health-promotion and encouragement for self-care. While social support wavered in their lives from time to time (e.g., workout buddies dropping off, simple sugars at family gatherings, alcohol-drinking expected at cultural celebrations), God's presence did not. In this way, camaraderie or social support extended for these individuals beyond the human realm to the spiritual worlds where God, or personified Creator, becomes their most reliable ally and consistent voice of support. Yvonne, a Creole woman, for instance captured this sentiment expressed by all participants when she expressed that “What helps me

stay motivated? Oh, everything! I'm a believer in God. He's the person who really keeps me going."

She identified as increasingly religious over time. Regardless of friends coming and going, parents passing on, and children growing independent, she felt her closeness to and trust in God through connecting daily in prayer and carrying that connection in her heart and body throughout her busy schedules and routines. Feeling this closeness of God's presence reinforced her capacity to commit to health. It is perhaps then not a coincidence that people became more spiritually centered as they grew older and that, in ten of eleven participants, their disease was diagnosed after they had reached middle age, as their bodies began to decline and their spirits prepared for what lay ahead.

Some participants in this study also described specific religious observances that helped to solidify their will power and positive choices, such as Lent. Lent is a six-week Catholic observance of sacrifice or self-denial from an individually meaningful, often food-related, object of personal choice; people often give up sugar or red meat for Lent. When asked what the most challenging aspect of living with diabetes was, Yvonne again explained: "I think the carbs and the crave for sugar... This is Lent, it's the Lent season. And that is what I said I am going to give up for this, and if I survive, I know I'm good (laughing)." Yvonne credited observing Lent with fortifying her ability to overcome daily sugar cravings. This discipline and health promoting activity may be a more difficult feat than one realizes as sugar induces psychological processes of craving and reward which surpass neurobiological responses to many addictive drugs (Ahmed, Guillem, and Vandaele 2013). Observing Lent in this way, therefore, sets high self-expectations of will-power and positive self-choice, and these are reinforced through

accountability to not only others in the spiritual community, but to God—faith in God helps one “rise to the occasion.” Once this strength and ability is discovered and experienced through action in fasting, and reflection on that action, the participants commented how this further strengthened faith in themselves-with-God while transforming old patterns of neurobiological responses and cravings.

For many of the participants, Lent also provided a powerful spiritual narrative and “hero,” to emulate, namely the Easter Biblical Christian story of the crucifixion, sacrifice, and resurrection of Jesus Christ. In Christianity, Jesus is interpreted as God personified and the highest expression of humanity. Participants often expressed how they draw strength from how Jesus endured being nailed to a cross while still emanating compassion towards his injurers, and through this story relate their own personal and temporary renunciation or sacrifice (e.g., sugar) as relatively small. In this way, the hero’s example provides profound inspiration to overcome craving and addiction by creating, affirming, then cementing new and healthier neuropathways and habits of spiritual activity, choice, reward, and power.

Finally, gaining spiritual determination to abstain from cravings also applied to alcohol. Alcohol consists of simple sugars, and alcoholism is well known to exacerbate diabetes (Barcia et al., 2015; Kim & Kim, 2012; Weaver & Mendenhall, 2014). Maurice and Henry both quit previously significant amounts of partying and alcohol-drinking when they were diagnosed with diabetes. Henry, an East Indian man, explained:

Well, I grew up in a Catholic mission. Then I have turned over to a New Covenant Church... Yeah, it helps! Because before, man, I used to be out there drinking a beer,

drinking all these things that don't agree with this diabetes thing... It's helped me a lot.

Living with diabetes can be more difficult, complicated, and fatal for those with a co-morbidity of alcoholism. Strong spiritual practices, such as prayer and fasting, coupled with accurate medical information, can facilitate limiting alcohol consumption and determination to choose a different path in life. Several participants expressed appreciation for the combined influences of both their physicians and their faith to understand "How to go on living this life", as Henry put it.

3.2.2 "I don't stress about it": Spiritual stress relief

Despite the seriousness of the topic, most participants smiled and laughed a lot throughout their interviews. Nine participants expressed that Bible readings, prayers, and meditations guided them to "not stress," that they were supported to maintain peaceful relationships with other people, and that their health benefitted accordingly. They described strategies like moving to the countryside, staying home more often, actively modifying their state of mind through meditation and prayer, not holding malice toward other people, emanating goodwill toward their community members, and asking God for what they need. In many cases, it was a matter of following their spiritual teachings regarding dwelling within a trusting relationship with God and nurturing a positive outlook on life, such as those found in Biblical texts, that was helpful at developing these positive attitudes and practices. When asked how she coped with the T2DM-related stress, Isabella, a Garifuna woman in her late eighties, outlined:

I pray a lot. I refer to my Bible readings. I interact with my past students, my friends, and

my family. They come to help me a lot. My children. So far, I try to live a stress-free life, realizing that I have lived a full life. I don't worry too much about other things that are not important. And I love people... I believe that as a Christian, as a child of God, I accept everyone. My mother used to say, 'You don't do to others what we don't want them to do to you'.

Yvonne similarly found stress-reducing reassurance and lifestyle guidance in sacred texts and prayer practice. As she expressed:

The Bible tells you not to worry about anything... Make your concerns known to God. And because I used to, I worked for years, and I had a supervisor position, and it was very stressful. And I realize that stress makes you ill. So, when I read that, that is my foundation. You don't worry about anything. You tell Him what you need, and He'll provide it. And He has. So, it has improved my mental health and my physical health of my body. It is a connection. And my health has improved because of that.

Reflective of these passages, when Felisha was also asked to say more about not holding malice, she explained her personal approach inspired by Biblical passages, as well as her prayer and meditation practices:

When having diabetes, you don't want to be frustrated. You don't want to be quarreling with people. You don't want to get into any mess, you know? So, if anybody want to quarrel with me, I don't pay them no mind. I just sit down there and let them talk, and when they get enough of talking, well, that's their thing. We are friends again. I don't hold malice and say, I am vexed with this one and I won't - No, no, no! That's the way

how I live my life. And it's good for everybody who have diabetes. Don't wanna have nothing holding over their shoulder. Diabetes is enough...cause can't hold malice at people when you're sick too.

Making peace and setting boundaries on interpersonal drama in relationships was inspired by spiritual practices and teachings. Natalia, a working mother of three, semi-jokingly warned all her family members and colleagues that if they gave her stress or made drama, then they would kill her. Isabella evoked a spiritual sense of kinship with her fellow human beings as a way of life. She explained: "I try to be pleasant and welcoming to everybody. I love my children and try to instill into them that you have to be pleasant to everybody. To me that is the important part of life". Cynthia also relayed that she had no stress except not being able to consistently afford what she needed. She and others described not stressing as a way of being in the world, and as a perennial rebuttal of negativity even in the face of poverty and chronic illness. Josefina, a busy Garifuna grandmother, offered: "I relax my mind and don't let nothing bother me." Meera, an East Indian woman, shared: "I just don't worry about it because the more I worry about it, the worse it gets for me." And finally, Isabella also expressed: "I pray a lot. I rebuke any negative thoughts." Prayer, meditation, and referring to sacred texts helped participants to feel peaceful inwardly, as well as outwardly caring toward other people, affecting their relationships positively while disarming their sources of stress to make for healthier, easier T2DM living.

3.2.3 “Once you pray, a lot of things get done easy”: Prayer as a way of life

Participants in this research described various types of prayer that they draw on in their lives. As explored above, participants prayed for strength, determination, and commitment to healthy behaviours and overcoming addiction, they prayed for acceptance of their condition and the ability surrender to God’s will, and they prayed for harmonious relations in their families, their communities, and peace within themselves. At the same time, they also talked about praying to stay mentally and spiritually strong even when they were feeling physically frail and facing poverty, which gave participants the “lift of God’s presence,” guiding their lives and making enduring chronicity easier.

Additionally, participants used prayer to feel closer with God and for returning to trust in times of turbulence. George had suffered four years of preventable medical complications and difficult experiences of the health care system that had left him partially blind and unsure which of his physicians (who were in disagreement) he could trust. He provided an example of the power of faith in enduring difficulties and of personal prayer for help in hard times:

I believe in God, you know. I believe in God. I know that once you pray, a lot of things get done easy... I’m sure it helps. A lot, lot, lot. When your situation is not going forward, not getting there, that’s when I pray.

Meera was experiencing health issues that were more pressing than her T2DM at the time of the interview. She decided not to think about or impose her will on the future, preferring to surrender to God. She used prayers like daily blessings to give thanks for each day of life. She provided an example of personal prayer for surrender to God’s will and gratitude for life: “I live just one day

at a time. Because then, there's no tomorrow. That's the way I see it. When you live to see another day, just say, Thank God."

Participants also shared how they prayed for protection of their health, including emergency surgeries in health care settings and daily preventative care practices at home. They often attributed good outcomes to the good will of God. They described using personal prayers for good health outcomes, protection in surgery, and gratitude for life. Meera said:

Recently, about a year now, ...I get a surgery on like Tuesday, and Wednesday, I was home, praise God. Just like I didn't get a surgery. And I was worried because they say, I am a diabetic and could get hard to heal. But no."

Felisha described a similar experience:

Two years ago, I got a hysterectomy... And thank God, I didn't catch not one infection.

The eighth day after my surgery, I'm driving the car. The ninth day, I went to take out my stitches, I washed my clothes, I do everything. Without an infection, praise God, no infection.

Praying for health protection and asking that one's health needs be met not only crystallized patients' priorities within themselves, but it also multiplied feelings of gratitude when those needs were met and allowed for acceptance when difficulties arose. Similar to prayers of trust that God will provide, as explored above, participants experienced feelings and thoughts of gratitude that replaced stress and worry with a sense of wellbeing. Prayers of gratitude for the blessings in life focused participants thoughts away from wishing for another reality in which they do not have diabetes. When Meera was asked about her toughest daily

challenges, she retorted: “I don’t really find it hard...I personally thank God for it.” Meera felt that complaining was not of any help to her, and that she had to sometimes fight for the state of her health and at other times, surrender. When Rosa, who was past the age of retirement, mentioned she was a (Methodist) minister, I asked her how her spiritual relationship may affect her health and/or her wellbeing. While she admitted that working her full-time job on top of her clergy work could tire her out, she shared an example of personal prayer for balance, health, trust, and in gratitude:

I think that probably helps me to keep it in balance. I pray about it, pray for healing. Over all these years, all the time, it used to be, oh, 200¹⁶, but it never affected my sight or anything. So, I said: probably God takes care of it. Praying and making sure that I meditate, and I watch it isn’t getting any worse. Cause I hear about people talk about 400 and 500¹⁷. Then their eyesight start going. But no, everything just kinda was normal, in order to live with it... (laughing) I don’t have time to be sad. No, no, no! No time for sadness. Give thanks for everything! Every little thing.

From a different angle, Isabella practiced a synergy of Garifuna and Roman Catholic spiritual traditions, sharing a unique insight into cultural variations on prayer practices. This included the spiritual work involved in divining the messages sent in dreams and calling on one’s spiritual inheritance through ones’ ancestors. She shared a little about the most sacred dance of

¹⁶ The range that is considered successful for blood glucose management for a person with diabetes is between 80 and 130 mg/dl (ADA, 2020).

honouring the ancestors by Garifuna family/community called the Amalihani (abbreviated to the Mali) which includes dance and prayers:

Well, you have the Mali. There is the belief. I personally admire our practices to invoke the help of the spirit of our ancestors. When we dream about the ancestors, and we talk with them as we are talking now. It is mainly in our dreams that we talk as Garifuna. It is a sad situation that the church condemns it and says it's paganism and what not. And this is what has caused a lot of people to look down on the culture, say negative things, and not want to accept themselves. And that is where we have gone wrong. That is it. But gradually now, the trend is changing because when our children go abroad to study, and they realize that has happened. They say, Well, this is me, I am Garifuna. I do not have to believe everything my Ancestors' believed, but I can sift out and get the good out of it. Because from every good there is some bad, and from every bad there is some good. (laughing).

Indigenous spiritualities, including those of the Garifuna people, have survived many colonial oppressions, thus providing its practitioners insight and fortitude in surviving types of social chronic adversity, including chronic disease. This spiritual philosophy and inheritance helped Garifuna people to survive, endure, be resilient, and thrive. It helped participants, Garifuna, and similarly other Belizeans, to accept the aspects of diabetes that seem negative alongside those experienced as positive, in the sense that they are two sides of the same coin, or two parts of a whole, and this lessened emotional vicissitudes of living with diabetes, even the literal spikes and drops in blood sugar which can feel dizzying, frightening, and weakening. Rosa, for example, described an incident where she was so dizzy and weak that she had to lie on the floor of her

room for an entire day. She said: “It was really scary because I tried to get up, and everything going around and around.” Throughout the time spent waiting for medical help and being assessed, she prayed and remembered spiritual teachings that helped her through the ordeal.

3.3 Plant Medicines and Geographies that Empower Self-Management

While daily struggles and barriers to health weighed people down, and spiritual/religious practices lifted people up, there was another set of influences. The third main theme of the results was that of how geographies can empower diabetes self-management, or in other words, the ways in which place and space can add momentum to pathways to wellness. Home was described as a domain of personal power for participants, where they controlled their health most easily and where they most frequently engaged in the spiritual/religious practices that helped them. People used sacred outdoor sites, bodies of water, forests, ritual temples, and shrines for healing purposes. Having a home or destination in the peaceful countryside was essential to health and healing for some participants, while savvy urban planning and active transportation made the biggest difference for others. Every participant in this study utilized local plant medicines. Medicinal plants exist in the community and personal domains of power, and their usage was symbolic of sovereignty and autonomy. Plant medicine usage could be organized into three categories, namely, those who exclusively use plants, those who primarily use plants but also use pharmaceuticals, and those who use plants to complement their prescription drugs. People had faith in plant medicines, as God-given and a gift of the land. See Table 3.3 for a summary of plant medicines and geographies that empower self-management.

Table 3.3

Summary of plant medicines and geographies that empower self-management

Home as a domain that nurtures personal autonomy & spiritual self-management practices	Sacred sites & relationship to land	Pervasive usage of local plant medicines
<p>Self-management at home as easier, more accessible & personalized</p> <p><i>“Staying home with my family. I really, really enjoy that...I just stay home, and I meditate to myself. I pray at home.”</i></p>	<p>Numerous examples of sacred healing sites temples, shrines, sea baths, rivers, spring waters, waterfalls, forests, traditional Indigenous healing centres, faith-based retreat centres, forests, caves, orchards, etc.</p>	<p>Traditional Indigenous plant medicines as symbolic of sovereignty and keeping ancient relationships alive.</p>
<p>Using one own’s judgement empowered by spiritual practices at home, differentiated from following authority figures</p> <p><i>“We seem to take the priest for God... We seem to take the church for God... I keep my distance. For what to do, when to do, what not to do, I pray. Not everything the pastor said is my thing. Because I know we have our own judgement.”</i></p>	<p>Getting out of the densely populated city to more peaceful places & living more autonomy</p> <p><i>“Because living in Belize City and being a diabetic, it was kinda rough for me. Very, very hard. Cause of the noise and everywhere is congested. Coming to [Belize City] is very nice for me. I feel a relief. I’ve been so free. I love this place. I wish and I hope that I spend the rest of my life here... Belize City, it is not good for someone who is sick. So, I believe for someone who is sick like me, need to come out here in the countryside, where they can have a peace of mind.”</i></p>	<p>Three categories of usage:</p> <ol style="list-style-type: none"> 1. Used plant medicines exclusively, 2. Used plant medicines primarily, and 3. Used plant medicines secondarily.
<p>Relationship to God when God-is-everywhere, guiding & uplifting</p>	<p>Urban planning for active living</p> <p><i>“The whole town is a gym. You could just run.”</i></p>	<p>Faith and trust in medicinal plants greater than pharmaceuticals, willing to be the natural experiment</p>

<p><i>“Living your own life, believing your own faith, you know that’s something just me. I know that God hears everyone. Once we trust in him. You don’t really have to go to a church.”</i></p>	<p><i>“Walking or riding my bicycle. I scarcely drive, I ride.”</i></p>	
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3.3.1 “I just stay at home”: Home as a domain of personal power

Hospitals and clinics exist within the power domain of physicians and administrators, churches represent the power domain of the clergy and religious authorities, and the home represents the power domain of the person and family. Self-management practices (e.g., glucose monitoring, exercising, praying) largely happen at home, a more accessible venue than a clinic, to a gym, or to a church. While clinics were as not as culturally safe nor appointments as satisfying as they could be, people were increasingly consulting the internet for health information from home on their cell phones. Gym memberships did not exist in many small towns, and though Belize City had gyms, it was not necessarily affordable. Most participants did not own personal vehicles or have drivers licenses so getting to church and clinics took extra efforts. One participant had installed a home gym after diagnosis which he used regularly and attributed his successful self-management to. Participants felt they could control their own dietary intake and fulfill nutrition requirements more easily at home. When asked if she could access diabetes-friendly food, Rosa, shared:

If I do it at home, I can. Because I cook vegetables, or I blend them. I make sure that I don’t eat rice and bread. But if you want to go out...I could get by. But they might put in too much salt or something like that.

While ten of eleven participants indicated they maintained spiritual practices, none regularly attended church. Participants did the bulk of their self-management at home where they did not have to pay any additional fees and where they could be in charge, thus individualizing and centering care within their domains of personal power. Those participants seasoned to living with diabetes partook in daily diabetes self-care routines typically included morning exercises, checking their blood glucose at varying intervals, examining their skin, noticing subtle changes in symptoms, eating carefully, testing their extremities for sensation, praying, and meditating; all of this happened at home.

Cynthia attributed greatly improved health to a regular home practice while she only attended church for special events:

I am not a churchgoer. I pray home... I like pray. That is a spiritual connection, only because I don't go to church. I think when you give thanks and pray, it alleviates most of your problems and feel healthy. That's the way I see it.

By nurturing a strong relationship to God in her own home, she felt spiritually connected, at peace, and strong in her personal power there. Felisha also preferred to stay home to pray. She felt staying home was better for her because she did not have to deal with hassles (e.g., traffic, taking buses, and finding appropriate food), and because she felt peaceful and close to God at home. Felisha explained: "Well, I don't go to church. I just stay home, and I meditate to myself. I pray at home and everything. We done do those things, but we don't go to church either."

George spoke about having a direct relationship with God and not relying on clergy or religion to moderate this ultimate truth or experience with God. Perhaps similar to his attitude

toward religious authority figures, George had a self-directed approach to treating his diabetes, distrusting the medical system after having been on the receiving end of negligence and misuse of power (described in section 3.1.1). George had an intensity to his need for autonomy and sovereignty over his own body that may be traced through his Garifuna heritage and the need for cultural survival through the resistance of further displacement and colonization. He took this to the extent of sourcing his own needles and making his own medicines. He was in a sense his own doctor to protect his own psychological resilience but also out of pragmatism in the face of chronicity, poverty, and an unresponsive health system. George discussed how his personalized home prayer practice surpassed his need for external religious authority figures while providing him with guidance for life choices. He expressed:

I don't make mistake with religion or with pastors or priests. We seem to take the priest for God, or the pastor. We seem to take the church for God. But that's -, I keep my distance. For what to do, when to do, what not to do, I pray. Not everything the pastor said is my thing. Because I know we have our own judgement.

His daily self-management routine was very disciplined and depended on him being at home with all his plant medicines, self-care tools, and health resources where he was the primary decision-maker and simultaneously the greatest stakeholder.

Meera was a homemaker who spent most of her time in her own house. She repeatedly elucidated the importance of putting trust in and praying directly to God through regular home practice where she felt her personal power was the greatest. She felt that while going to church was good, it was not as important as her direct relationship with God, her capacity to use her own

judgement, and her understanding of God's presence as everywhere, for everyone. She reflected:

Yes, church is good. I don't go, no. But living your own life, believing your own faith, you know that's something just me -. I know that God hears everyone. Once we trust in him. You don't really have to go to a church.

All the participants felt that it does not matter where they prayed, given that God is present everywhere, including in homes. With a regular home prayer practice, God became very accessible to those living with this chronic disease, some of whom had mobility issues. The domain of personal power thus became strengthened by the spiritual connection pervasive and energetically tangible in the home. Participants indicated that their self-care tasks in turn became more peaceful, spiritual, and healing. Behavioural patterns and habits were easier to improve within the home because participants could exercise more autonomy in the personal domain (as opposed to institutionalized living, for example). Healthy home domains were thus empowering, peaceful, and culturally safe spaces that greatly facilitated diabetes self-management; however, those with more resources had relative advantages in this regard.

3.3.2 “Where you can have a peace of mind”: Sacred sites and healing relationship to land

Numerous communities of worship have integrated relationships with land, water, and other elements of nature for health and healing. During the long hours of travel required by the field work, research team members and I stopped at several sacred healing sites. Water was often a predominant geographical feature. There were waterfalls, rivers, springs, and sea baths all used for healing and purification. Orchards, caves, and forests contained sacred sites. In Mayan communities, traditional healing centres were set in nature within proximity to homes and

workplaces. Christian church groups often had land dedicated to spiritual health retreats. In most Garifuna communities, there are shrines and temples called *Dabuyaba* in which healing rituals are led by High Priests and Priestesses (Ellis, 2010a). The *Dabuyaba* used to be hidden away to survive the systemic oppression of colonization but now are found more central to the communities and/or near the sea for the purposes of the purifying rituals (Ellis, 2010a).

These spiritual healing sites have important geographical implications on empowering T2DM self-management. Communing with one's environment is a central pillar to Garifuna spiritual healing tradition, for example (Ellis, 2010a). Garifuna people seek spiritual-emotional cleansing, healing, and relief from chronic illnesses at sacred water pools, springs, rivers, burial grounds, and lands surrounding the *Dabuyaba*, and they use the forest for medicinal plant and sacred ritual objects (Ellis, 2010a). The Garifuna's sacred geographies include important sites along the Caribbean coast that mark their historic struggle for freedom and where re-enactment rituals allow participants to express their traumas and their suffering, as well their joy and their power, through song and dance (Ellis, 2010a). Garifuna rituals are informative of spiritual healing processes in sacred space; expressions of emotion are not repressed or hidden from public places. Healing from loss is found through communal catharsis at celebratory wakes and funerals where the space is safe for Garifuna people to experience powerful spiritual-emotional releases, feeling held by their community and their ancestors (Ellis, 2010a). Maurice spoke to this:

Even if you watch the way we mourn, we mourn different than most other cultures... We party when we mourn. We joke, we tell stories. We have, the night at a wake, you'll probably find a band playing. We have a saying that says 'ae a ya hay na a ya ha ahay na'

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– ‘we laugh and we cry but we are going to bury’. That is part of our culture here. Then we get together again and party again.

Though this interview excerpt describes rituals around death, which is distinctly different than promoting T2DM wellness, there are important parallels to consider related to diabetes care. As noted in the section on struggles and barriers, receiving a diagnosis can be a very emotional experience. It can signal the end of one’s prior life, identity, and lifestyle which needs to be mourned, grieved, and let go of to make room for accepting one’s new reality and taking the steps necessary for ameliorating one’s health, and effectively, to choose to go on living. Diabetes threatens one’s life and survival. Further, people are grieving those whom they have lost to diabetes while trying to manage their own condition. Most participants and key informants disclosed that they had recently lost friends, family members, coworkers, and neighbours to the disease. They told stories of the power of bringing loved ones to bathe at sacred sites during the processes of dying and letting go. There are sacred caves and shrines in Belize that have been used for healing rituals since ancient times (King et al., 2012). Therefore, preserving these sacred geographies is essential in the landscape of T2DM self-management and wellness promotion.

Participants spoke to the concepts of peaceful places, sacred spaces, and relationship to land in healing. They shared how some spaces held in the community domain were more conducive to meeting health needs than others. Six were glad they lived in smaller communities rather than the densely populated city. Living with more space and smaller populations granted people more autonomy over their lives. Controlling diabetes was easier, for example, in the peaceful countryside, away from the perpetual noise and chaos of the city. Felisha shared her frustration with the place and her relief around moving away:

Because living in Belize City and being a diabetic, it was kinda rough for me. Very, very hard. Cause of the noise and everywhere is congested. Coming to [Cayo] is very nice for me. I feel a relief. I've been so free. I love this place. I wish and I hope that I spend the rest of my life here...Because the people there [in Belize City], they are so animal, they are so, they are always upset. Everything touches. Everything gets on their mind.

Everything was so close together, you don't have that breathing space. And a lot of noise. And I couldn't handle the noise. Who wants the congestion, the houses so close, the loud music, and the people, they don't sleep...Anyone could tell you, in Belize City, it is not good for someone who is sick. So, I believe for someone who is sick like me, need to come out here in the countryside, where they can have a peace of mind.

Moving to the countryside helped Felisha gain peacefulness and connected her to the land where she grew numerous plants, where her children could play outside unhindered, and where she enjoyed increased autonomy in her diabetes management.

Land and space were important to Cynthia, Felicia, and Josefina who greatly appreciated that they could grow fresh vegetables, culinary herbs, and medicinal herbs in spacious garden around their homes. Cynthia was happy that her neighbourhood had very little vehicle traffic, adding momentum to her resolve to bicycle and walk everyday. Rosa, who lived centrally in a small town, explained that she used to walk and bike everywhere but that now her street was too congested with traffic, so it did not feel safe anymore. People were more likely to walk, run, and bicycle in the towns (and in the parts of towns) that had designated sidewalks, trails, and pathways. Participants greatly appreciated when their towns had built-in access to sports fields, arenas, trails, recreation spaces, outdoor gym equipment, exercise machines, and/or safe seaside

swimming, though these key elements were not available in many places. The male participants all described an enjoyable relationship with exercise and could be seen amongst the small collection of morning joggers using their towns and surrounding landscapes as instruments of their daily wellness routines. George lived in Belize City and described the first thing he did in the morning: “I run a mile and back. I run in the sun.” Maurice lived in a small town asserted: “The whole town has like, one gym. It’s a small little gym. But the whole town is a gym. You could just run.” Henry, who lived rurally, agreed: “I get up in the morning early, and I do maybe two miles, just jogging.”

Thus, the preservation of sacred sites, access to safe places for running and cycling, spaces of peace and quietude, fertile land for gardens, and intelligent urban designs that encourage physical activity are all important in the landscape of T2DM severity and prevalence reduction.

3.3.3 “There are so many that grow here”: Pervasive usage of local plant medicines

People had enormous faith in the power of medicinal plants, often more faith than they placed in allopathic medicine. Plant medicines were believed to be, experienced as, and conceptualized as spiritually harmonious, pure, natural, incapable of creating adverse effects, and God-given. They were often free, conveniently growing nearby and thus more readily available than pharmaceuticals, many of which were not as trusted because they were deficient in efficacy, causal of worrisome side effects, and/or unjustly profitable for distant corporations. Plants existed in the community domain, thus their usage served to maintain local power and autonomy,

resisting dependence. The traditional Indigenous medicines were thus symbolic of sovereignty.

All the participants used plants medicines for their diabetes self-management.

Participants plant medicine usage could be conceptualized in three categories, namely, those who exclusively use plants, those who prefer plants but complement them with pharmaceuticals, and those who are committed to following pharmaceutical prescriptions but complement them with plants.

The first category of plant medicine usage includes those who exclusively use plants for diabetes, such as Rosa. She refused to use pharmaceuticals and controlled her blood glucose levels with medical plant preparations from her herbal doctor (who is also a retired medical doctor). She expounded:

[I use] some herbs that... for the past two years I've been drinking three times a day. She [the herbal doctor]¹⁸ makes it. Every six months or so, I do a complete blood test, and she checks the A1C. It has gone down. One time, it used to be like two hundred. Whoo! For ages.... I don't take any pills. No. I don't like pills. I don't even drink Tylenol.

Rosa did not know exactly which combination of plants she was taking, but she had faith in their efficacy and was determined against taking pills. George discussed how he had tried pharmaceuticals that only exacerbated his condition, and now he only believed in his herbal preparations. He made his own herbal eye drops and pain medications. He shared: "That start to make my eyes heal... All the medication I was getting, it wasn't working... I was using, like

¹⁸ This particular herbal doctor was also a retired physician who had a relationship with local HCPs and an arrangement for glucose testing.

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three medication... for the pain... Herbs, for that purpose, they are very, very effective.” These participants still interacted with their western-trained medical doctors, but they assumed more autonomy and control over their treatment plans, utilizing several of the local plant medicines available to them. They were empowered by key flora in their environment.

The second category of plant medicine usage was those who preferred plants but complemented them with pharmaceuticals for diabetes, such as Josefina. She used pharmaceuticals when they were available in her town and she could afford them, but this was not consistent, so she also accumulated plant medicines from her gardens and trees, from neighbours, and from acquaintances passing through town. They costed her very little money and were easily accessible. Josefina pointed out the plants were growing in her yard and neighbourhood, imparting:

I have fevergrass tea that I buy, and sage... I use moringa...It's a flower, white. That's it right there. And the soursop too... Whenever somebody else come tell me about the herbs, I'll buy it, and I drink it, and it helps.

She did not require certification, regulation, or standardization; she trusted in plant medicine categorically, she trusted in the grassroots information sharing, and she was keen to use them without necessarily distinguishing between different plants. Maurice had been only very recently diagnosed. He wanted to use insulin for as little time as possible, perhaps a few weeks, until he adjusted to his new diagnosis. He shared: “I am on insulin, but I'm trying to ween myself off of that. I'll be trying neem.” He planned to work with a renowned Belizean herbal doctor to control his blood glucose with plants like neem because he considered them more natural, accessible,

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and effective, and he did not want to become dependent on foreign pharmaceuticals.

Instinctively, he wanted to avoid taking pharmaceuticals and trusted what medicines could be found in his own environment.

Yvonne described her preferences for herbal medicines that empowered her by saving her money and enabling her to avoid going to the clinic for appointments and the pharmacy for refills. She lived near numerous medicinal plants even in Belize City. Yvonne communicated:

I would take a lot of natural stuff like I use turmeric, ginger, cinnamon, moringa, things like that.... I'm using it as a powder, but my neighbour has a lot of moringa trees, so, I will go and pick the seeds because the seeds are good too. And the leaf. I would dry it as you dry tea. Then you drink that.... Well, I haven't been to the doctor for diabetes in a long time.

She had an aversion to going to the clinic and felt that natural products supported her health. Her processes of sharing plants with her neighbours and preparing the medicines were empowering interactions with her social and environmental surroundings.

Felisha sometimes purchased anti-diabetic drugs but would not take them everyday because she found them ineffective, and she preferred to use plants medicinally when she could. There were numerous plants growing near her house and her neighbours' houses which she could use for T2DM. She explained:

I eat the aloe vera...The neem work for me... The soursop clean your blood...When it comes to the pills, you can't depend on the medication, because that's a waste a time...We have people who have it in their yard, and you can ask them to give it to you.

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People have moringa, they can give it to you.

Participants listed plants like neem, moringa, soursop, and numerous others commonly known to help with treating diabetes blood glucose levels and/or diabetes-related symptoms such as skin irritations, numbness, poor circulation, sleep disturbances, and fatigue. They typically used several herbs together in concert with western pharmaceuticals to complement. Participants were empowered to use their local plants, so even in places where biomedicine was not available or in times of medication shortages, they were still modulating their blood glucose levels with medicines found in their communities.

The third category of plant medicine usage in T2DM included those who are committed to using physician prescribed medications but use plant medicines for issues which may or may not be related to diabetes. There was a little known about contraindications or what may or may not interact with pharmaceuticals or other medicines. Natalia had a complicated case of T2DM with co-morbidities, and she relied on prescribed medications but also used herbal medicines for blood glucose, as well as for dengue fever, high blood pressure, and other maladies. She explained:

When you boil the papaya leaf, it's for dengue. Yes. It is for dengue. When you get dengue, you can't drink aspirin. And I know I need my aspirin. So, I boil it to drink, in case for the dengue. And people say it is good for the sugar. I just drink it like natural herbs for me. That's not everyday that I drink it. Sometime I take it, but most of the time, I just stick to my medication...I have the Metformin, Glimepiride, and Tylenol, and I take the aspirin. It's like seven of these, or six, a day.

Cynthia had worked as a licensed nurse providing diabetes prevention and health-promotion workshops before her recent retirement. She was dedicated to following her physician's treatment plan for her including taking prescriptions medications daily. She also kept a garden with some herbs, regularly used plant medicines that grew nearby, and enjoyed learning from other Belizeans about what they used. She described:

You hear about all types of herbal medication that you can take along with your pills. All kind of herbs...I drink the noni. That is what I use for diabetes. Two leaf for cup when dry for tea. I use the moringa, with parts or just eat it like that, or drink water after it. Two a day. I drink the gumbo-limbo bark to make tea with it. So, this tree they tell me about it, and I use it. I use it. But I don't know if it helps because I still take my medication. But I still drink it as a complement...I am careful. My thing is, if I don't take my diabetic medication, my organs will damage quick. So, I stick to my pills. I stick to my pills...I stick to it. I take the herbal tea as a complement, but I stick to my medication.

There were no participants in this study who did not use plant medicines to some degree. It is unknown which percentage of the population of Belize uses plant medicines daily, but it is likely a high percentage, so there is merit in pursuing more knowledge in the directions of understanding more fully, for example, what plant medicines people are using, in what frequency and consistency, how they impact T2DM, and how they interact with other medicines. When asked if they discussed their plant medicine usage with their physician, participants typically did not. A few believed that their HCP would be unreceptive and even angry due to their previous experiences of having difficult patient-provider communication. This led to fear of disclosure and partial reporting. Though many of these plants have not been studied in the same way as

prescription drugs, people were not willing to wait around for empirical evidence, nor did they feel it was a prerequisite to their usage. This could be considered a very large natural experiment if monitored for results.

The flora of Belize is an important part of the healing landscape for people diabetes, offering medicines that grow freely from the land and shared by neighbours, family, and friends. The pervasiveness of plant medicine usage suggests many possible implications for clinical practice, as well as many leads into areas of new ethnomedicinal and ethnopharmacological diabetes research. These directions would require local Indigenous leadership and community participation to prevent exploitation, appropriation, and cultural harm (Cidro et al., 2017). Plant medicine was a very important part of health care practices in Belize on the individual, community, and cultural levels. The culture of plant medicine usage speaks to the people's relationship with the land, with nature, and with faith.

Chapter 4: Discussion

In the discussion section, I integrate the findings from my study into existing literature on its main themes from global academic sources. I discuss how my findings fit with current thought on chronicity homework, spirituality in diabetes management, and the relationship between Indigenous medicines and biomedicine. I discuss how my research contributes to this literature. The implications for health care providers and planners are then explored, as well as areas for future research, and the strengths and limitations of the study.

This study identified that the daily struggles that existed for those living with T2DM in Belize included challenges of navigating a tiered health care system, difficulties communicating with HCPs, setbacks of facing diagnoses and complications, lacking comprehensive prevention and education programs, and needing more social supports. People living with T2DM in Belize often use spiritual/religious practices (e.g., prayer, fast, meditation, ritual, sacred texts) that build their commitment to health-promoting behaviours, lessen the otherwise compounding stresses of dealing with chronicity, and provide the lift, strength, and endurance needed to live each day. Spiritual/religious practices helped people overcome addictions to sugar and alcohol. Home prayer practice was integrated into daily self-management tasks. It provided participants with a direct spiritual connection to a higher power, unlocking psycho-spiritual help in many forms (e.g., acceptance of their diabetes, determination to be healthy, lifestyle guidance, protection in surgery). Home practices centered power in the personal domain as opposed to in a church or in a clinic; participants differentiated their spiritual practices from the need to attend church or abide by religious authority figures. Similarly, many valued self-responsibility and autonomy in providing for their own health care (e.g., avoiding clinics, making their own medicines). Using

medicinal plants was a culturally grounded tradition and a symbol of sovereignty. There was trust and belief in local plant medicines which were reliably available, affordable, and effective.

Access to outdoor sacred sites, peaceful countryside, fertile land for gardening, roads safe for cycling and walking, urban environments built to encourage exercise, and locally growing plant medicines were important aspects of the geographical conduciveness for T2DM health and wellness. These themes will be explored in the discussion section in the order they have been presented in the results section, and findings will be integrated into existing literature.

4.1 Chronicity Homework

Patients and their families are increasingly expected to carry out a complexity of tasks, including clinical tasks, with no medical training. Medical anthropologists Mattingly and colleagues (2011) conceptualized this trend of moving health care tasks from the clinic to the home as creating “chronicity homework”. By advancing the notion, authors drew attention to the kind of cultural work carried out in the home (also called the “popular health sector”) in the day-to-day management of their chronic conditions. Such low-tech social technologies and day-to-day strategies or “the work of coping”, these authors argue, have received minimal attention in the academic literature. My findings have added that similarly, spiritual and faith-based coping practices in this setting happened mostly at home without attention, recognition, or valuation. There is a gap in documentation of spiritual/religious practices involved in chronicity homework.

This movement of work away from clinical settings has saved health care systems tremendous amounts of money, leading to its popularization (Fierlbeck, 2011). Health care

economists promote the strategy of moving as much care as possible from high-resource settings (such as hospitals) to low-resource settings (such as homes and long-term care facilities) to conserve health care spending (Fierlbeck, 2011). This trend shifts the impetus and burden of care away from the formal health care system to the patient and their family. Social scientists have called this a form of “colonization of the popular domain” and a vehicle for governmentality (Mattingly et al., 2011). Foucauldian scholars have argued chronicity homework serves to function as subjugation of the patient, to set experts apart from patients, together with other powerful social technologies that maintain the institutions that force capital to flow to those already living in affluence with societal status and institutionalized credibility (Mattingly et al., 2011). People who are facing chronicity then become under the management and discipline of clinical experts not only in the hospital and the clinic, but now also within the domain of their own homes.

Mattingly and colleagues (2011) have argued that, while these conversations are crucial, what also needs to be understood is “how chronic conditions are lived, even creatively lived, by individuals, families, and in communities” (p.351). From a separate body of work in sociology, anthropology, and feminist scholarship, the idea of “kin work” had previously emerged (Stack & Burton, 1993). Kin work is defined as “the collective labour expected of family-centered networks across households and within them. It defines the work that families need to accomplish to endure over time” (Stack & Burton, 1993, p.160). This work arose out of studies on the lifecourse of the individual; there was a need to extend this to the lifecourse of the family for a fuller picture (Stack & Burton, 1993). Familial expectations around a family member’s kin work roles and responsibilities can be at times oppressive, though may at times be empowering

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(Stack & Burton, 1993). I would argue the same is true of chronicity homework. I would also argue that there is overlap between chronic homework and kin work, and that this is often a gendered experience with working mothers carrying a lot of the burden. This can be fit into literature by gender scholars on the concept of “care work” about the work done in families and in society that may be paid work or unpaid work, with the valuation having impacts on (and implications for) gender inequality (England, 2005).

In Belize, chronicity homework was supported by kin work, and kin work was typically done by women. Families were made stronger and more resilient to T2DM through the unpaid caregiving work of women. Further, there was transnational kin work at play. Participants who had family members in more affluent countries were better resourced for self-management because their loved ones sent them glucometers, testing strips, medications, and other supplies. Those with family members professionally employed in Belize were similarly better off than those with less affluent families (inclusive of extended families). Those who lived with more isolation had fewer T2DM chronicity homework supports. This was exacerbated by the isolation required under covid-19 public health restrictions.

My study found very real, systemic barriers to health for families enduring poverty while trying to shoulder T2DM self-management tasks. It also found plenty of hope, strength, endurance, and resilience. There were empowering aspects to self-management and room for creative reinterpretations of health care. To focus on the burdens represented in chronic homework, kin work, and care work, is not to negate the beauty, strength, resilience, and meaning-making participants derived from performing the tasks. While Foucault’s concern with medicalizing the home remains valid, another part of what was happening in this setting was the

spiritualization of the medical. Prayers were said while testing glucose levels, prayers were said while preparing and eating nutritious foods, and prayers were said while preparing plant medicines, all at home, as a continual part of self-management, within the culture of the home.

Moving away from the clinic to the home, a domain of personal power, triggered new manifestations of health care grounded in the patients' home culture. This represented the potential to improve cultural safety in health care. It began the work of building connections between the often-discordant realms of the medical and the spiritual. It also contributed to the movement toward more holistic and person-centered health care.

4.2 Spiritual Practices as Diabetes Self-Management

Going into the study, the interview guide¹⁹ did not have a major component dedicated to spiritual/religious health. Using Constructivist Grounded Theory allowed for the participants' stories to lead the research, for themes to organically emerge, and for theory to be developed from the ground up. It became clear in the first interview that spirituality/religiosity was a major support for coping with chronicity in this setting. While my study did not seek to measure spirituality/religiosity empirically, I found many studies that did. There are issues with this.

One critical issue arising from attempts to measure Indigenous spiritual practices. This is because applying a biomedical epistemology to appraise traditional Indigenous knowledge is a harmful colonial approach that assumes one cultural worldview is superior and can validate or

¹⁹ It was originally the Diabetes Quality of Life Questionnaire, as mentioned in chapter 2.6. I amended and added to it through the iterative Constructivist Grounded Theory process with participants, informants, and stakeholders for greater relevancy, comprehensiveness, and cultural safety.

disprove the other (Allen et al., 2020). Waldram argued, “The use of biomedical concepts and the English language in examining traditional medicine tends to obscure the form and function of the latter” and that “even the basic concepts of *traditional* and *medicine* are fraught with Eurocentrism and English-language biases” that may be “very crude approximations, at best, of complex Indigenous thought” (James B Waldram, 2000, p.607).

In Koenig’s *Concerns for measuring “spirituality” in research*, scales designed to measure spirituality are critiqued as producing vaguely defined, redundant associations with mental health (Koenig, 2008). If, for example, participants agreed that they feel peaceful and have a reason for living, they rated higher in spirituality which was correlated to them having good mental health. This, Koenig argues, is an obvious finding that represents circular thinking. Research has since moved toward measuring specific spiritual/religious practices and their correlations to specific health behaviours (Roger & Hatala, 2018). This study named some specific spiritual practices and health behaviour practices (e.g., praying, meditating, staying home, using plant medicines) that could be measured in future research.

A quantitative analysis between religiosity and self-management in older adults with diabetes in Mexico, Belize’s neighbour to the north, (Rivera-Hernandez, 2016) found a positive association, confirming earlier work by Newlin et al. (2008) and Hill et al. (2006). These authors illustrated that those involved in their church activities exercised more, smoked fewer cigarettes, and drank less alcohol than their peers in the control group. While several studies have “used church attendance as the main measure of religiosity” (Rivera-Hernandez 2016, p.9), my study clearly indicated that in Belize, though many people have faith in God and spiritual practices are key to coping with T2DM, they but do not necessarily attend church or religious events on a

regular basis. Therefore, church attendance would not be an adequate measure of religiosity or spirituality in this setting.

Another study demonstrated that in youth (aged 11 to 15) in Canada, those who had higher spiritual health scores engaged in less health risk-taking behaviour (e.g., less smoking, alcohol use, drug use, sex); the study concluded that spirituality is a protective factor (Hatala et al., 2020). Spiritual practices in Canadian youth were found to help people to process emotionally painful experiences, to reclaim positive outlooks, to make meaning of difficult times, and to find better ways of handling challenging situations in the future (Hatala et al., 2020). My findings concur that in Belize, spiritual practices helped people to transcend denial, stress, negativity, health-harming behaviours, addiction, and daily struggles in ways that were necessary for them to carry on.

My findings suggested that optimizing spiritual practices that are health-enhancing would assist in improving both T2DM clinical management and self-management; this is in agreement with similar findings from countries such as Iran, Indonesia, Malaysia, Thailand, Sudan, Nigeria, Sweden, United Kingdom, Australia, Canada, and the United States (A. M. Ahmed, 2003; Arifin et al., 2020; Brown et al., 2013; Heidari et al., 2017; Jacklin et al., 2017; Lundberg & Thrakul, 2013; Marshall & Archibald, 2015; Permana, 2018; Rubin et al., 1990; Saidi et al., 2018; Unantenne et al., 2013). Rather than dismissing spiritual/religious practices categorically as unscientific or admonishing patients who deviate from treatment plans for spiritual or cultural reasons, HCPs can open dialogue with patients to assess how best to work together. Fasting, observing Lent and other rituals, praying, meditating, and referring to sacred texts are some of the spiritual practices found in Belize that represented a source of wellness and health resource

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underutilized by HCPs. Health Care Providers and planners can enhance patient health by being open to discussion around T2DM care and collaborating with spiritual/religious leaders who have influence over the same communities they practice in.

A cross-sectional study on spirituality, social support, and diabetes in Peru defined social support as nurses counseling and collaboratively goal-setting with the patients (Krederdt-Araujo et al., 2019). The literature in this area more typically defines social support as the care one receives from one's spiritual community. Authors found that when nurses provided spiritually intelligent social support services in their regular visits with diabetes patients, adherence levels to care plans increased. Though health outcomes were not assessed subsequently, authors theorized that adherence to care plans would be expected to improve outcomes (Krederdt-Araujo et al., 2019). They concluded that this strategy could improve clinical management of T2DM by mobilizing spiritual and social supports to optimize patient self-care. My findings confirmed that these are worthy directions for health care to pursue in Belize. While studies often lump together spirituality with social support, this assumes people attend (church, mosque, etc.) and benefit from the outreach of these communities (Darvyri et al., 2018; Permana, 2018). My interviews showed that the individual's at-home spiritual practices are important elements of T2DM self-management, and key informants reported that these were even more crucial in the times of covid-19, thus they merit more inquiry in and of themselves. This line of questioning would be useful to understand spiritual practices separately from social support, as well as in relationship to the fluctuations occurring within the range of people's access to social supports and levels of isolation.

Living with diabetes predisposes people to higher risk of psychological challenges like

depression and excessive stress, both of which already disproportionately affect those living with poverty (Sam et al., 2015; Weaver & Mendenhall, 2014). While depression and stress are typically more prevalent in people living with diabetes, the Belize situation may or may not agree with the literature. The small sample of people in this study consistently reported very little to no stress, but this cannot be generalized to the population at large. In a sample of impoverished youth living in Belize City, for example, different results could be anticipated. Stress and depression were possibly under-reported because of stigma, lack of language around mental health issues, under-diagnosis, and/or low help-seeking behaviour. Alternatively, the pervasive feeling that was shared by participants (e.g., “I honestly have no stress”, “I don’t get down”, “I don’t let it bother me”) could be indicative of the richness of the cultural and spiritual/religious practices in Belize. Participants laughed a lot, even when discussing the gravest consequences of having the disease, with remarkable capacity to find humour in dark circumstances and lightness in chronicity. Scheper-Hughes wrote about resilience as people “having a talent for life” and the ways people adapt and endure not only chronic illness, but also tough living conditions perpetuated under the forces constructed by macro political economic movements (Vign 2008, p.18). Participants exercised spiritual autonomy when faced with oppressive circumstances. Resilient spiritual health originated in the domains of personal power, not in the domain of institutionalized power.

4.2 Ethnobotany, Cultural-Spiritual Healing, and Biomedicine

Ethnopharmacological literature has begun to uncover that hundreds of medicinal plants in CASA are used for treating diabetes and diabetes-related complications and symptoms (Ferrier

et al., 2018; Giovannini et al., 2016). My findings agreed, having easily gathered dozens of names of relevant plant medicines from this small sample of participants. This study agreed with other work in Central and South America that understands plant medicines to be traditional medicines with cultural and spiritual significance to Indigenous and local populations, and while knowledge and application are diverse, place-specific, and with variation, they are generally popular, accessible, and effective (Ferrier et al., 2018; Giovannini et al., 2016).

Belize has preserved many forests and special flora, as well as cultural heritage, and thus supporting the protection of plant medicines (Chanecka, 1998; Ferrier et al., 2018). Informants at the National Institute of Culture and Heritage (NICH) and the University of Belize discussed how because eco-tourism was an important industry to Belize, many people and organizations were interested in creating plant medicine experiences for visitors, as well as expanding economic, educational, and medicinal opportunities for local people. While twenty-five percent of Belize citizens did not have access to public health care, traditional Indigenous healers (including herbalists, midwives, and spiritual healers) were accessed by many, especially in remote villages (Bowser et al., 2013; Chanecka, 1998). Administrators discussed the tension they experienced between not having adequate funding for covering all Belizeans' health care costs while also not wanting to turn away people who travel to their clinics over the Guatemalan border. Previous studies indicated that traditional healers were essential in Belize communities (Chanecka, 1998; Waldram & Hatala, 2015). My study found that people continue to turn to local medicine people, as well as knowledgeable neighbours, who hold an array of speciality areas. Community Health Workers and Health Educators work their caseloads in their own communities, and they are organized as connectors between their communities and the formal

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health care system. In the 1970s, there were a small number of traditional birth attendants trained for upgraded skills in western medicine, and there was presently a council of nurses and midwives (Maraesa, 2012; NMCB, 2020). Given the prevalence of diabetes in Belize, these health workers undoubtedly dealt with gestational diabetes, and it would be helpful to understand more about the cultural, spiritual, and plant medicine treatments used in these cases. All the participants in my study utilized plant medicines in their self-management routines. The pervasiveness of plant medicine usage suggested the need for more research on the usages of plant medicines, as well as their interactions with western medicines. Deeper understanding of how integrative medicine could best work in this context is merited.

There was one case study on HIV/AIDS in Belize with findings that Indigenous Mayans felt torn between two systems of medicine, traditional Indigenous healing (inclusive of plant medicine) and biomedicine (Waldram & Hatala, 2015). Authors warned against the eradication of traditional healing and the domination of biomedicine, and instead urged that the two medicine systems dialogue through engaging with their areas of mutuality or “windows of compatibility”, building on similar work in South Africa (Dickinson, 2008). Overlap and agreeance were found to include that practitioners of both systems were primarily concerned for their patients’ health, held high standards of patient self-responsibility, built their practices on long-established epistemological legacies, and used intricate procedures for diagnosis and treatment (Waldram & Hatala, 2015). My findings agreed that there were two systems of medicine in Belize, and that people felt torn between them. This tension represented an unnamed barrier to health care. This tension requires that patients maintain the unspoken segregation of systems, placing another burden on their shoulders. People had to choose between a culturally

safe system and a medically established, more resourced system, or else they had to hide their participation in one from the practitioners of the other. This extended beyond the Maya peoples as found by Hatala and Waldram (2015) to other Belizeans as well.

Hatala and Waldram (2015) found that traditional Indigenous healers welcomed dialogue with biomedicine practitioners, but this had never been clearly reciprocated, so that going forward would require bridge-building from the side of the formal health care system. Given that practitioners of both systems are concerned with the health of the patient, theoretically both have shared motivation to improve communication across systems. Case studies on intercultural health initiatives in Guatemala, Chile, Colombia, Ecuador, and Suriname described the shared principles required, namely, mutual respect (e.g., between individual practitioners, systems of medicine) and openness (e.g., to being in relationship, adapting to new learnings) (Mignone et al., 2007). In integrative scenarios in international settings, biomedicine practitioners have learned from the cultural safety movement, and traditional Indigenous healing practitioners have organized associations to communicate their standards, needs, aims, and visions to health care system (Allen et al., 2020; Dickinson, 2008).

These initiatives require resources and come with legal considerations; they require careful selection between practice models, role clarity, and appropriate surrounding agreements (Mignone et al., 2007). In various settings and models around the world, Indigenous-led intercultural health services have demonstrated benefits, such as timelier patient uptake of services, faster emergency response times in remote settings (Allen et al., 2020; Mignone et al., 2007). Such interventions have improved trust in HCPs, community and cultural pride, childhood vaccinations, patient satisfaction in cultural safety, access to prenatal care, infant

weights, addiction treatment centre retention and drug urine tests, and remote maternal and infant birth outcomes (Allen et al., 2020). They have reduced emergency department use, staff turnover, fetal alcohol syndrome incidence, malnutrition, and HIV mortality rates (Allen et al., 2020). Key informants shared their enthusiasm for this direction in Belize.

Diabetes self-management required self-responsibility; this is facilitated by cultural-spiritual practices partnered with culturally safe health care (Allen et al., 2020; Arifin et al., 2020; Unantenne et al., 2013). While colonization has oppressed traditional Indigenous healing, and biomedicine has been privileged with more resources and status, the original medicines of Belize have survived because they are needed. Dialogue across systems of medicine would require community engagement to ascertain proper cultural-spiritual protocols and protections for plant medicines and their uses, as well as other forms of traditional Indigenous healing. Further research is needed to understand the interactions of and to improve the dialogue between Belizean cultural-spiritual and plant medicine practitioners and HCPs.

4.3 Implications for Health Care Providers

Literature has recently emerged on the clinical management of diabetes for those who practice fasting. It has outlined risks (e.g., hypoglycemic events, malnutrition) and benefits (e.g., weight loss, reduced insulin intake, lower risk of heart attack and stroke) for patients and providers to be aware of (Grajower & Horne, 2019). There is some literature on Ramadan-specific diabetes care (Al-Arouj et al., 2010; Lee et al., 2017). My findings agree with this literature that it is important for HCPs to ask their patients about health-related spiritual practices

such as fasting to advise patients on diabetes management implications of their spiritual fasting practices, and to work collaboratively with patients to develop appropriate care plans.

Similarly, HCPs can ask about spiritual practices such as prayer. Medical doctor and researcher Rossiter-Thornton described a non-denominational approach to addressing patient-centered needs that included a model called the Prayer Wheel with eight types of prayers that can benefit health (Rossiter-Thornton, 2002). My research findings suggest that this tool, or a similar tool created in the Belizean context, would likely: 1) be welcome by patients, 2) facilitate patient-provider communication, 3) support adherence to care plans, 4) promote positive health behaviours, and ultimately 5) help improve health outcomes. While physicians may be reluctant to address spirituality as a part of health care provision, there are important implications to clinical practice which can be addressed with a few short questions embedded into medical history interviews (George et al., 2013; Koenig, 2004, 2014; Rossiter-Thornton, 2002).

The literature calls for training HCPs on overall awareness of their patients' cultural and spiritual practices, spiritual resource assessment, positive associated factors, and further, on negative shifts to look out for (Roger & Hatala, 2018). These can include depression and apathy due to loss of faith in God with diagnosis, debilitating guilt originating from a sense of failing to live up to stringent religious standards and expectations, negative fatalism deterring self-help effort, and anti-biomedical science sentiment (Roger & Hatala, 2018). Though none of my participants described negative aspects of spirituality/religiosity in this setting, it is important to acknowledge this is in the international literature. My findings agreed with previous work suggesting that it can be beneficial for HCPs to routinely ask about patient spirituality in their medical history taking (Heidari et al., 2017). HCPs can improve adherence to care plans through

being open to patient spiritual practices, referring patients to spiritual resources, and engaging with faith leaders (Heidari et al., 2017). The findings also suggested that individual HCPs in Belize can facilitate improved outcomes by sharing diabetes information with faith leaders and by becoming more knowledgeable about local spiritual practices, cultural activities, and resources, but that these efforts would further flourish with support from health care administrators.

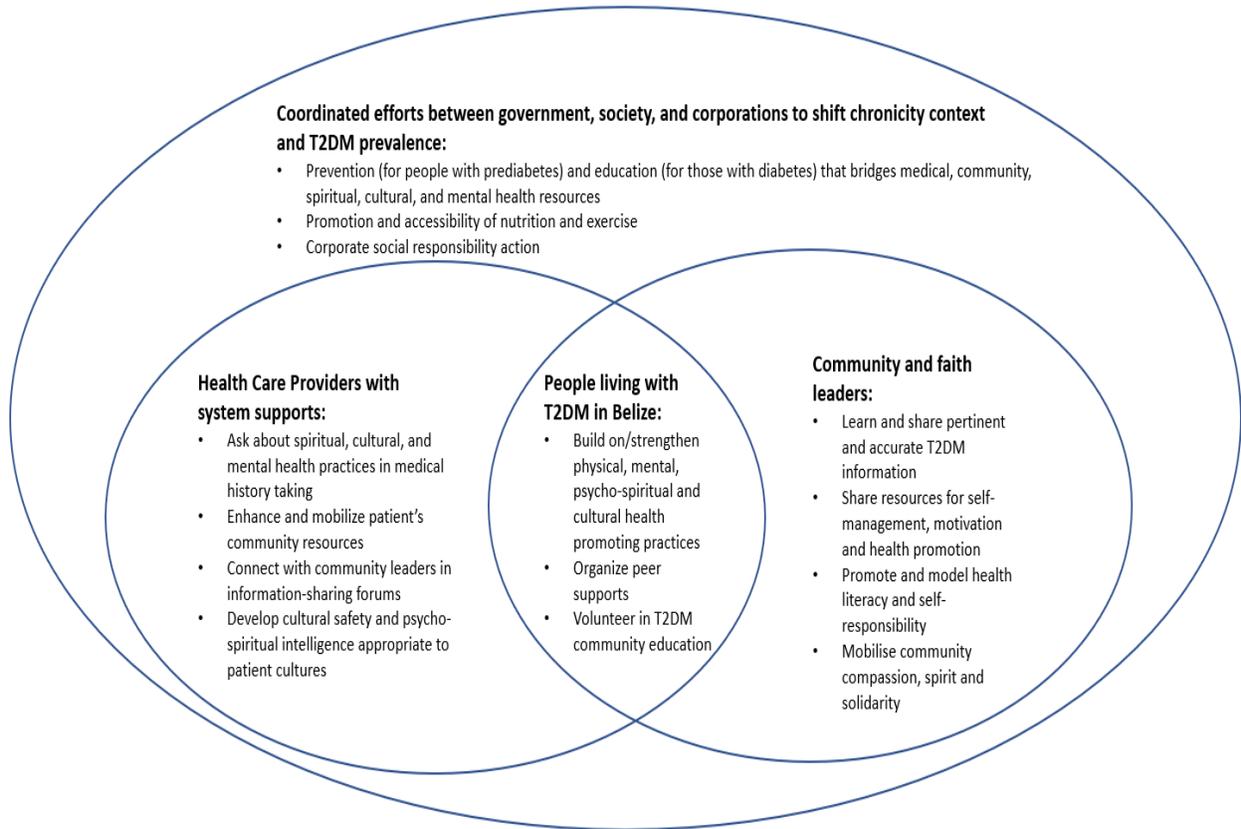
An important area of emerging health care literature involves concepts like diversity, inclusivity, cultural competency, cultural safety, cultural sensitivity, cultural humility, anti-racism, and anti-oppression. It is key for the purposes of health equity to focus on how these concepts overlap with barriers to care, Indigenous rights, and social and political determinants of health (Crowshoe et al., 2019; Curtis et al., 2019; Jacklin et al., 2017; United Nations, 2008). For example, in a 2019 review of international literature on cultural competency and cultural safety, the former was found to be a requirement of achieving health equity for Indigenous populations (Curtis et al., 2019). While mandating cultural competency for HCPs may be a useful step in the right direction, fostering cultural safety is more important because it goes further than simply learning about the culture of the patients being served; it addresses underlying power imbalances that are otherwise continually reinforced in societal institutions and in provider-patient relationships that perpetuate health inequities (Curtis et al., 2019). Given that the existing structures of power serve to perpetuate the living conditions that impede health equity for Indigenous peoples in Belize, the health care system (and health research) must address determinants of health underlying problems of preventable suffering with diseases like T2DM (DiAngelo & Dyson, 2018; Jacklin et al., 2017; TRC, 2015). To effectively address chronic

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illnesses like T2DM, health inequity and the social determinants of health must be addressed by moving towards culturally safe practices (Curtis et al., 2019; ICS, 2019; Krotz et al., 2018; Tremblay et al., 2020; Walter & Andersen, 2013). The figure that follows this subsection depicts a visual summary of recommendations for governmental, societal, provider, patient, community, and faith leaders' efforts for improving services and quality of life for those with T2DM with a mind to decreasing its prevalence. See Figure 4.3 for a visual model that summarizes recommendations going forward.

Figure 4.3

Recommendations going forward



4.4 Implications for Public Health Care and System Planners

The health care system can further facilitate care for T2DM patients through destigmatizing mental health issues. Key informants described the need for screening all T2DM patients for depression and mental health issues. The BDA started routinely educating patients that the mental and emotional aspects are important aspects of health, using non-judgemental inquiries, and offering links to supports and resources for the people that come through their doors. More such efforts could help those living with T2DM in Belize through the difficulties and struggles of chronicity.

Acknowledging and meeting the need for mental health services can be helpful in reducing social stigma, reducing depression and anxiety, and improving T2DM outcomes (Hackett & Steptoe, 2017; Permana, 2018; Weaver & Mendenhall, 2014). Telling people matter-of-factly that mental health is an important part of health, that depression can be a part of diabetes but does not have to be, and that there is support available can be very helpful to overcome a cultural climate which was described by informants as: “We’re a people who don’t want to talk about our health, especially old people”, and “If you say you have depression here, it casts you as an outsider, so, no people won’t talk about themselves like that”, and “Diabetes, like cancer, people are afraid to talk about it because they don’t want people to know. If they talked about it, they could help it. But they give up hope.” There were stories of a friend whispering confessions that of having diabetes after years of hiding it, and of diabetes being confused with HIV/AIDS. It would be useful to get underneath this issue to help people share about diabetes in a safe space, and there is a role for health system planners in this.

Day camp programs aimed at education for prediabetic youth in the United States have

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been successful at reducing prevalence and improving outcomes; physician organizers stressed the importance of consistent messaging (Stevens, 2019). Authors defined the struggle against diabetes as a war against the violence enacted by voracious sugar and sweet beverages (SSB) marketing campaigns, evoking a powerful sense of urgency (Stevens, 2019). Stevens (2019) noted the challenge posed by the fact that eating right and exercising do not show youth immediately gratifying effects while sugar and sweet beverages consumption does. My key informants discussed how the Belize economy has been transitioning toward more sedentary forms of employment, and that their population was increasingly consuming processed foods. Further, drinking sugar and sweet beverages was often perceived as a symbol of higher social status, and that the companies that produce them often sponsor elementary schools which would be otherwise underfunded. Sugar and sweet beverages billboards can be seen central in schoolyards promoting consumption to children, as permanent influential messages. Still, evidence has shown that as little as two-day diabetes day camps filled with education and fun sports make a demonstrable difference in health outcomes while simultaneously mobilizing communities (Stevens, 2019). Supporting and evaluating educational day camps and prevention efforts in the context of Belize is an important area for future study.

Studies in marginalized communities in the United States have also shown success in faith-based intervention strategies with adults with T2DM from Pentecostal church groups (Marshall & Archibald, 2015; Stevens, 2019). My findings described an underlying need for more T2DM prevention and education programming in Belize and suggested that intervention approaches such as collaborative educational sessions with combined health care and faith organizations would be beneficial in slowing the spread of diabetes in Belize. Bringing people

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together from the silos of biomedicine and traditional Indigenous medicine could be beneficial in promoting interdisciplinary dialogue, understanding, problem-solving, innovation, research, and development initiatives with the shared purpose of improving care for people living with diabetes in Belize.

Rates of T2DM among the Indigenous peoples of Belize, including the Mayan (Yucatec, Mopan, and Q'eqchi'), the Mestizo, and the Garifuna peoples who made up roughly 65% of the entire Belizean population, were some of the highest in the country (MoH et al., 2018; SIB, 2013). Despite high prevalence rates, there were no T2DM prevention, education, or treatment strategies that involve cultural safety or cultural sensitivity with the Indigenous peoples (MoH et al., 2018; SIB, 2013). In fact, there were no comprehensive diabetes prevention or education strategies in the country at all (MoH et al., 2018). T2DM prevalence has been impacting Indigenous Mayan communities most dramatically due to histories of colonization, poverty, inequity, and isolation, all of which have eroded access to traditional foods and health practices (Ferrier et al., 2018; A. R. Hatala & Waldram, 2016). Research in other Indigenous contexts like Canada suggests that T2DM can often be prevented and managed with adequate nutrition and exercise, factors that can be supported through culturally appropriate health education and promotion interventions, as well as progressive socio-economic and health policies (Crowshoe et al., 2019; Jacklin et al., 2017; Krotz et al., 2018; McGavock, 2015; Ndjaboue et al., 2020; Tremblay et al., 2020). Prevention, education, and treatment interventions that are grounded in the cultural understandings of health of the people they serve can most positively affect T2DM outcomes (Oetzel et al., 2017). Supporting culturally safe self-management and health services for Indigenous peoples living with T2DM in Belize would be beneficial.

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In a joint position statement, the American Association of Diabetes Educators and the Academy of Nutrition and Dietetics, asserted that diabetes self-management education and support (DSME/S) is crucial for patients to gain the knowledge, skills, and abilities necessary to cope with their disease (Powers et al., 2017). Diabetes self-management education and support has been shown to reduce incidences of T2DM complications, hospital admissions, readmissions, and lifetime costs, and it is well-accepted by patients (Powers et al., 2017); however, not enough people in Belize were receiving the education they needed. There were a few ways that people in Belize learned about T2DM. The first was through diagnosis in a clinical setting for those who access a health care provider (MoH et al., 2018). This was far from ideal for the purposes of prevention, and it typically left the patient without adequate information or resources to self-manage their disease. The second was through outreach by Community Health Workers who worked in rural and remote communities. In the past, Community Health Workers were tasked with project-based, diabetes-specific education, but it has been demonstrated that they were too overwhelmed with heavy workloads to take on more, and this has only increased as they shoulder additional tasks related to covid-19. The third way people learned about diabetes was through outreach efforts of the Belize Diabetes Association (BDA) whose mandate is to promote education and support for those living with diabetes. While the BDA has a handful of dedicated staff, they are over-stretched, under-resourced, and operating with large geographical gaps. Overall, there are large disparities where a comprehensive, universally accessible diabetes prevention, education, and treatment strategy is needed.

There is an area of literature on diabetes education. When diabetes self-management education was made available to people, the main reasons patients did not attend are accessibility

issues, psychological blocks, and cultural incongruences (Horigan et al., 2017). Healthy lifestyle mentorship and diabetes education programs that are developed and delivered by members of Indigenous communities are typically more accepted by Indigenous recipients and more impactful across the health of the communities (Petrucka et al., 2016; Potaka-Osborne & Gifford, 2018; Stevens, 2019). Community-based diabetes self-management education and support delivered by Indigenous community members is therefore an important strategy. The Institute of Patient- and Family-Centered Care goes further to stress the importance of T2DM interventions that also understand the influence of family members on those living with the chronic disease (Baig et al., 2015). Family members have very significant impact on the T2DM patient's self-management behaviours (Baig et al., 2015). Research also shows that family members should also be included in educational interventions because this improves adherence to lifestyle changes (e.g., smoking cessation, weight loss, exercise, diet) and to treatment (e.g., successful blood glucose control) (Baig et al., 2015; Denham et al., 2011). This kind of care is not consistently available in Belize, however, and it could represent an important overlooked resource (Anderson & McGibbon, 2017; Balboni et al., 2015; Koenig, 2014). Education efforts could eliminate the proportion of the growing prevalence of diabetes and its complications that are due to misunderstood pathogenesis and pathophysiology. As it stood, the lack of prevention and education programs led to misinformation, exacerbation, and social stigma.

My findings also showed that patients were having difficulties communicating with their Health Care Providers (see Chapter 3.1.2.). HCPs are dealing with short intervals of time per patient, and between patients, in an under-resourced setting. Some countries bypass the need for expensive physician appointments for routine prescriptions filling by connecting patients directly

to a pharmacist and/or nurse practitioner. One key informant who was a physician suggested that patients make more frequent appointments to ensure enough time to address arising questions and concerns, reporting that this is an area of difficulty as diabetes is a disease that encompasses many aspects of health.

HCPs who are continuously exposed to the suffering of other people are at risk of developing compassion fatigue (Delaney, 2018). Compassion fatigue is defined as “as a state of exhaustion and dysfunction as a consequence of prolonged exposure to suffering and stress” (Delaney, 2018, p.2). Reviews indicate that forty to sixty percent of HCPs experience burnout at some point in their careers, interfering with their ability to provide caregiving with empathy and compassion (Delaney, 2018). A mixed methods interventionist evaluation showed that mindfulness and self-compassion training improved HCP resilience and positive outlook while decreasing secondary traumatic stress and burnout (Delaney, 2018). The HCPs and administrators who were key informants in this study described high levels of job stress. They were dealing with shortages of medical supplies, equipment, and staff. Literature has shown that training providers in self-compassion and mindfulness interventions are not financially costly and can reduce burnout and staff shortages, while promoting healthier workplaces and interpersonal communication (Delaney, 2018). Thinking longitudinally, if prevention and education efforts were boosted for improved patient self-management capacity, and system supports were in place, then it is possible that diabetes clinicians and doctors would have to treat less patients per time unit (rather than the current trend of increasing numbers of patients per time unit). This would allow HCPs a few minutes between patients to regain composure as needed, such as after especially difficult appointments. HCPs could also use more time allotted

to each appointment to develop positive communication with their patients, to foster cultural safety, and to support patient-centered care.

The following two figures are concept maps depicting the main themes that arose from the findings in the study. The barriers and struggles were oppressive to patients who were otherwise supported by their spiritual practices and empowering geographies. Overall, the barriers existed in the domain of structural and systemic power, and the strengths existed in the domains of community power and personal power. See Figure 4.4.1 for a visual summary of these main themes and how they were related. If the barriers and struggles were removed and eased, then the systemic forces could become supportive of patient strengths and empowerment. Components of structural and systemic supports would include equitable access to health care, open communication with HCPs, and comprehensive education. See Figure 4.4.2 for a visual model on conceptually shifting barriers into supports.

Figure 4.4.1

Main Themes

Concept Map of main themes in exploratory study of living with T2DM in Belize

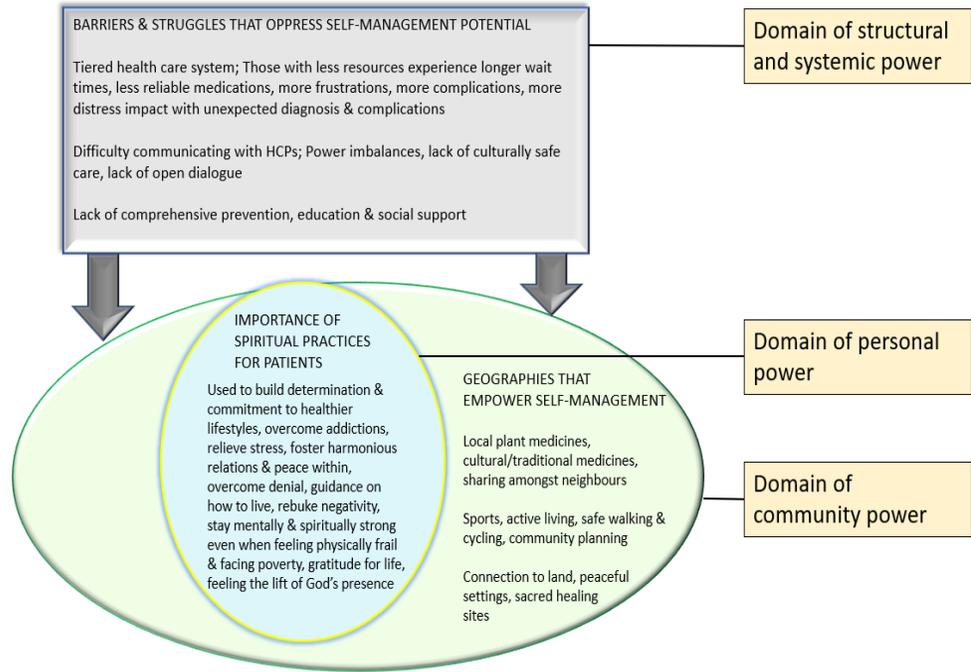
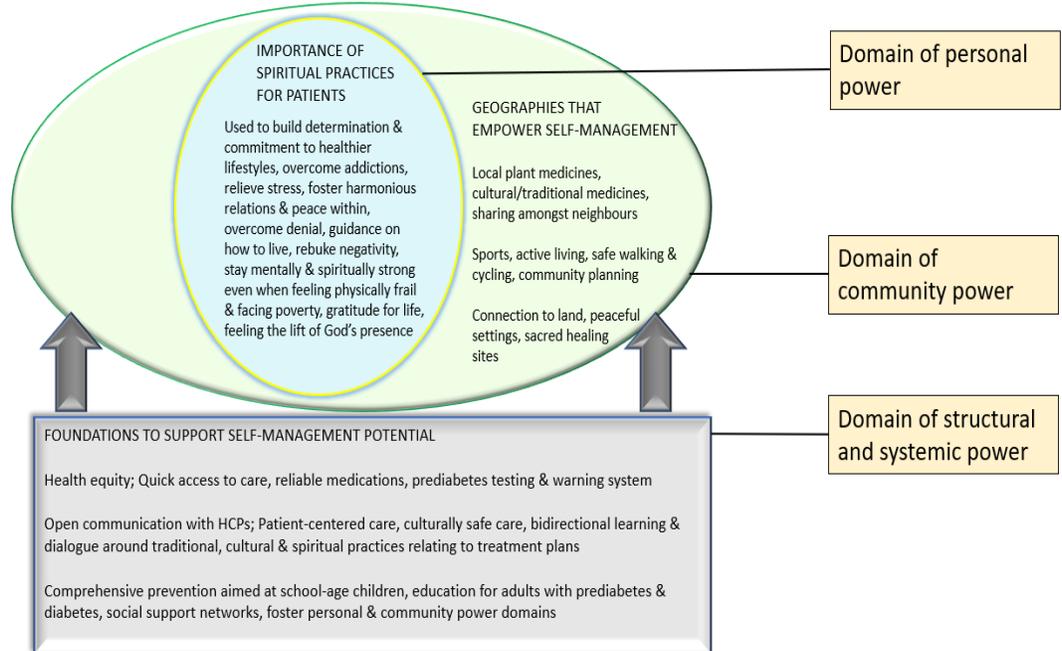


Figure 4.4.2

Shifting Barriers into Supports

Concept Map shifting barriers into supports for self-management



4.4 Areas of Future Research

Participatory action, transformative, and capacity building research would be useful approaches going forward to increase research and development opportunities for aspiring researchers in Belize. Boosting local capacity may be especially important to Indigenous Mayan communities where people are more comfortable working within their own worldview framework and speaking in their first languages with local interviewers. Decolonial, anti-colonial, and Indigenous methodologies will be vital pursuing these directions.

Interviews with local Community Health Workers, Health Educators, Traditional Birth Attendants, Health Care Providers, Allied Health professionals, herbal doctors, cultural-spiritual healers, and faith leaders could contribute much to the literature. It would be useful to understand more about culturally specific (e.g., Mayan, Mestizo, Garifuna, etc.) diabetes-related practices and beliefs, and how they affect diabetes and other health outcomes. Developing the understandings of what culturally safe care means for specific communities would be an important avenue of inquiry.

More research is needed to explore how to enhance self-management resources for those living with chronic poverty. Research on prevalence differences across socio-demographic categories would be useful to identify priority populations for prevention and education programs. Further, an environmental scan or a needs assessment could be helpful in determining gaps in services (e.g., optometry, ophthalmology, dialysis, dentistry, foot care), how to stop patients from falling through the cracks in the system, and how to prevent life-altering complications.

Research could inform emerging guidelines for HCPs on how to address their patients' spirituality toward best health outcomes. Further research could also inform how the sectors of health and faith can exchange knowledge and collaborate in health-promotion efforts. The intersections of spirituality and plant medicines could be more explicitly studied in this context. Plant medicine interactions with pharmaceuticals, as well as interdisciplinary health partnerships could be explored. Research on best practices for marrying income-production and land preservation for the protection of plant medicines in Belize remains an area to be studied, as well as inquiry on how Low-Middle Income Countries (LMICs) can proudly protect while also presenting their medicinal plants and rich traditions of spiritual healing to world. Studying the role of transnational corporate social responsibility in their host countries, communities, and employees would be key in this setting. Research aimed at addressing the underlying issues and impacts of poverty, colonization, forced migration patterns, and class and racial inequity on type 2 diabetes outcomes would be crucial work. Further, studies to deepen the understanding of Indigenous food sovereignty and its protective role against T2DM would make significant contributions.

4.5 Strengths and Limitations

One strength of the study was that Constructivist Grounded Theory had the inherent flexibility required for working qualitatively with human participants, allowing a process of bi-directional discovery as the research evolved, as per Charmaz (2011). Constructivist Grounded Theory provided in-depth knowledge within context, so it could be used to inform location-specific health care policy decision-making possibly leading to new understandings, new

theories, or building on established theories (Charmaz, 2011). It lent to the generation of ideas, policies, solutions, action, and theories from the grassroots level by having dug into local realities (Charmaz, 2011). It was a good way to listen to the voices of people most impacted by issues, avoiding the importation of theories from elsewhere as a starting point (Charmaz, 2011; Creswell & Poth, 2018; Hesse-Biber, 2017). It was useful for understanding a situation that was already occurring, not requiring an artificial setting (Charmaz, 2011; Creswell & Poth, 2018).

This study was not generalizable to larger populations because of its small sample and its focus on a place-based phenomenon (Creswell & Poth, 2018). A limitation of the study was that I did not have the opportunity to interview a more representative sample which would have required more interviews with people from communities such as the Mayan, Mestizo, Mennonite, Chinese, migrant workers, other visible minorities, and people from the Corozal and Orange Walk districts. Hearing from Indigenous people and groups more specifically would have made an important contribution to the study. Another limitation of the study was that it was not possible to analyse demographic differences across class, ethnicity, race, gender, age, geography, access to NHI, or other describers. It did not represent voices of people who are not yet engaged in the topic.

Conclusion

The voices of the people of Belize are diverse, important, and insightful. This qualitative exploratory study allowed for some understandings to emerge where there had been a lack of knowledge generated directly from listening to people living with diabetes. The main findings include that there are many barriers to optimal health care, such as the class-stratification across

private-public services, the difficult communication patterns with HCPs, the setbacks of diagnosis and complications, the urgent need for more prevention and education, as well as for social supports.

Findings include that a central instrument of wellness in the face of chronicity is a rich and pervasive spirituality which guides people to healthier lifestyles, to find meaning, and to transcend suffering. Church attendance is not an adequate measure of spiritual practice in Belize because people frequently pray, meditate, and refer to spiritual texts at home as an important part of T2DM daily homework and self-management. Further, people visit sacred sites outdoors for healing purposes. Plant medicines usage is pervasive, and people have faith in plant medicines for many reasons (e.g., efficacy, accessibility, safety, cost, status as natural and God-given), often more than they have confidence in pharmaceuticals.

There are important implications for patients and HCPs, for policy and planning, and for research and development. In working toward becoming more hospitable to patients' spiritual understandings and experiences of this chronic disease, the health care system has the potential to stop the silencing and marginalization of those living in chronicity, topics of spiritual health, and the ways these forces coalesce. This, in turn, can lead to new innovations and collaborations for quality, integrative care.

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Appendix 1: Summary of Participants

Interviewees:

	Pseudonym	Town, District	Ethnicity	Gender	Age	Occupation
1.	Isabella	San Ignacio, Cayo	Garifuna	W	80s	Retired teacher
2.	Felicia	Mount Hope, Cayo	Creole	W	50s	Wife/Mother
3.	Rosa	Punta Gorda, Toledo	Garifuna	W	60s	Shopkeeper/Minister
4.	Cynthia	Punta Gorda, Toledo	Creole	W	60s	Retired Nurse
5.	Henry	Elridgeville, Toledo	East Indian	M	50s	Labourer
6.	Meera	Elridgeville, Toledo	East Indian	W	40s	Housekeeper
7.	Josefina	Dandriga, Stann Creek	Garifuna	W	60s	Grandmother
8.	Maurice	Dandriga, Stann Creek	Garifuna	M	40s	Retired military, Barkeeper
9.	George	Belize City, Bz	Garifuna	M	60s	Surveyor
10.	Yvonne	Belize City, Bz	Creole	W	50s	Retired Supervisor
11.	Natalia	Belize City, Bz	Garifuna	W	30s	Legal secretary

Site Visits with Key Informants:

The National Institute of Cultural Heritage (NICH)

The Ministry of Health (MoH)

The National Health Insurance (NHI) office

Belize Diabetes Association (BDA) Punta Gorda, Dangriga, and Belize City locations

Punta Gorda Polyclinic

San Antonio Clinic

Health administration offices in Punta Gorda, Dangriga, Independence, and Belmopan

University of Belize (U of B) in Toledo

In community

Online capacity-building workshop trainees

Online meetings with research team and stakeholders

Appendix 2: Qualitative Interview Guide

(Note: The interview questions were originally based on the Diabetes Quality of Life Questionnaire. Through an iterative process and ongoing discussions with the Steering Committee, stakeholders, participants, and trainees, I included additional questions and amendments to develop the following guide. It was used as a conversation guide in semi-structured interviews.)

1. SITUATE PERSON. Can you tell me a little bit about who you are? Things like your gender, age, cultural background, the district you live in, your work, your role in your family (e.g., mother, son, live alone, number of siblings), hobbies, and other stuff like that place you in the social fabric of Belize. Demographics:

Gender	
Age	
Marital Status	
Education completed	
Cultural background	
Religion/spirituality	
Occupation	
Region	
NHI coverage/ Clinic	

2. EXPERIENCES AND PERCEPTIONS. What is it like to have diabetes on a day-to-day basis? Do you remember how you were diagnosed with diabetes? What was it like to learn about it for the first time? Where were you? What was happening in your life? How was telling your family about it? Are they understanding and supportive? How is your family and community affected by diabetes? Do people talk about it? What do they say?
3. ROOT CAUSES. What do you see as the root causes of your diabetes? Does it run in your family? What are your family members' attitudes about diabetes? What kind of foods are best for you to eat? Is there diabetes-friendly food available where you live? Is there food that is good for

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you at family gatherings? Are there foods you wish you could get, but often do not have access to? Are there kinds of exercise you enjoy? What motivates you? Where do you exercise? Do you exercise with a buddy? Do you have sports and leisure programs or equipment? Is this a bike-friendly place? Are there good places to go walking? What do you like to drink? Which drinks are good for you? Where do you get your water? Does the price of water affect what you drink? Does the quality of water affect what you drink? Does the availability of water affect what you drink?

4. **PRIORITIES.** Do you have a daily routine that helps you with diabetes-related care? What is the most important thing? What parts of caring for yourself makes the biggest difference for your health? What parts of diabetes services makes the greatest difference?
5. **CHALLENGES.** What is the most difficult part of having diabetes? Are there physical challenges? How do you feel emotionally and mentally about diabetes? Some people struggle with feeling down, having a hard time getting going, feeling too tired to move, or feeling stuck - Does this happen to you? What helps you when you feel this way? Do you have stress in your life? What kinds of stress? How do you handle it? What makes it better? Can you tell me about if your relationships with your spouse or living companions may support your health or may make living with diabetes more challenging?
6. **SPIRIT/MIND.** Do you practice any forms of spirituality? This might include meditation, prayer, going to church, drumming, dancing, singing, or other uplifting things you enjoy. It could be the state of mind you have. Or the attitude you cultivate. Can you tell me about that part of your wellness? How does it affect your diabetes? Has having diabetes changed your spiritual practices over time? Do you believe your spirit affects the physical health of your body? Or do you believe your mind affects the physical health of your body? Can you talk a little more about that?
7. **SERVICES.** Do you see a doctor regularly? How do you get to the clinic – do you have any trouble getting there? Do you use medications that the doctor prescribes? Which ones? How

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often? Do you use natural remedies? Which ones? How often? Have you noticed a difference whether you use them together or separately? Which do you prefer and why? How would you describe your interactions with your Health Care Providers? How do you feel when you are talking to them and listening to them? Are you comfortable talking to your doctor about any natural remedies you may use? Where do you get your medicines? Are they accessible? Do you go to the eye doctor? How about the dentist? Do you get your feet checked? Do you get other types of help from, for example, an herbalist, massage therapist, acupuncturist, nurse, or dietician? What are your relationships with each person like? What do you have to pay for and what is covered? Do you have the BDA meetings here? Do you go? Why or why not? If you could talk to a person who makes policy about diabetes services, what would you suggest? What is on your wish list?

8. PROGRAM. What have you learned throughout being involved in the diabetes program? What has been helpful? What could be more helpful if done differently?
9. VISION. If you imagine your best self in ten years from now, what does that look like? What are your visions, goals, dreams? How could our health services, programs, and communities be improved to help you be the healthiest person you can be? What do you still want to learn about in terms of self-care and self-management?
10. OTHER. Is there anything important missing from our conversation that you would like to add?

Reminders: Thank you! Discuss expectations about next steps in the study. Provide contact info, copy of consent form, bookmark, or any further info they want.

Appendix 3: Consent Form



**University
of Manitoba**

University of Manitoba
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Max Rady College of Medicine
Winnipeg, MB, Canada R3E 0W3
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Consent to Participate

Informing Diabetes Service Through Patient Perspectives in Belize

Introduction

- You are being asked to be in this project to improve the quality of diabetes services in the Belize Health System.
- You were selected as a possible participant because you are a) recently diagnosed with Type 2 Diabetes and b) over eighteen years of age.
- We ask that you read this form and ask any questions that you may have before agreeing to participate in the project.

Purpose of Project

- The purpose of the project is to expand the quality of health service to diabetes patients throughout Belize by developing a deeper understanding of their treatment and day-to-day experiences with diabetes.
- Ultimately, this project will be evaluated by the organizers to make recommendations on how to improve the quality of care for diabetes patients.

Description of the Project Procedure

- If you agree to be in this project, then you will be asked to participate in a 60 to 90 minute interview with a university researcher.
- Interviews will be audio-recorded and later transcribed verbatim for analysis.
- You will have the opportunity to review and make changes to your transcripts. We ask that changes or modifications be made within a 30-day period upon receipt of the transcript (or audio recording) to allow analysis and writing to happen in a timely fashion.

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- You can stop participating at any time. If you decide to stop participating in the study, we encourage you to please talk to the research team first.

Risks of Being in the Study

- There are no foreseeable (or expected) risks. There may be unknown risks.

Benefits of Being in the Study

- There may or may not be direct personal benefit to you from participating in this study.
- We hope the information will contribute to the state of knowledge about diabetes, prevention, education, management, treatment, and services in Belize.

Costs of Being in the Study

- All the procedures performed as part of this study are provided at no cost to you.

Compensation for Participation

- As a participant, there is no monetary compensation for your time in taking part in an interview.

Confidentiality

- Information gathered during interviews may be published or presented in public forums. Your name and other identifying information will not be revealed unless you specifically request and choose to keep your name attached to your story and transcript. Otherwise, we will de-identify the data and use a pseudonym. It is possible that your identity may be understood to people who know you simply through the content of interviews.
- It is possible some authorized individuals will read the transcripts from the University of Manitoba Health Research Ethics Board who may review records related to the study for quality assurance purposes. The research team including authorized individuals from the Belize Diabetes Association (BDA) may also have access to the transcripts. All records will be kept on a secure server at the University of Manitoba. If any of your research records need to be copied to any of the above, your name and all identifying information will be removed first (unless you choose otherwise).
- No personal information (e.g., your name, address, or telephone number) will leave the University of Manitoba where the participant list will be kept on a password-protected computer on an encrypted file.
- The data will only be used for the present study and will not undergo secondary analysis. The data will be stored on a password-protected computer for up to 5 years before moving to a locked archival unit for storage at the University of Manitoba and/or at appropriate units in Belize.

Right to Refuse or Withdraw

- Your decision to take part in this study is voluntary. If you decide not to participate, to withdraw from the study, or to decline answering questions in the interview, then it will not affect your relationships to the research team or your access to the study results. If the investigators feel that it is in your best interest to withdraw you from the study, they will remove you without your consent. We will tell you if any new information arises that may affect your health, welfare, or willingness to stay in this study.
- You may refuse to take part in the project *at any time* without affecting your relationship with the health service provider of this project (BDA). Your decision will not result in any loss or benefits to which you are otherwise entitled.

Right to Ask Questions and Report Concerns

- You have the right to ask questions about this project and to have those questions answered before, during, or after the research. If you have any questions at any time, please feel free to contact the BDA at [REDACTED] or call [REDACTED] OR Dr. Andrew Hatala, University of Manitoba Researcher at [REDACTED] or call [REDACTED].
- For questions about your rights as a research participant, you may at any time contact the University of Manitoba Bannatyne Campus Research Ethics Board Office at bannatynereb@umanitoba.ca or call +1 (204)789-3389.

Consent

- Your signature below indicates that you have decided to volunteer as a participant for this project, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep, along with any other printed materials deemed necessary.
- Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all your questions.

Participant Name (print):

Participant Signature:

Date:

Interviewer Name (print):

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Interviewer Signature:

Date:
