DIABETES KNOWLEDGE, RISK PERCEPTION AND QUALITY OF LIFE

AMOUNGST SOUTH ASIANS

EXPLORING DIABETES KNOWLEDGE, RISK PERCEPTION OF DEVELOPING

DIABETES AND QUALITY OF LIFE AMONGST SECOND GENERATIONAL

SOUTH ASIAN YOUNG ADULTS CARING FOR PARENTS WITH TYPE 2

DIABETES MELLITUS

By

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A Thesis

Submitted to the School of Graduate Studies, School of Nursing, McMaster University

In Partial Fulfillment of the Requirements

for the Degree

Master of Science in Nursing

McMaster University

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MASTER OF SCIENCE (NURSING) 2018

McMaster University

Hamilton, Ontario

TITLE:                            Exploring diabetes knowledge, risk perception of
                                  developing diabetes and quality of life amongst South
                                  Asian young adults caring for parents with Type 2
                                  Diabetes Mellitus

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NUMBER OF PAGES:                  xix, 175

## ABSTRACT

**BACKGROUND:** Type 2 diabetes mellitus (T2DM) has an earlier onset and disproportionately impacts those of South Asian descent. Traditionally, the management of T2DM in the South Asian community has required the support of adult children to provide care for their parents. Diabetes caregiving tasks can be culturally mediated which can lead to differentiations in the caregiving tasks between genders. The implication of providing care can impact quality of life, diabetes related knowledge and perception of developing diabetes amongst these caregivers.

**OBJECTIVE:** To investigate South Asian young adult's knowledge of diabetes, quality of life, and risk perception of developing diabetes compared to their actual risk of developing diabetes amongst South Asian young adults whose parents have T2DM.

**METHODS:** A cross-sectional study design was completed. A convenience sample of South Asian young adults aged (18-29) years of age completed an online questionnaire (N=150). Data were collected using the following tools: 1) 24-item DKQ 2) CANRISK 3) RPS-DD and 4) WHOQOL-BREF questionnaire. Independent t-tests, Pearson chi-squared tests, linear regression and multiple regressions were conducted.

**RESULTS:** The t-test revealed that there was a statistically significant difference in diabetes knowledge between males (M=30.16, SD=4.87) and females (M=34.31, SD=4.41); p<0.001, 95% CI [-5.64, -2.65]. Risk perception and diabetes knowledge statistically significantly predicted physical health F (2, 146)=6.751, $p$=0.002 of caregivers. 79.5% of male and 65.8% of female caregivers had a low risk perception of developing diabetes $\chi^2(1)$= 3.49, $p$=0.06.

**CONCLUSION:** Findings from the present study highlight the importance of examining the South Asian family milieu when providing care to those affected by T2DM. The findings highlight the need for gender-specific diabetes educational interventions for this young adult South Asian population. Based on our findings, a majority of caregivers had a low risk perception of developing diabetes.

**ACKNOWLEDGEMENTS**

First and foremost, I would like to thank Dr. Diana Sherifali, for her patience, guidance and words of encouragement throughout the course of my thesis study. I'm grateful to have had the opportunity to learn under your guidance and supervision.

I would like to extend my gratitude and appreciation to Dr. Sandra Carroll and Dr. Zubin Punthakee for always providing thought-provoking feedback, and their support throughout this study. It has truly been an honour to work with you both.

To all the individuals and community groups who generously shared their time to participate in the study, I would like to extend my sincerest thanks and appreciation. I'm so grateful for the opportunity to gain insight into your experiences.

I am forever thankful to all my friends, who have always been there for me especially during moments where I struggled in this journey. Thank you for providing me with the necessary distraction from my research. You have been a major source of support and encouragement. To my colleagues, I've had the immense privilege of working with you, learning from you and growing alongside you. You have made this journey more enjoyable.

I would like to express my gratitude to my family for their unconditional love. Thank you to my parents, Treasa and Johny Koipuram for instilling the value of hard work and for all of the sacrifices you have made for me. This thesis is a product of your loving support. To my sister, Anita, your unwavering faith in me has helped me get through moments of self-doubt and without you this would not be possible. To my in-laws (Dominic, Ritha, Tania, Dony, Lyla & JD), I can't begin to thank you enough for

your endless supply of laughter, prayers, and delicious sandwiches. And to my husband, Ebin, you have always been a steady source of encouragement and happiness in my life. Your patience and motivation was truly invaluable. I would not have gotten through those long nights without your support and understanding. Last but certainly not the least, to my Ammachies (grandmas), sacrificing your education to provide for your families has made me even more grateful to be completing my graduate education. Your selflessness is something that I will always look up to and strive to emulate. Thank you for always encouraging me to pursue my interests and I am forever grateful for the values you've instilled in me.

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## Abbreviations

**α**: Alpha

**A1C:** glycosylated hemoglobin

**ABC: A**1C, **B**lood pressure, LDL **C**holesterol

**ADA:** American Diabetes Association

**ACS:** Acute Coronary Syndrome

**ADL:** Activities of Daily Living

**AHEAD**: **A**sset and **Hea**lth **D**ynamics

**BIPQ:** Brief Illness Perceptions Questionnaire

**BMI:** Body Mass Index

**CANRISC:** Canadian Diabetes Risk Assessment Questionnaire

**CTFPHC:** Canadian Task Force on Preventive Health Care

**CVD:** Cardiovascular disease

**DC:** Diabetes Canada

**DKQ:** Diabetes Knowledge Questionnaire

**DKT:** Diabetes Knowledge Test

**DM:** Diabetes Mellitus

**DRCT:** Diabetes Risk Communication Trial

**DRK:** Diabetes Risk Factor Knowledge

**DSME:** Diabetes Self-Management Education

**FINDRISC**: Finnish Diabetes Risk Score

**GTA:** Greater Toronto Area

**HADS:** Hospital Anxiety and Depression Scale

**HBM:** Health Belief Model

**HPLP:** The Health Promoting Lifestyle Profile

**IADL:** Instrumental Activities of Daily Living

**LDL:** Low-density lipoprotein cholesterol

**M**:  Mean

**MEC:** Mobile Examination Centre

**MeSH**: Medical Subject Heading

**NL**: Natural Language

**OGTT:** Oral Glucose Tolerance Test

**QoL:** Quality of Life

**RCT:** Randomized Control Trial

**REALM-R:** Revised Rapid Estimate of Adult Literacy in Medicine

**REB:** Research Ethics Board

**RPS-DD:** Risk Perception Survey for Developing Diabetes

**SAHF:** South Asian Health Foundation

**SAP**: South Asian Population

**SD**: Standard Deviation

**SDSCA**: Summary of Diabetes Care Activities

**SES:** Socioeconomic Status

**SF12:** Short-form 12

**SPSS:** Statistical Package for the Social Sciences

**T2DM:** Type 2 Diabetes Mellitus

**UDM:** Undiagnosed Diabetes Mellitus

**UK:** United Kingdom

**US:** United States

**WHO:** World Health Organization

**YSAC:** Young South Asian Caregivers

**Glossary of Terms**

| Term | Definition |
| --- | --- |
| A1C: glycosylated haemoglobin | A1C Is an indicator of plasma glucose levels over three to four months. The target A1C level for adults is typically <7% (Esposito, Chiodini, Bellastella, Maiorino, & Giugliano, 2012; Imran, Rabasa-Lhoret, & Ross, 2013). However, these target levels are influenced by one's age, duration of diabetes, risk of hypoglycemia, presence/ absence of cardiovascular disease and life expectancy (Berard, Blumer, Houlden, Miller, & Woo, 2013; Diabetes Canada, 2018c) |
| ACS: Acute Coronary Syndrome | A broad term describing a situation where blood flow to the heart is impeded or blocked. This includes unstable angina, non-St elevated myocardial infraction and ST elevated myocardial infraction (Diabetes Canada, 2018c; Kumar & Cannon, 2009) |
| ADL: Activities of Daily Living | The necessary skills needed to manage one's basic physical needs. This includes: grooming/personal hygiene, dressing, toileting/continence, mobility, and eating (Mlinac & Feng, 2016) |
| BMI: Body Mass Index | It is calculated based using a person's height and weight to measure one's body fat. BMI is calculated by a person's weight in kilograms (kg) divided by one's height in meters squared (BMI = kg/m$^2$). The following are different categories of BMI: underweight (BMI less than 18.5), healthy weight (BMIs 18.5 to 24.9), overweight (BMIs 25 to 29.9), obese (BMI 30 and over) (Diabetes Canada, 2018a, 2018c). |
| Diabetes Caregiver | A family member/friend who provides unpaid or arrange for paid or unpaid help |

| | |
|---|---|
| | to manage their loved ones' diabetes (e.g. driving to appointments, checking blood sugars, promoting exercise, helping adhere to a healthy lifestyle, managing/administering medication etc.) (Scarton et al., 2016) |
| CVD: Cardiovascular disease | A broad term that includes all diseases of the cardiovascular system. People with diabetes are at increased risk of cardiovascular disease (Canadian Diabetes Association, 2018c) |
| DM: Diabetes Mellitus | A chronic illness that impacts the production of the body's insulin or there is ineffectiveness of the insulin produced. This results in an increase in blood glucose concentrations that can cause damage to the body's nerves and blood vessels (World Health Organization, 2018). |
| Filial piety | Although the notion originated in China. It a framework that guides caregiving amongst the South Asian population. It is a mutual arrangement that demands respect and obedience towards one's elders in exchange for their kindness and care (Holroyd & MacKenzie, 1995; Hsü, 1991). |
| IADL: Instrumental Activities of Daily Living | IADLs refer to activities that are necessary to function independently and adapt to the environment. This includes shopping, transportation, housekeeping etc.) (Spector, Katz, Murphy & Fulton, 1987) |
| LDL/ LDL-C: Low-density lipoprotein cholesterol | Particles that carry cholesterol in the blood and around the body for use by cells. LDL-C is commonly known as 'bad' cholesterol because high levels of LDL-C lead to increased risk of cardiovascular disease. Individuals diagnosed with diabetes are at an increased risk of developing heart disease (recommended LDL-C targets 2.0 |

| | |
|---|---|
| | mmol/L or lower for most people with diabetes) (Diabetes Canada, 2018c). |
| OGTT: Oral Glucose Tolerance Test | A test to quantify one's body's ability to break down and use carbohydrates. OGTT is utilized to diagnose diabetes and prediabetes. The OGTT consists of giving a standard dose of glucose as a drink and subsequently measuring blood glucose levels at regular intervals (usually fasting, one hour and two hours after drinking the glucose drink) (Diabetes Canada, 2018b, 2018c). |
| QoL: Quality of Life | An individual's view of their life in relation to their culture and value systems in comparison to their goals, expectations, standards and concerns (WHO, 1998) |
| RCT: Randomized Control Trial | A study in which participants are randomly allocated to the intervention group and subsequently followed to determine the effect of interventions. This study design allows causation conclusions to be formulated. (Cullum, Ciliska, Haynes, & Markes, 2008). |
| SAP: South Asian Population | Refers to anyone from Bangladesh, India, Pakistan, Sri Lanka, Bhutan, Nepal, and Maldives (Bannerji-Stevens, 2009; Bhatia & Ram, 2004). |
| Second generational immigrants | Refers to individuals who have at least one parent born outside Canada which includes those who are born in Canada (Statistics Canada, 2018). |
| SES: Socioeconomic Status | SES is combined measure of one' education, income and occupation (Winkleby, Jatulis, Frank, & Fortman, 1992). Higher SES is typically correlated with better health outcomes (Baker, 2014) |

| | |
|---|---|
| South Asians | Those who self-identify as having ancestors who are of South Asian descent, including those from India, Pakistan, Sri Lanka, Nepal, Maldives, Bhutan and Bangladesh (Banerjee-Stevens, 2009; Bhatia & Ram 2004; Statistics Canada, 2007b). |
| T1DM: Type 1 Diabetes Mellitus | Refers to a chronic condition where the immune system attacks and kills the beta cells of the pancreas and little to no insulin is released in to the body (Diabetes Canada, 2018b). |
| T2DM: Type 2 Diabetes Mellitus | A chronic condition where the pancreas either does not produce enough insulin or the body does not effectively use the insulin it makes (Diabetes Canada, 2018b) |

## CHAPTER 1: INTRODUCTION AND PROBLEM STATEMENT

**Introduction**

Type 2 diabetes mellitus (T2DM) is a chronic illness, which can have debilitating complications (Hu, 2011). This has created a public health concern from its associated complications, impacting millions of people globally (Shah & Kanaya, 2014). In Ontario, the economic burden associated with diabetes is estimated to increase by 42%, which will be approximately $6.9 billion by 2020 (Diabetes Canada [DA], 2009).

T2DM disproportionately affects those of South Asian descent due to their genetic predisposition, anthropometry (e.g. having greater central obesity) and sedentary lifestyle (Gujral, Pradeepa, Weber, Narayan, & Mohan, 2013). South Asians are three to five times more likely to develop diabetes than the general population (Sohal, 2008; Statistics Canada, 2017). The term 'South Asian' is comprised of a heterogeneous population, with several definitions of the term (Islam, Khanlou, & Tamim, 2014). Across the literature, South Asians are defined as those who self-identify as having ancestors who are of South Asian descent, including those from India, Pakistan, Sri Lanka, Nepal, Bangladesh, Maldives, and Bhutan (Banerjee-Stevens, 2009; Bhatia & Ram 2004; Statistics Canada, 2007b).

The South Asian population (SAP) is one of the fastest growing immigrant populations in Canada, with the majority of the population residing in Ontario (Statistics Canada, 2007b). The SAP comprises of 25.1% of Canada's visible minority population (Sohal, 2008; Statistics Canada, 2017). To successfully manage diabetes, individuals are required to adhere to a myriad of treatment recommendations. These can include dietary

modifications, adherence to medication, routine physical activity or exercise, and

monitoring of blood glucose levels (Miller & DiMateo, 2013). Social supports such as

family, can promote medication adherence and minimize the stress of managing diabetes

(Miller & DiMateo, 2013). A South Asian household is typically multigenerational,

where grandparents or older adults live in the same household as their children and

grandchildren (Gupta & Pillai, 2005). This has resulted in an increased dependency on

adult children typically for providing care for their parents within the same household

(Gupta & Pillai, 2005). According to Statistics Canada, in 2015, approximately 1.9

million young Canadians aged 15-29 were engaged in caregiving tasks to family members

with chronic conditions (Charles et al., 2012; Statistics Canada, 2015). In immigrant

South Asian families, young adults feel strong cultural values, which can influence the

support they provide for their family members (Das, & Kemp, 1997; Gupta & Pillai 2005;

Parveen et al., 2012). The implication of providing care to one's parents can influence

caregiver's quality of life.

Diabetes related knowledge and one's risk perception are critical elements in

fostering health-promoting lifestyles (Barnhart et al., 2009; Gray et al., 2007; Rouyard et

al., 2017). Knowledge and education can improve glycemic index and self-management

behaviours amongst adults with T2DM (Atak, Gurkan, & Kose, 2008, Norris et al., 2001).

However, there is a paucity of research examining diabetes knowledge amongst high-risk

populations, specifically South Asians. Additionally, inaccurate perceptions of risk can be

a result of lack of information which can act as barrier in self-care behaviours can result

in negative health consequences (Rouyard et al., 2017). Reports in the literature have

shown that the uptake of health protective behaviours (e.g. engaging in 150 minutes of physical activity per week) can prevent/delay the onset of T2DM amongst high-risk populations (Knowler et al., 2002). Yet compared to the general population, the SAP is less likely to adhere to a healthy diet and they maintain a very sedentary lifestyle (Gray et al., 2007). This coupled with the fact that this young adult South Asian population is at greater risk of developing diabetes, highlights the importance of examining this cohort's knowledge of diabetes, their quality of life (QoL) and risk perception of developing diabetes (Sohal, 2008; Statistics Canada, 2007a, 2007b). Additionally, gaining insight into possible cognitive biases (i.e. one's beliefs about control over diabetes development) associated with diabetes risk perceptions and knowledge gaps can help facilitate the delivery of tailored health interventions to curtail the diabetes epidemic seen in the SAP (Rouyard et al., 2017).

**CHAPTER 2: LITERATURE REVIEW**

**Literature Review**

The purpose of this literature review was to identify studies that are relevant to young South Asians that are caregivers for a parent living with T2DM. Moreover, the review was expanded to include studies relating to diabetes related knowledge, caregiver QoL, and risk perception of developing diabetes amongst high-risk populations. The literature review was conducted using OVID Medline, PUBMED, CINAHL, and SCHOLARS PORTAL (all data sets) (Appendix A). To take advantage of a natural language (NL) search, Google Scholar was utilized and the literature search was limited to English language studies and was based on the 6S pyramid (Hariri, 2013; Haynes et al., 2005). No restrictions were placed on the publication year of articles. Keywords and subject heading appropriate to the database were utilized (i.e. MeSH for Medline). Some of the key terms used in the search strategy included: *South Asian, immigrant, caregiver, informal caregiver, diabetes, diabetes knowledge, health promotion, risk perception, quality of life, health protective behaviour, and young carers*. Studies that examined caring for children with diabetes, or focused on type 1 diabetes mellitus, or gestational diabetes were excluded (Appendix A). A majority of the studies that were found focused on caring for older adults with diabetes and other chronic illnesses, or caring for elderly patients with diabetes who were not of South Asian descent; thus, limiting the applicability of findings to this study. There were limited articles found using a systematic search approach; thus, the search strategy was expanded to utilize different combination of search terms to yield more findings (Appendix A). A total of 2300 studies

were found using only Google Scholar, of which only four were relevant for the study literature review (Appendix A1). Additionally, Canadian Health Research Collection was used to obtain relevant grey literature.

**Diabetes and Diabetes Management in the SAP**

South Asians living in Canada are twice as likely to develop diabetes compared to Caucasians (Vuksan et al., 2012). They are also at an increased risk of developing diabetes at an earlier onset and with lower body mass index (BMI) compared other populations (Chiu et al., 2011; Sohal et al., 2008). Additionally, this population has been shown to have greater insulin resistance with lower BMIs relative to Caucasians (Unnikrishnan, Anjana, Mohan & 2014). This is likely because of the greater central obesity found in this population (Sniderman et al., 2007). The South Asian Health Foundation (SAHF) in the United Kingdom (UK) recommended lower BMI cut-off values for the classification of over-weight and obese BMI's amongst South Asians to reflect this difference (Misra et al., 2009). Moreover, evidence suggests South Asians have a poor compliance rate with exercise and maintaining diabetes dietary practices (Sohal, Sohal, King-Shier, & Khan, 2015).

The increase in prevalence of early onset of T2DM is often associated with risk factors seen in early childhood development (Wilmont & Idris, 2014; Yajnik et al., 2008). Yajnik et al., (2002) conducted a study that compared body size, cord blood leptin and insulin among newborns in South India (n=157) to Caucasian newborns (n=67) in the UK. The findings demonstrated that newborns from South India had increased adiposity and higher umbilical cord blood insulin (41.5 compared to 21.3 pmol/liter; $p<0.001$)

compared to newborns from the UK. This suggests that insulin resistance amongst South Asians begins during fetal development and this increases their propensity in developing diabetes (Yajnik et al., 2002). Similarly, Vuksan et al., (2012) conducted a cross-sectional study amongst immigrant Chinese, European and South Asian adolescents in the Greater Toronto Area (GTA) (N= 203). Diet, physical activity, blood pressure and anthropometric characteristics were taken to determine if South Asians have higher rates of cardiovascular disease (CVD) and diabetes risk factors. Despite having a lower BMI, South Asian adolescents had higher triglyceride and lower HDL cholesterol levels and lower rates of physical activity, which are all risk factors for the development of T2DM and CVD (Haase, Tybjærg-Hansen, Nordestgaard, & Frikke-Schmidt, 2015; Vuksan et al., 2012). These studies highlight how risk factors for CVD and diabetes develop at an early age among South Asians.

The barriers and facilitators of T2DM management amongst the SAP was examined through a systematic review conducted by Sohal et al., (2015) that included both qualitative and mixed methods original research studies (N=20). However, the systematic review did not stratify the results based on age group. This is an important factor to consider as older adults are believed to have different barriers compared to young adults. The results demonstrated that there was a lack of understanding about diabetes medication management, misconceptions related to nutrition and failure to incorporate cultural sensitivity or needs. This review emphasized the importance of cultural specific knowledge when managing T2DM amongst the SAP.

Healthy eating and dietary modification is a key component in the management of diabetes. Typically, South Asian dietary patterns are high in saturated fats, carbohydrates and large quantities of sweets, often consumed as a part of cultural celebrations and events (Sohal, 2008).  For example, traditional Indian desserts such as jalebis or ladhus, which comprise approximately 33% sugar and 33% fat (Hill, 2006). Hill (2006) conducted a review to explore challenges of diabetes management amongst the South Asian communities in the UK.  Hill highlighted how diabetes management amongst the SAP was intertwined with religious and cultural beliefs (Hill, 2006; Macaden & Clarke, 2010; Osman & Curzio, 2012).  Food is viewed as a component of their social identity and is obligatory in a cultural context (Lucas, Murray, & Kinra, 2013). Those with diabetes may be reluctant to refuse consumption of certain foods because they fear that it will alienate them from their families and community (Hill, 2006).  Additionally, Hinduism has several festivals (i.e. Holi, Navratri, Diwali etc.) that have periods of fasting and feasting; these eating habits can cause fluctuations in one's blood glucose (Hill, 2006).  The effects of religious and cultural beliefs may be diminished in subsequent generations (Hill, 2006). To examine the impact of acculturation and the role of culture on subsequent generations on diet amongst the SAP in Canada, Lesser, Gasevic, Lear, (2014) completed a cross-sectional study. Lesser et al., (2014) examined first generational immigrants and utilized length of residence as an indicator for acculturation. The study reported that the SAP adopted positive dietary practices, such as an increased consumption of fruits and vegetables and an improvement in food preparation. However, they also reported an increased consumption of convenience foods

(i.e. sweetened beverages, red meat etc.). This further compounds the challenge of successfully managing chronic illness such as T2DM amongst this population.

Patel et al., (2015), gained insight into the impact of sociocultural context on illness beliefs and diabetes self-management on the SAP in their mixed methods study. Using tools such as Brief Illness Perceptions Questionnaire (BIPQ), Summary of Diabetes Self Care Activities scale (SDSCA), Short-form 12 (SF12) and semi-structured and face-face interviews, the findings demonstrated that South Asians are dependent on their family for emotional support, assistance in diet control, and lifestyle modification. Additionally, the study found that some participants' believed diabetes onset was associated with fatalism (Patel et al., 2015). For instance, some first generational immigrants attributed the trajectory and onset of their diabetes to God and fate. In contrast, second generational immigrants attributed diabetes to genetic predisposition, eating habits, exercise and diet. Similarly, Fleming and Gillibrand (2009) conducted a meta-synthesis of eleven qualitative studies of how culture influences diabetes self-management amongst the SAP. These findings revealed that culture interacts with several factors including interpretation of past experiences, socioeconomics, and health beliefs related to diabetes self-management. Taken together, these studies highlight how culture is a key element of a multi-faceted individual when managing diabetes amongst the SAP.

**Emerging Adulthood**

Developmental psychologists refer to the period of life between 18 to 29 years of age as emerging adulthood (Arnett, Žukauskienė, & Sugimura, 2014). This stage of life is comprised of several milestones for young adults such as: entry into parenthood,

marriage, workforce, entry or completion post-secondary education (Arnett, 2006; Markowitz, Parsons & Advani, 2017). It is also a developmental stage that is characterized by identity exploration and instability, meaning they are exploring commitments regarding relationships and work and experiencing changes in residence (Arnett, Žukauskienė, & Sugimura, 2014). The instability primarily arises from relationships and job changes occurring during this stage (Arnett, 2006). As a result, this stage can lead to longer transitions into adulthood. The instability in their jobs can have financial implications to young adults supporting their parents (Cheng, Birditt, Zarit, Fingerman, 2015).

Although there is no published literature describing the role of young South Asian adults caring for parents with diabetes specifically, literature was identified related to young South Asian adults in other caregiver roles and the influence culture has on their caregiving. Parveen, Morrison, & Robinson (2012) conducted a cross-sectional study to examine the influence of ethnicity on caregiver motivation for caring, coping responses and mood amongst both Caucasians and South Asians in Britain (N=235). Caregivers were recruited through various caregiver support groups throughout the UK. Some of the reasons behind caregiving were a diagnosis of cancer, dementia, Parkinson's, multiple sclerosis and stroke. Findings demonstrated that South Asian caregivers were younger (M=40.91) than Caucasian caregivers (M=63.78); and South Asian caregivers provided care based on obligation, and reported more depression (p<0.05). With a convenience sample recruitment strategy from support groups and pre-existing differences between the two ethnic groups,

limited conclusions can be taken from the study. Findings underscore how motivation to provide care and cultural perception of illness can impact the caregiver's quality of life.

Dellmann-Jenkins & Brittain (2003) conducted a small cross-sectional study examined the caregiving experience, motivations and strains in young adult children (n=40) who were the primary source of support to their older family members and from a comparator group who were 18-40 years old, who had not assumed caregiving roles (n=40). Investigators developed a questionnaire that included Ohuche and Littrell (1989) filial responsibility scale to obtain quantitative measures regarding one's opinion about supporting and caring for older adults and added six open-ended questions to assess attitudes toward filial responsibility (Dellmann-Jenkins & Brittain, 2003). The tool was reliable as it was field tested (reliability = 0.76; SD = 2.02). Although the study sample was culturally diverse; a majority were of Caucasian descent (88%), and 90% of the caregiver population was female. The study found that young caregivers had high levels of filial responsibility, whereby they felt a sense of responsibility and obligation to provide care to their parents (Dellmann-Jenkins & Brittain, 2003). Due to the small sample size, limited conclusions can be drawn and cannot be generalized to South Asian caregivers.

In order to gain a greater understanding of young adult caregivers for illnesses, frail elderly or disabled family members or friends, Levine et al., (2005) conducted two national survey studies in the United States 1998-2004. The first was conducted by the Harvard School of Public Health, the United Hospital Fund, and the Visiting Nurse Service of New York (Harvard/UHF/VNS) and the second survey was conducted by

National Alliance for Caregiving and the Association for the Advancement of Retired Persons (NAC/AARP). Both studies utilized random telephone surveys with similar screening methods and sample size.  A majority of participants were male (74.5% and 50.8%), and Caucasian (71.7% and 69%). The results demonstrated that majority of young adults were caring for a female and that young caregivers performed the same tasks as older caregivers. Based on the findings from both studies, 98.2% and 99.8% of the young carers performed tasks such as shopping, housework, transportation managing finances, arranging government services and meal preparation (Levine et al., 2005). It was also noted that due to caregiving activities 36.4% of participants reported having less time for family and friends while 43.1% gave up hobbies and social activities (Levine et al., 2005). This study uniquely identified some of the caregiving tasks that young adult caregivers provided and the impact this had on their lives. However, the study did not differentiate the different types of caregiving (i.e. caregiving related to illness, frail elderly or versus disabled family members or friends) nor differentiate the intensity of caregiving involved. Furthermore, due to the lack of South Asian participants and possible underrepresentation of immigrant families, the results may not be directly applicable to young South Asian caregivers in a Canadian context.

A qualitative study using a phenomenological approach was conducted by Katbamna et al., (2004). The study explored the experiences and needs of 105 South Asian caregivers (aged 20-72; 68% female and 31% males) using in-depth interviews and focus groups. The study revealed that the majority of male and female carers provided care to spouses, children and parents. Findings highlighted how the quality of care

provided was influenced by a multitude of factors, including caregiver's employment, housing, strength of social networks and the nature of care needed. Lastly, it emphasized a gender-based division of caregiving duties. The study demonstrated that females were typically responsible for providing personal and practical care (e. g. cooking, cleaning) while males were likely to engage in 'compensatory tasks' (i.e. organize welfare benefits or housing situation) (Katbamna et al., 2004). Furthermore, the level of engagement and the tasks male and female caregivers complete as part of their caregiving responsibilities may impact their QoL differently. For example, it was suggested that providing care for diabetes associated complications (e.g. foot ulcers, neuropathy, managing hypo/hyperglycaemia), typically provided by females may be more demanding physically and would impact the caregiver's social life.  Conversely, managing family finances, typically provided by males may cause greater stress and anxiety which can impact caregiver's psychological well-being. However, since the study was conducted in the United Kingdom, the family structure and carers experience of informal support may not be directly transferable to a Canadian context.

**Gender differences and caregiving**

Caregiving amongst South Asians is heavily intertwined with their cultural values (Pharr, Dodge, Francis, Terry, Clark, 2014; Spitzer, Neufeld, Harrison, Hughes & Stewart, 2003). The cultural aspect of caregiving can include having different expectations of male and female caregivers.  South Asian countries have strong patriarchal norms and it has been suggested that this places a greater reliance on women to take on caregiver responsibilities within households because they are considered to be

to be the most appropriate caregivers for children and older adults (Spitzer et al., 2003; Zimmerman, Litt, & Bose, 2006). Moreover, due to the effects of migration family support networks are limited or dispersed making it challenging to provide care (Spitzer et al. 2003). Despite length of residency in Canada, immigrant South Asian women are faced with the challenges of balancing cultural expectations with the demands of their work (Spitzer et al. 2003). This made women more likely to develop caregiver burden relative to their male counterparts (Spitzer et al. 2003). Previous research has shown that women focus on the benefits or rewarding aspects of caregiving (e.g. spending time with loved ones) which can explain why they reject the notion of having caregiver burden (Spitzer et al. 2003). However, a majority of this research is based on caring for older adults with dementia, Alzheimer's, or mental health illnesses, and may not be directly applicable to a young adult population caring for parents with T2DM, due to the differences in chronic disease management, severity and trajectory.

**Caregivers of family members with diabetes**

Diabetes has both economic and health implications, which has caused a greater reliance on informal caregivers. To determine the amount of time and the associated cost of providing care to elderly individuals with diabetes (DM) a cross-sectional study was conducted in the United States (Langa et al., 2002). The 1993 survey of the Asset and Health Dynamics (AHEAD), was used to gain insight into the health transitions among elderly individuals (N = 7,438) and the impact it has on families and society. Data regarding the number of hours of care provided by caregivers and functional status (based on ADL/IADL impairments of care recipient) were collected. Participants were

interviewed in person or over the phone and a logistic regression was utilized to examine

the relationship between DM and the hours of informal caregiving. Results revealed that

those with DM had at least one ADL (activities of daily living) or IADL (instrumental

activities of daily living) impairment and received an average of 6.1 hours per week of

informal care (Langa et al., 2002). Additionally, the majority of respondents with DM

using insulin took three or more medications. This suggests that individuals with diabetes

related disabilities rely on the informal caregiving they receive (Langa et al., 2002).

Although the findings cannot be directly transferable to a younger group of South Asian

caregivers findings highlight the significance of supporting individuals affected by DM

and those caring for them when managing DM and its complications.

Informal caregiving provided by family members is becoming more common

with the rise of chronic illnesses, shorter hospital stays and technological advances. The

demands of this caregiving role can vary based on the progression of the illness and needs

of their loved ones. This commitment can result in caregiving burden and distress

amongst the caregivers. Understanding the impacts of the caregiving role is pivotal in

developing strategies to effectively support a population of carers. A comparative analysis

of caregiving burden and distress amongst caregivers of persons with cancer (n=99),

dementia (n=271), diabetes (n=101) and frail elderly persons (n=135) was conducted in

the United States (N= 606) (Kim & Schulz, 2008). The sample population included

Caucasian, African American, Hispanic and Asian caregivers. There was no mention of

the proportion of male and female participants. The sample was obtained using random

digit–dial technique (Kim & Schulz, 2008). Kim & Schulz created a 5-point Likert scale

to examine caregiver outcome variables (physical, emotional, and financial caregiver strain). The results indicated that caregiver's emotional stress was correlated with being older, being female and the type of illness of the care receiver. Greater levels of emotional stress were found amongst caregivers of those with cancer and dementia. Kim & Schulz (2008) also found that 44.9% of caregivers providing care for patients with diabetes reported having high levels of caregiving burden. Moreover, amongst caregivers who had longer hours of caregiving there was a greater likelihood of having financial difficulty regardless of the illness that the patient had (Kim & Schulz, 2008). This is likely because carers experience difficulty managing both the demands of their work and their caregiving role (Kim & Schulz, 2008). This study provides some valuable insight into some of the impacts of caregiving but fails to capture the differences in caregiving experiences between caregivers. Due to the lack of validated tools used within this study to measure outcome variables, limited conclusions can be made.

Caregiver needs are an important element of their own ability to provide care and how they cope with their role as caregivers. In order to understand the needs and concerns of family caregivers with T2DM. Scarton et al., (2016) conducted a qualitative study (N= 32). A convenience sample of American Indians, African American and Caucasian family caregivers were recruited. A majority of participants were female (68.8%) and 31.2% of participants were males. Data were collected using semi-structured interviews over the telephone. Content analysis was performed using predetermined categories adapted from the needs/ concerns of stroke patients (Bakas Austin, Okonkwo, Lewis & Chadwick, 2002; Scarton et al., 2016) (Table 1). To ensure rigor in the study,

triangulation was done using in-depth interviews, field notes and co-authors participating

in the interpretation and coding of data. Results demonstrated that a majority of

participants required more information about diabetes management (i.e. warning signs,

dietary restrictions etc.). Caregivers reported it to be challenging to manage and make

time for their own health related issues, difficulty determining what an 'adequate diet'

would consist of, challenges to help manage medications and adhere to an exercise plan.

These findings are important in understanding some of the needs and challenges that

caregivers face when trying to manage diabetes. It also highlights areas where caregivers

may require more educational support regarding diabetes management.

Table 1

*Caregiver Needs and Concerns*

| Category | Subcategory |
| --- | --- |
| Information and resources related to Type 2 diabetes | • Information on diabetic diet and exercise<br>• How to find local resources<br>• Information on preventing complications |
| Dealing with the emotions and behaviours of the care recipient | • Helping the care recipient with their emotions<br>• How to help keep the care recipient socially active |
| Providing physical care | • How to communicate with the care recipient<br>• Helping the care recipient with meal planning and medication<br>• Managing fluctuations in blood glucose |
| Providing instrumental care | • Skin care<br>• Activity and exercise<br>• Paying for medical expenses<br>• Transportation<br>• Finding care while away |
| Dealing with one's own personal responses to caring | • One's own emotions and health<br>• Dealing with new responsibilities<br>• Keeping one's social life active |

*Note*. Adapted from "Needs and Concerns of Family Caregivers of American Indians, African Americans, and Caucasians With Type 2 Diabetes", by Scarton, L., Bakas, T., Poe, D., Hull, M., Ongwela, L., Miller, W., 2016, Clinical Nursing Research, 25, p.145.

**Caregiver and Quality of life**

The World Health Organization (WHO) defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1998, p.354). Engaging in caregiving can impact the quality of life (QoL) of the

caregiver because it can have mental, physical, social and emotional implications (Awadalla, Ohaeri, Al-Awadi, & Tawfig, 2006). However, there are limited studies that have explored such impacts on caregivers when caring for those with diabetes. Moreover, the majority of the literature concerning South Asian caregivers involved caring for elders with dementia, Alzheimer's or stroke. Due to the severity and different trajectory of these diseases it may not be comparable to the role demands of caregivers managing diabetes.

Awadalla et al., (2006) conducted a cross sectional study to determine the QoL of caregivers of Sudanese patients with Type 1 Diabetes Mellitus (T1DM) and T2DM using the validated WHO 26-item Quality of Life (QoL) Instrument (WHOQOL-BREF). The responses of caregivers (N=240) of patients with T2DM were compared to that of the general population. The results demonstrated that caregiver's education level, marital status, was directly correlated to their quality of life. Moreover, the findings illustrated that caregivers had higher QoL scores compared to the patients with T2DM. Additionally, the study found that the caregiver's QoL was significantly influenced by their assessment of the patient's QoL, and the longer the duration of diabetes the greater impact it had on the caregiver's psychological and emotional well-being. This is because providing care for a greater duration impacted the caregiver's independence and social relationships. This finding was similar to another cross-sectional study (Sinclair et al., 2010), the study examined the impact that older adults with diabetes had on their informal caregivers. The Diabetes Knowledge Questionnaire, EuroQol, Caregiver Strain Scale and General Health Questionnaire were utilized to measure diabetes related knowledge, QoL, caregiver strain and mental health respectively. The study found that both patients and carers had low

levels of diabetes related knowledge (median scores 9 versus 8 p<0.05) and 50% carers

reported feeling overwhelmed by the caregiving duties.

Jorwal, Verma & Singh (2015) examined depression and anxiety levels amongst

caregivers. Participants were recruited from an outpatient clinic within a tertiary care

hospital in India. Using the Hospital Anxiety and Depression Scale (HADS)

questionnaire, a cross-sectional design was employed to assess caregivers of patients

living with T2DM (N=100). The results demonstrated that DM affects the psychological

health of both caregivers and patients.  Approximately, 24% of patients and 10% of

caregivers were found to have depressive disorder; 44% of patients and 18% of caregivers

had anxiety disorder. Amongst caregivers, a majority of caregivers had mild and

moderate levels of anxiety and none had severe depression (Jorwal, Verma & Singh,

2015). These findings highlight the impact diabetes can have on the mental health of

family members caring for those with DM. Likewise, Gupta and Pillai (2005) conducted a

cross-sectional study in the United States to examine caregiver burden amongst South

Asians (N=118) providing care for the elderly. Data obtained from interview surveys

demonstrated that caregiving was influenced by cultural factors that determine the level

of caregiver burden. South Asian participants in this study had a network of established

extended family contributing to lessened emotional distress, while providing

informational, and psychological support. These findings provide a recommendation to

include extended family members and social supports when providing education

regarding management of diabetes amongst this population. Given that both of these

studies focused on an adult population of caregivers providing care to elders, the level of

dependency on this group of caregivers may differ from those who are younger caregivers. The age of young carers may impact the amount of social support they provide and their identification with filial piety norms, such as providing care for elderly parents financially and emotionally. Their caregiving role can impact the level of perceived caregiver burden and role demand experienced by this group of caregivers (Gupta & Pillai, 2005)**.**

**Diabetes Knowledge**

Diabetes knowledge is a key element in successfully managing this chronic disease (Kamel, Badawy, el-Zeiny & Merdan, 1999). The majority of research related to diabetes knowledge involves examining knowledge of patients that live with diabetes. However, a cross-sectional study examined diabetes knowledge of family caregivers, as well as patients with T2DM and T1DM (Arora, Marzec, Gates, & Menchine, 2011). The study had 291 participants (149 were caregivers; 142 were patients with diabetes). Furthermore, a majority of participants were of Hispanic descent (79.9%); other ethnicities included were Asian (3.8%), Caucasian (7.7%) and African American (8%). Participants ranged in age from 18- 76 years old with average age being 47.3 years. The Diabetes Knowledge Questionnaire (DKQ), a validated tool, was administered to determine level of diabetes knowledge. Although study findings demonstrated there was a higher knowledge of diabetes amongst patients; both patients and their caregivers significantly lacked knowledge regarding diet, signs of hyperglycemia/hypoglycemia, wound care and organ function. Similarly, Islam et al., (2015) conducted a cross-sectional study (N=515) to examine the association between knowledge and glycemic control

amongst patients with T2DM in Bangladesh. More than half of the participants were females (55.9%) and the average age of participants was 50. The results demonstrated that there was a lack of knowledge with respect to diabetes risk factors, causes and management of diabetes. However, male participants had higher knowledge scores ($p<0.001$). Overall, these studies highlight that there is a lack of knowledge amongst caregivers and patients with DM.

Chilton et al., (2006) conducted a cross-sectional study examining the relationship between diabetes knowledge, demographics and health promoting lifestyle amongst Hispanic American adults. Participants (N=40) were recruited from two local Hispanic churches in the southeastern United States and a large proportion of participants were female (55%) and 45% of participants were male. The Health Promoting Lifestyle Profile (HPLP) II and DKQ questionnaire was used to examine perceived control of health and diabetes related knowledge respectively. Findings suggested that there were low levels of physical activity, poor dietary habits and poor diabetes related knowledge amongst participants ($p<0.05$). Additionally, income was shown to be correlated with physical activity ($p<0.05$), which emphasizes how socioeconomic status (SES) may contribute to participation in health promoting activities. The lack of knowledge regarding diabetes may have prevented the Hispanic Americans from engaging in self-care behaviours. Although the findings may not directly apply to other ethnic minorities; these findings highlight the importance of examining diabetes knowledge and income when examining diabetes management.

***Diabetes knowledge and management of diabetes***

Chavan et al., (2015) conducted a cross-sectional study examining diabetes knowledge and its correlation with both pharmacological and non-pharmacological compliance amongst patients in India with T2DM (N=307). The mean age of participants was 55.6 years and there was a disproportionate number of male (72.6%) and female (27.4%) participants. The study utilized a pretested (Spearman correlation coefficient, $r$ = 0.81; internal consistency Cronbach's α, $r$ = 0.78) questionnaire. The results demonstrated that gender was associated with knowledge (p=0.005), where males had moderate to good knowledge levels relative to females. The study reported that diabetes related knowledge was associated with compliance to pharmacological and non-pharmacological management. Additionally, Kassahun, Gesesew, Mwanri, and Eshetie (2016) conducted a cross-sectional study examining the diabetes related knowledge, adherence to medication and self-care behaviours (i.e. dietary patterns, physical activity, self-glycemic control and foot care) amongst patients (61.8% males; 38.2% females) with T2DM in Southwest Ethiopia (N=309). The study utilized culturally validated tools including: Diabetes Knowledge Test (DKT), the Summary of Diabetes Self-Care Activities (SDSCA) tool and the Morisky 8-Item medication adherence to measure diabetes related knowledge, self-care behaviours and adherence to medications respectively. The study revealed that a large proportion of patients had low levels of diabetes knowledge (44.9%), poor self-care behaviours and medication adherence (37.2%). Despite the fact that the results cannot be directly transferable to a Canadian context, findings highlights the impact knowledge has on diabetes management.

***Diabetes knowledge and physiological impact***

Casagrande et al., (2012) conducted a secondary data analysis using data from the National Health and Nutrition Examination Survey (N= 1,233). They examined the prevalence of diabetes knowledge such as knowledge of A1C, blood pressure, and LDL cholesterol (ABC) levels. Diabetes knowledge was ascertained using an in-home interview, physical examination and laboratory measures at a mobile examination centre (MEC). There was no mention if the study utilized a validated questionnaire in assessing ABC knowledge. The study demonstrated that ABC knowledge was not significantly associated with meeting American Diabetes' Association's (ADA) recommended ABC levels (p >0.05). The findings also suggested that diabetes knowledge was greater amongst non-Hispanics and those with higher levels of education and income (p<0.02). These findings are consistent with a prospective study following patients over a nine-month period (Sanchez et al.,2005). The study demonstrated that there was no association between diabetes risk factor knowledge (DRK) and successful management of glycosylated haemoglobin (A1C) or low-density lipoprotein (LDL) control among patients with Acute Coronary Syndrome (ACS) (N=200). Similarly, Berikai et al., (2007) conducted a retrospective study exploring whether diabetes self-management education (DSME) could help predict target A1C levels at six months (N=155).  A majority of participants (n=93) were classified as knowledge gainers (received DSME), and 63 participants were grouped into the non-gainers (comparator group) category. Participants had a baseline A1C level ≥ 7% and A1C level was measured after one month and six months of receiving DSME. Education was measured using the ABC test tool. Findings

indicated that there was an increase in diabetes knowledge after receiving DSME. The increase in diabetes knowledge could predict achievement of target A1C levels (p<0.001). Having a greater understanding of diabetes knowledge may have motivated participants to adopt a healthy lifestyle and improve glycemic control. In contrast, Bains and Egede (2011) examined the correlation between diabetes knowledge, self-care, glycemic control and health literacy in low-income minorities with T2DM (N=125). Reliable tools such as the DKQ, Revised Rapid Estimate of Adult Literacy in Medicine (REALM-R), and Morisky scale were used for evaluation. A1C values were obtained from medical records. The results demonstrated that there was a statistically significant association between diabetes knowledge and perceived health status with glycemic control (p<0.001) and no association between health literacy and glycemic control. However, it was noted that health literacy was only significantly associated with diabetes knowledge. Based on these results, it can be inferred that one's health literacy may impact diabetes knowledge and indirectly impacts glycemic control. Additionally, both DRK and perceived health status were critical to obtaining glycemic control. The inconsistent findings between studies emphasizes the importance of examining diabetes related knowledge amongst populations who are at high risk of developing T2DM using validated tools to quantify knowledge. Overall, the literature regarding diabetes knowledge primarily focuses on those affected by diabetes. There is a paucity of studies that examine the diabetes related knowledge of caregivers of those affected by T2DM.

***Diabetes knowledge and its relationship with quality of life***

Diabetes is a chronic illness, which may require those affected by diabetes or their caregivers to dedicate large amounts of time for effective management, which can impact their quality of life (QoL) (Awadalla et al., 2006; Kueh el al., 2015). However, there is limited research examining the relationship between diabetes knowledge and QoL of those with DM or their caregivers (Kueh el al., 2015).

Kueh et al., (2015) conducted a cross-sectional study examining the relationships between the key variables including knowledge, attitudes, self-management and QoL amongst 291 patients with T2DM in Melbourne, Australia (192 males, 99 females). Participants ranged in age from 20 to 70 years of age.  Questionnaires measuring diabetes knowledge (Diabetes Knowledge Scale), attitudes (Diabetes Integration Scale -19), self-management (Summary of Diabetes Self-care Activities Scale), and QoL (Diabetes Quality of Life Scale) were administered (Kueh et al., 2015). The results demonstrated that a higher level of knowledge was associated with an increase in the level of positive attitude and more frequent self-management with regards to blood glucose testing. Additionally, findings indicated that knowledge indirectly through self-management and one's attitudes to living with diabetes was associated with QoL (p=0.007). These findings may not be directly transferable to those who are at risk for developing diabetes and providing care to those affected by diabetes. However, these findings highlight the importance of examining the inter-relationship between diabetes knowledge and its influence on health related behaviour (i.e. diet, exercise etc.), diabetes management and quality of life when targeting diabetes prevention.

**Risk Perception**

Risk perception of developing diabetes and level of engagement in risk reducing behaviours amongst South Asians remains uninvestigated, yet perception of risk is a key factor that facilitates the adoption and performance of health-promoting behaviours (Becker, 1974; Janz & Becker, 1984). If individuals who are at high risk of developing diabetes do not perceive themselves to be at high risk, they may be less inclined to engage in risk reducing activities (e.g. engage in healthy diet, exercise, smoking sensation, etc.) (Godino, Sluijs, Sutton & Griffin, 2014).

Perceived risk can act as a form of protective behavior or motivate behaviour (Gerrard et al., 1996; Graham et al., 2006). When risk perception and actual risk of developing a chronic condition are incongruent, it is unlikely that people will engage in health promoting behaviours (Graham et al., 2006). Due to the fact that there has been a considerable amount time since these studies have been conducted, and perceptions of risk vary among different populations, it is vital to explore the relationship between risk perception and actual risk of developing diabetes amongst young adult South Asians.

Hivert et al., (2009) conducted a cross-sectional study to examine the perceived risk of developing diabetes in primary care patients using the Risk Perception Survey for Developing Diabetes questionnaire (RPS-DD) and additional questions regarding participant's intention to modify current behaviour. A total of 150 patients without diabetes were recruited from Massachusetts General Hospital. It was reported that patients with high-perceived risk of developing diabetes are indeed at a greater risk of developing diabetes and were more likely women (p= 0.005) and had a family history of

diabetes (p<0.0001) (Hivert et al., 2009). Yet, these patients did not plan to change their

lifestyle more than patients with a low perceived risk (p>0.05). Moreover, limited

conclusions can be taken from this study due to the small sample size. However, findings

highlight the importance of examining individual's perceived health and their intention to

change current behaviour when designing interventions to support high-risk populations.

Similarly, Godino et al., (2014) conducted a cross-sectional study to investigate the

association between perceived risk of T2DM and behaviour change. This study was a

sub-study from the Diabetes Risk Communication Trial (DRCT) in the United Kingdom

(UK). A total of 569 middle-aged participants were recruited. The Framingham Offspring

Diabetes Risk Score was used to determine perceived risk and health assessment was

used to determine actual risk. The study demonstrated that participants who perceived

themselves to be at high risk of developing T2DM were at higher risk (p<0.001).

Moreover, the findings highlighted that additional T2DM risk factors, such as body fat

percentage and self-rated health, were similarly related to perceived risk. The results of

the study may not be directly transferable to other populations because the participants

were all middle-aged and were from the UK.

The development of T2DM has a strong genetic component and as such it may

play a role in influencing an individual's decision to adopt healthy behaviours and impact

their risk perception of developing T2DM (Hivert et al., 2004; Pijl et al., 2009).  Using a

qualitative approach Pijl et al., (2009) explored the impact familial history of T2DM had

on beliefs, risk perception and control over developing diabetes amongst participants

(aged 57 to 72 years) in the Netherlands. Semi-structured interviews were conducted on

participants with (n= 9) and participants without (n=12) a family history of diabetes. The

findings highlighted how participants viewed diabetes as a multifactorial disease.

Furthermore, participants who acknowledged their family history of diabetes did not

perceive themselves to be at higher risk or worry about getting diabetes. Additionally,

participants who viewed genetic predisposition as a cause of diabetes felt they had no

control over the onset/prevention of diabetes. However, participants who viewed

behaviour as the cause of diabetes believed that diabetes was preventable. Additionally, it

can be postulated that because the sample population was older, that participants may

view developing diabetes as a part of aging and therefore may not be inclined to engage

in health preventative behaviors (Pijl et al., 2009). The study does highlight how one's

beliefs could help formulate risk perception and control over developing diabetes. These

findings suggest that an individual's beliefs can act as a motivating factor in the decision

to adopt healthy behaviours. Although the study has small size; it underlines the

importance of examining risk perception when developing diabetes prevention strategies.

Farmer et al., (1999) investigated the risk perception of developing diabetes

among siblings (N=3693) of those affected by T2DM in the UK. Participants ranged in

age from 35 to 74. Less than half of the siblings considered themselves likely to develop

diabetes (n=454). Those who considered themselves to be at high risk were likely to be

female, younger in age (35 to 54 years of age) and had a parent who had DM (p

<0.00001). BMI was shown to be a strong predictor for developing diabetes, however

BMI failed to predict participant's risk perception (p=0.02). Limited conclusions can be

taken from the study as these findings may not be applicable to a Canadian population and because there has been a considerable amount of time since this study was conducted.

To describe risk perception of developing diabetes among foreign-born Spanish-speaking Latinos in the United States (US) Joiner et al., (2016) conducted a cross-sectional study (N = 146). Participants were 20 years of age or older (M=39.5). Additionally, 74% of participants were female and 35% reported having a family history of diabetes. The RPS-DD was translated into the Spanish-language used to measure perception of risk for developing diabetes. A small proportion of participants (31.5%) perceived themselves to be at moderate/high risk for developing diabetes. Additionally, participants who perceived themselves to be at moderate/high risk were more realistic about developing diabetes, had a greater degree of worry, risk perception of developing other chronic illnesses (i.e. Heart disease, high blood pressure, arthritis etc.) and perceived more comparative environmental risk relative to participants who perceived themselves to be at lower risk (p<0.005). Similarly, Bapiste-Roberts et al., (2007) conducted a cross-sectional study to understand the role of family history of diabetes and how it impacts awareness of diabetes risk factors, and engaging in healthy behaviours. There was no mention of the questionnaire used in the study. Participants were African American adults without diabetes who were participating in Project DIRECT (Diabetes Interventions Reaching and Educating Communities Together) at baseline (i.e., before implementation of any interventions) were recruited for the study (N=1122). A majority of participants were women (62%). The study demonstrated that African Americans with a family history of diabetes were more aware of diabetes risk factors and were more

likely to engage in certain health protective behaviours than those without a family history of the disease with a relative risk of 1.09 (95 % CI: 1.03–1.15). Although the findings from these studies focus on other ethnic minorities and may not be directly transferable to the South Asian population; they serve as a useful comparison.

A Randomized Control Trial (RCT) conducted in the US assessed the relationship between key variables including perceived risk, diabetes self-care and glycemic control (Shreck, Gonzalez, Cohen, & Walker, 2014). Diabetes self-care and risk perception were assessed using the Summary of Diabetes Care Activities (SDSCA) and Risk Perception Survey-Diabetes Mellitus (RPS-DM) questionnaires (Shreck et al., 2014). Participants were in a telephonic intervention group or an active control group for one year (N=526). A majority of participants were female (67.1%). Those in the telephonic group received up to 10 phone calls from trained health educators. The results demonstrated that those in the intervention group (post intervention) had high levels of perceived risk, which influenced dietary habits, exercise, and medication adherence amongst diabetics. This study highlights how risk perception is an important factor in promoting protective health behaviour (Shreck, Gonzalez, Cohen, & Walker, 2014).

Early detection of diabetes can promote healthy behaviours and can lead to a reduction in diabetes related complications (Colagiuri & Davies, 2009; Kowall et al., 2017). Kowall et al., (2017) conducted a longitudinal study to evaluate how undiagnosed diabetes mellitus (UDM) or individuals with prediabetes perceive their likelihood of developing/ having diabetes and factors that influence diabetes risk perception in Germany (N=2279).  Participants ranged in age from 24-74 years of age. Recruitment of

participants was performed using a German population-based Study (KORA FF4 Study). Participants had no history of diabetes and took an oral glucose tolerance test (OGTT) and estimated their likelihood of having UDM and developing diabetes. Risk perception was evaluated using 3 questions (composed of categories) and there was no reporting of validity of these questions in assessing risk perception. Results demonstrated that 74% of participants with UDM believed that they were at a low risk or a very low risk for developing diabetes. Amongst those with prediabetes more than 70% of participants believed that they were not at risk of developing diabetes. Moreover, participants with prediabetes were more likely to perceive themselves at risk of developing diabetes if they had low self-rated health, their mother/ father had diabetes, they were obese, they were female, their educational level was high, and if they were younger (Kowall et al., 2017). Moreover, a negative association was found between age and perceived risk of diabetes development which may have been the case due to shorter life expectancy. Despite being at risk for developing diabetes, this population grossly underestimated their likelihood of developing/ having diabetes. Because the participants were of German descent the findings cannot be transferred to those of South Asian descent or other ethnic minorities. Additionally, due to the large age range of participants it is difficult to understand their rationale behind risk perception. However, these findings allude to how a population at risk of developing diabetes may have optimistic bias regarding health outcomes (Kowall et al., 2017).

**Literature Review and Theoretical Models**

The Health Belief Model (HBM) is a framework that helps explain why individuals engage or fail to engage in health related behaviour (Janz &Becker, 1984). This model has been applied to a wide range of health behaviours and has been utilized to understand uptake of preventative health behaviours. The HBM posits the notion that risk perception plays an integral role in behaviour change. Based on the HBM there are six main factors that can predict health behaviour which include: perceived susceptibility, risk severity, perceived benefits, perceived barriers, self-efficacy, and cues to action (Becker, 1974; Champion & Skinner, 2008; Jones et al., 2015; Rosenstock, 1974) (Table 2). The concept of self-efficacy and cues to action were added to the original framework in later years (Janz & Becker, 1984). Taken together these constructs help evaluate one's willingness to take-up health preventative behaviours (Champion & Skinner, 2008; Janz & Becker, 1984).

Table 2

*Health Belief Model Concepts.*

| Concepts | Definitions |
|---|---|
| Perceived susceptibility | Is defined as an individual's perception of developing a health condition. This is subjective construct and feeling of vulnerability can vary between individuals. |
| Risk severity | It is one's likelihood of having a heath condition, which is based on evaluations of possible medical and social implications. |
| Benefits to action | It is defined as one's beliefs regarding uptaking actions for the prevention of a disease/ health condition. |
| Perceived barriers | It is an individual's beliefs of negative consequences or obstacles as a result of uptaking recommended behaviours. |
| Self-efficacy | It is defined as an individuals' belief of their own ability to successfully complete a task or behaviour. |
| Cues to action | Refers to factors, which can facilitate one to change behaviour. |

Adapted from "The Health Belief Model: A Decade Later" by Janz, N. K., & Becker, M. H. (1984). Health Education & Behavior, 11(1), 1-47. https://doi.org/10.1177/109019818401100101

Based on the HBM, if an individual perceives a threat to his/her health and the perceived benefits of an action are greater than the perceived risks, then it is likely than the individual will take-up the recommended preventive health actions. The decision to take-up the preventative health behaviours is also influenced by other variables such as demographics, sociopsychological state, educational level etc. (Janz & Becker, 1984). Overall, the HBM emphasizes the key role risk perception has on health behaviours. This model can be used to help explain why individuals who are at high risk of developing

T2DM and its associated complications may or may not engage in preventative self-care activities.

### *Application of Health Belief Model*

Janz & Becker's HBM (1984) is the theoretical framework that guided the selection of some of the variables in the present study. Having a family history of diabetes may provide family members the opportunity to be involved in diabetes management and to witness some of the complications associated with T2DM. The HBM suggests this experience may bolster one's self-efficacy in improving their own health behaviours (Jones et al., 2015). Moreover, having a family history can influence one's perceived susceptibility as well as their knowledge of the illness.  Thus, knowledge and ones perceived risk are considered to be important variables in understanding why one may or may not engage in risk reducing behaviours. When applying the HBM to young adult caregivers there are a variety of factors (e.g. knowledge level, risk perception, resources, social support) that can influence decisions to take-up health promoting behaviours (Table 3) (Janz & Becker,1984; Jones et al., 2015).  It is important to examine the different factors in order to effectively support this population of caregivers.

Table 3

*Health Belief Model Applied to Young Adult South Asian Caregivers For Parent(s) With T2DM*

| Concepts | Application to young adult caregivers |
|---|---|
| Perceived susceptibility | • Having a family history of diabetes<br>• Genetics<br>• Inactive lifestyle<br>• Poor dietary habits |
| Risk severity | • May underestimate risk based on their low BMI<br>• Seeing some of complications associated with T2DM can contribute to greater perception of risk |
| Benefits to action | • Delay/ avoid onset of T2DM<br>• Greater quality of life when engaging in health promotion |
| Perceived barriers | • Fatalism<br>• Lack of social support<br>• Lack of diabetes related knowledge<br>• Limited resources (i.e. financial)<br>• Low risk perception/ambivalent attitude<br>• Poor dietary habits<br>• Social stigma |
| Self-efficacy | • Being involved in diabetes management (i.e. medication administration, exercising, driving to appointments etc.)<br>• Witnessing complications associated with T2DM |
| Cues to action | • Recommendations made by health care professionals |

Adapted from: "Theory at a glance: A guide for health promotion practice" by Rimer, B., Glanz, K. (2005).

**Conclusion**

T2DM is caused by interplay of genetic, behavioural and environmental factors. The SAP has an increased risk of developing diabetes at a younger age coupled, with an increased prevalence of diabetes (Sohal, 2008). T2DM can result in severe medical complications and can impact the Canadian healthcare system. To date, few studies have investigated young adult South Asian caregivers for family members with T2DM in Canada; most of the literature regarding similar populations is from the UK and the US. Given the significance of this problem in Canada, the need to further explore this population within a Canadian context is well supported. The young adult South Asian caregiver population is an understudied group of caregivers. Although, previous research on South Asian caregivers has suggested differences in caregiving tasks between genders, findings were based on caring for individuals with different illnesses (e.g. mental illness, dementia, stroke) and cannot be or may not directly applicable to young adult South Asian caregivers of parents with T2DM.  Also, these studies suggest that South Asian females typically take on personal caregiving tasks. In contrast, males tend to engage in compensatory tasks. Experiences from taking part in different diabetes caregiving roles can result in differences in diabetes related knowledge, risk perception and QoL between genders. Greater exposure in providing personal care can result in greater diabetes risk perception and knowledge amongst these young adult South Asians. This highlights the need to explore differences in caregiving between genders to help provide a greater understanding of how to support this South Asian caregiver population. Additionally, examining key variables such as diabetes knowledge, risk perception and quality of life in

young adult SAP caregivers can help to identify and develop interventions tailored for this population in an effort to promote upstream diabetes prevention programs. Gaining insight about young adult South Asian caregivers is an integral component in developing appropriate interventions to support this population in their caregiving role; and help decrease the likelihood of T2DM development amongst this high-risk population.

## CHAPTER 3: RESEARCH QUESTIONS AND METHODOLOGY

**Purpose**

This study explored second generational South Asian immigrant caregivers' knowledge of diabetes, quality of life, and risk perception of developing diabetes compared to their actual risk of developing diabetes.

**Research question(s)**

Amongst second generational immigrants of South Asian descent who are 18-29 years of age, who are caregivers for parents that have been diagnosed with T2DM for at least one year; what is their knowledge of diabetes (primary outcome), risk perception of developing diabetes (secondary outcome), their actual risk of developing diabetes (secondary outcome), and their QoL (secondary outcome)?

The research questions and hypotheses that guide the investigation are listed below. Amongst young adult South Asians who care for parents with type 2 diabetes:

1. What is the diabetes related knowledge of South Asian males compared to females? (primary outcome)

   *Hypothesis: It is hypothesized that female participants will have greater diabetes knowledge scores relative to male participants.*

2. What is the quality of life of the males compared to females?

   *Hypothesis: It is hypothesized that male participants will have greater quality of life scores relative to female participants.*

3. What is the risk perception of the males compared to females in developing diabetes?

*Hypothesis:  It is hypothesized that female participants will perceive themselves to be at greater risk than male participants*.

4.  What is the 'actual risk' of developing diabetes of males compared to females?

    *Hypothesis: It is hypothesized that male participants will be at greater risk of developing diabetes relative to females.*

5.  Is there a relationship between knowledge of T2DM and perceived risk for developing T2DM?

    *Hypothesis:  It is hypothesized those with greater diabetes knowledge will perceive themselves to be at greater risk for developing diabetes.*

6.  Is actual risk of developing diabetes associated with risk perception of developing diabetes?

    *Hypothesis:  It is hypothesized that those who are at greater risk of developing diabetes will perceive themselves to be at greater risk of developing diabetes.*

7.  Does their diabetes knowledge impact their adoption of exercise habits?

    *Hypothesis: It is hypothesized that those with greater diabetes knowledge would likely engage in health promoting behaviours.*

8.  Does their risk perception and diabetes knowledge impact their quality of life?

    *Hypothesis:  It is hypothesized that risk perception and diabetes knowledge influence quality of life. Participants with greater diabetes knowledge are predicted to have better quality of life and participants who perceive themselves to be at greater risk are predicted to have lower quality of life.*

**Rationale for the study**

The SAP accounts for 4.8% of Canada's total population and this population is typically younger than the overall population (Statistics Canada, 2007b). Research has shown that there is an increased risk of developing DM amongst South Asian children and adolescents 10 years earlier than European populations (Chowdhury, Grace, & Kopelman, 2003). However, there is a lack of evidence examining this population within a Canadian context (Appendix A). Moreover, before the age of 30 South Asians are typically expected to begin supporting their parents financially/emotionally if required (Gupta & Pillai, 2002; Pillai, 1985). Examining a population who is at high risk of developing T2DM and who are providing caregiving support to their parent(s) with T2DM can inform health promotion within this population. Additionally, gaining insight into a population that is at high risk for developing diabetes can guide healthcare professionals to target diabetes screening and prevention programs to the young adult South Asians caregivers (Appendix A). A cross-sectional design was utilized because it is appropriate for preliminary investigations of association due to the low demand on participants, low cost relative to other study designs and short data collection duration (Levin, 2006).

**Study Design**

A cross-sectional study design was utilized to explore diabetes knowledge, risk perception and quality of life amongst young adult South Asians. This design was selected because it facilitated rapid data collection over a short period of time, making it feasible. Also, due to the nature of the study design, the findings provided an

understanding of associations between variables and not cause or effect (Levin, 2006). Lastly, the cross-sectional study design findings will be used to generate hypotheses to develop future study designs.

**Inclusion Criteria and Exclusion Criteria**

**Inclusion Criteria**

1. Participants were considered eligible for the study if they were male or female between the ages 18-29, whose parent(s) have been diagnosed with T2DM for at least one year;

2. Parent(s) must have immigrated to Canada;

3. Participants must self-identify as South Asian

   - South Asian was defined as anyone from Bangladesh, India, Pakistan, Sri Lanka, Bhutan, Nepal, and Maldives (Bannerji-Stevens, 2009; Bhatia & Ram, 2004);

4. Participants must be able to speak and read English;

5. Participants must be residing in Canada; and

6. Participants must have provided unpaid or arranged for paid or unpaid help to manage their parents' diabetes (e.g. driving to appointments, checking blood glucose, promoting exercise, helping adhere to a healthy lifestyle) (Scarton et al., 2016).

**Exclusion Criteria**

1. Participants were excluded from the study if they had any form of diabetes.

**Sampling and Recruitment**

A convenience sample of males and females was recruited through multiple modalities such as community services, religious organizations, emailing members of different cultural groups and social media (i.e. Facebook, Instagram, Twitter) (Appendix B, C & D). Previous research has demonstrated challenges in engaging ethnic minorities such as those of South Asian descent (Douglas et al., 2011). The use of social media offers speed in its ability to recruit potential participants compared to traditional methods (i.e. use of flyers, word of mouth), efficiency and the ability to be cost-effective (Whitaker, Stevelink, Fear, 2017; Yuan, Bare, Johnson & Saberi, 2014). Additionally, social media offers users the ability to share, repost, comment on and endorse information (Whitaker, Stevelink, Fear, 2017).  This perpetually advertises the study to other social media users/ potential study participants which helped recruit more participants. This method has the ability to overcome barriers to study recruitment such as distance, transportation, and time constraints (Yuan et al., 2014). Social media also provides participants with the added benefits of anonymity (Yuan et al., 2014). A schedule was created by the researcher to regularly update and maintain postings on social media sites for a total of eight hours per week (Yuan et al., 2014). Previous research that used both Twitter and Facebook for participant recruitment had a greater success rate recruiting using Facebook (Kapp, Peters, Oliver, 2013; Whitaker, Stevelink, Fear, 2017; Yuan et al., 2014).

**Facebook**

The researcher contacted administrators of both open and closed Facebook groups and gained permission to make a post inviting participants to take part in the study (Hugelius, Adolfson, Gifford, & Oretenwall, 2017; Kapp, Peters, & Oliver, 2013). Additionally, a Facebook page called Young South Asian Caregivers (YSAC) study was created to generate interest and knowledge about the study. The page included the same posts made in the Facebook groups and weekly posts related to diabetes to garner more interest on the page (Appendix B). The first posting reached 400 Facebook users (Appendix B).

**Twitter/ Instagram**

The Twitter (@YSACStudy) and Instagram (@YSAC_ study) accounts were updated with content related to diabetes and the study by interacting with other Twitter feeds on a weekly basis (Yuan et al., 2014).

**Recruitment Posters and Email**

Recruitment posters were distributed amongst cultural student associations, churches, and temples, community organizations (Appendix B & D). In addition to using social media and posters to recruit participants, invitational emails were sent to a variety of South Asian social groups (Appendix F).

**Data Collection**

An online survey was developed by the investigator using LimeSurvey ©, a Canadian open source survey application. The questionnaires were completed online. To ensure proper function of survey software, the researcher tested its functionality

throughout the research study. Using the LimeSurvey platform, data was collected using the following tools: 1) 24-item DKQ; 2) RPS-DD; 3) Canadian Diabetes Risk Assessment Questionnaire (CANRISC); and 4) WHOQOL-BREF. Additionally, demographic characteristics including age, gender, religion, education level completed, marital status and caregiving tasks provided were collected (Appendix E, F).

**Response Rate**

To enhance response rate, the invitational email was sent to prospective participants using a modified Dillman approach (Dillman, 1991). This approach involved sending the initial invitational email, and sending a reminder email every two weeks for a period of six weeks to members of South Asian social groups. The invitational email sent outlined the purpose of the study, how the data obtained will be utilized, and the hyperlink for the online questionnaire. As incentive to participate in the study, respondents were offered the opportunity to enter a draw to win one of three $50 gift cards after completion of the survey.

**Instruments**

To effectively measure diabetes knowledge amongst populations at high risk of developing diabetes, the 24-item DKQ was utilized (Appendix G). This questionnaire is derived from the original 60-item DKQ (Garcia, Villagomez, Brown, Kouzekanani & Hanis, 2001). The 24-item DKQ is shown to have construct validity and a reliability coefficient of 0.78 (Garcia et al., 2001) (Table 4). This tool has been used to evaluate the knowledge of caregivers of family member with diabetes and the knowledge of those with diabetes (Arora, Marzec, Gates & Menchine, 2011). Additionally, the DKQ-24 has

previously been utilized on ethnic minority populations including Latino and South Asian

populations (Arora et al., 2011; Garcia et al., 2001). Each correct answer is given two

points, an answer of "I don't know" is scaled at one point and an incorrect answer is zero

points (Appendix H).

The validated RPS-DD was used to provide a greater understanding of the risk

perception of participants (Hivert et al., 2009) (Appendix I). This tool had 33 questions

and evaluates personal control (4 questions), worry (2 questions), optimistic bias (2

questions), personal disease risk (15 questions), and comparative environmental risk (9

questions) (Table 4). The raw scores from each question are converted into transformed

scores (Appendix J). The environmental risks component for the questionnaire section,

asks participants had to rank the environmental hazard from 1 (Almost No Risk) to 4

(High Risk). However, to minimize any redundancies in the questions asked the diabetes

risk knowledge potion of the questionnaire was eliminated. According to the creator of

the RPS-DD this would not alter the reliability or validity of the tool as the diabetes risk

knowledge question is not included in the composite score calculation (E. Walker,

personal communication, December 22, 2016).

The CANRISK is a 12-item prognostic tool was used to evaluate actual risk for

developing diabetes based on risk factors, which include ethnicity, health behaviours and

body-weight (Table 4) (Robinson, Agarwal & Nerenberg, 2011). The CANRISK tool was

based on the original Finnish Diabetes Risk Score (FINDRISC). The FINDRISC was

validated using the Finnish population to identify individuals at risk of developing T2DM

(Robinson et al., 2011). However, the CANRISK tool was utilized as it has been validated

using a sample of Canada's multi-ethnic population (Robinson et al., 2011) (Appendix K).

The CANRISK questionnaire consists of multiple choice questions and the response to

each question is attributed a specific number of points. The total amount of points

indicates actual risk for developing diabetes, where higher scores represent greater risk of

developing diabetes (Appendix L).

In order to measure the QoL of young South Asian adults the WHOQOL-BREF

was utilized (WHO, 1998) (Appendix M). The WHOQOL-BREF has been utilized

amongst South Asians and in 23 different countries. It has been shown to have cross-

cultural competency ensuring congruency and consistency amongst the SAP (Cronbach's

$\alpha > 0.70$) (Skevington, Lotfy, & O'Connell, 2004; Vahedi, 2010) (Table 4). The

WHOQOL-BREF consists of four domains, which include physical health, psychological

health, social relationships, and environment (Vahedi, 2010). The answers to the

questionnaire are on a Likert scale of one to five where high values represent a better QoL

(Vahedi, 2010) (Appendix N). The raw score ranges for each domain are as follows:

Physical Health= 7-35, Psychological= 6-30, Social Relationships= 3-15, and

Environment= 8-40. The physical health domain examines mobility, daily activities,

functional capacity, fatigue, pain, and sleep (Vahedi, 2010). The psychological domain

examines self-image, negative thoughts, positive attitudes, self-esteem, mentality,

learning ability, memory concentration, religion, and the mental status (Vahedi, 2010).

The social relationships domain examines 'personal relationships, social support, and sex

life' (Vahedi, 2010). Lastly, the environmental health domain examines: financial

resources, safety, health and social services, living physical environment, opportunities to

acquire new skills and knowledge, recreation, general environment (noise, air pollution, etc.), and transportation (Vahedi, 2010). The higher scores denote better QoL. The four domains are then scored and transformed into a 0 to 100 scale. This was done based on the scoring of WHOQOL-BREF (Appendix N). It will allow the results to be compared to other validated instrument tools such as the WHOQOL-100 (Power, Harper, Bullinger, 1999). In order to ensure that comparisons to other studies can be made, transformed scores were used for the statistical analysis (Gholami, Jahromi, Zarei & Dehghan, 2013).

Table 4

*Summary of Instruments*

| 24 item-DKQ | RPS-DD | CANRISK | WHOQOL-BREF |
|---|---|---|---|
| • Derived from the original 60-item DKQ<br>• Utilized among ethnic minority populations which include Latinos and South Asians<br>• Utilized amongst both individuals diagnosed with diabetes and their diabetes caregivers | • Composed of 33 questions<br>• Evaluates personal control, worry, optimistic bias, personal disease risk, and comparative environmental risk.<br>• Utilized amongst minority populations | • 12-item prognostic tool<br>• Evaluate one's actual risk for developing diabetes based on risk factors<br>• Validated against gold standard blood tests<br>• Validate using Canada's multi-ethnic population<br>• Utilized in practice and pragmatic | • This 26-item tool consists of four domains, which include physical health, psychological health, social relationships, and environment<br>• Demonstrated to have cross-cultural validity |

**Sample size Calculation**

A sample size calculation for conducting a t-test comparing diabetes knowledge between genders was done (primary outcome). The sample size was obtained using an

alpha (α) of 0.05, which is the accepted level of significance (Green, 1991). The power

was set at 80% and effect size set at 0.5 for our primary outcome (Green, 1991).

According to Cohen (1988) this sample size would be able to maintain adequate power

(80%) while detecting any differences between groups using t-tests with a medium to

large effect size. A sample size of 63 males and 63 females (a total of 126 participants)

was obtained (Hulley, Cummings, Browner, Grady, & Newman, 2013). The sample size

was calculated using the following:

$$N=[(1/q_1 +1/q_2)S^2 (Z_a +Z_b)^2]\div E^2$$

$q_1$ = proportion of participants in group 1 $\quad$ $q_2$ = proportion of participants in group 2
$Z_a$ = the standard normal deviate for α $\quad$ $Z_b$ = the standard normal deviate for β
Standardized Effect Size = E $\qquad\qquad$ $N$ = total number of participants required
A= $(1/q_1 + 1/q_0)$ = 4.00000
B=$(Z_\alpha+Z_\beta)^2$ = 7.84887
N = AB/$(E)^2$ = 125.582

To further add to the rigor of the study a sample size calculation was completed

for conducting a multiple regression (secondary outcome). This sample size was

determined based on the following formula: N > 50 + 8 m (where m is the number of

independent variables). For the purposes of this research study a total of 132 participants

were needed, where 66 participants should be males and 66 participants should be

females. This sample size would enable the smallest significant difference to be detected

when conducting the multiple regression (p=0.05) (Green, 1991). After incorporating

oversampling by 10% for any incomplete data, N=146 was obtained, where

approximately 73 participants should be male and 73 participants should be female. To

enhance the rigor of the study we utilized the larger sample size.

**Pilot Testing**

After creating the survey, user testing was completed on several participants to test implementation and comprehension. The survey was tested with four different browsers; Firefox (Version 55.0.3), Chrome (Version 55.0.2883.95), Explorer and Safari (Version 10.1.2). Additionally, the online survey was tested using two different operating systems including OS X Yosemite (Version 10.10.5) and Windows XP (Schleyer and Forrest, 2000) and for both I-phone and android smartphone operating systems. During this phase, three questions asked in the demographics questionnaire were eliminated to minimize any redundancies between questions found within the other questionnaires of the survey. Additionally, any typographical errors found in the survey were corrected.

**Data analyses**

All statistical analyses were completed using IBM Statistical Package for the Social Sciences (SPSS) Version 20 Statistical Software. After data was obtained from LimeSurvey, it was subsequently transferred to an encrypted excel and SPSS document.

**Descriptive Statistics**

The categorical data were expressed as frequencies and percentages. Descriptive statistics were expressed as means and standard deviations to highlight the dispersion of the data around the mean (Simpson, 2015). Descriptive statistics were used to summarize the means and standard deviation of various variables. In order to organize participant demographic and clinical characteristics into a form that is easily interpreted, a frequency table was constructed (Manikandan, 2011). Where data were not normally distributed, non-parametric tests were used. A p-value of 0.05 was considered to be statistically

significant. Cross-sectional surveys are often faced with the issue of missing data. For the purposes of this study, missing data was reported but was the participant case was excluded from data analysis.

**Analysis Approaches Per Research Questions**

The following analytic approaches were used for each of the following research question:

*1. What is the diabetes related knowledge of South Asian males compared to females?*

To compare diabetes related knowledge (total and domain specific) between male and females and detect statistical differences, an unpaired t-test was employed using the DKQ (Appendix O).

*2. What is the quality of life of the males compared to females?*

Parametric (unpaired t-test) and non-parametric tests (Mann-Witney U) were employed to compare male and female QoL scores.

*3. What is the risk perception of the males compared to females in developing diabetes?*

The perception of developing diabetes may differ due to differences in gender (Katbamna et al., 2004). Thus, a chi-square test comparing gender versus risk perception level was conducted.

*4. What is the 'actual risk' of developing diabetes of males compared to females?*

To determine actual risk of diabetes amongst male and female participants, an unpaired t-test comparing gender and CANRISK score was conducted.

*5. Is there a relationship between knowledge of T2DM and perceived risk for developing T2DM?*

To examine the relationship between diabetes related knowledge and perceived risk for developing diabetes, a bivariate linear regression analysis was conducted (Appendix O). The diabetes related knowledge was the independent variable in this analysis.

*6. Is actual risk of developing diabetes associated with risk perception of developing diabetes?*

A bivariate linear regression analysis was performed based on one's actual risk of developing diabetes and one's risk perception of developing diabetes. The actual risk of developing diabetes was the independent variable in this analysis.

*7. Does their diabetes knowledge impact their adoption of exercise habits?*

A-chi-square test of the level of diabetes related knowledge and engagement in high-risk behaviours was conducted (Appendix O).

*8. Does their risk perception and diabetes knowledge impact their quality of life?*

A multivariate regression analysis was utilized to examine how risk perception and diabetes related knowledge can influence quality of life of young caregivers (Appendix O).

**Ethics**

Approval from the Research Ethics Board (REB) from McMaster University was obtained prior to study initiation (Appendix P). The use of social media is becoming increasingly popular in research recruitment. However, it is a relatively novel tool as there are no set guidelines for its use (Gelinas et al., 2017). As such, the use of social media required maintenance of ethical sensitivity which is why explicit permission from group administrators were obtained prior to making a posting on behalf of the study.

Moreover, in order to avoid deception, the investigator maintained transparency by presenting as a researcher and avoided the creation of online identities to gain access to online communities (Gelinas et al., 2017). Informed consent was obtained prior to completing the questionnaire (Appendix P, Q). Participants submitted their information to the investigator through LimeSurvey. Participants that provided email addresses were kept separate from the survey responses to ensure that there would be no identifying information leading to participant revealing or identification.

## CHAPTER 4: RESULTS

**Characteristics of the Sample**

150 participants aged 18-29 years (77 females, 73 males) participants completed the survey. However, only 149 surveys (76 females, 73 males) were fully completed (Table 5). One respondent only completed the demographic and DKQ portion of the questionnaire. Table 5 details the demographic characteristics of the study participants. Continuous data were expressed by means (M) and standard deviations (SD) and categorical data were expressed by frequencies and percentages.

A large proportion of female participants (38.2%) were in the 24-26 age group. In contrast, the majority of male participants (39.7%) were in the 27-29 age group. More than half of the female (68.4%) and male (64.4 %) participants were of Indian descent; 18.2% females and 20.5% males reported being of Sri Lankan descent. 79.2% of females and 64.4% of males live in the same household as their parent(s) with T2DM (Table 5). 34.67% of participants were recruited from social media (Facebook, Instagram, Twitter) and 35.3% of participants were recruited through a friend/colleague.

When examining the different caregiving tasks completed by both male and female caregivers there was there was a gender-based division in caregiving tasks completed. The results indicated 32.5% of females and only 11% of males took part in administering insulin for parents (p<0.05) (Table 6). Also, 84.9% of males and 64.9% of females drive their parents to their diabetes appointments (p<0.05) (Table 6). The findings indicate that a greater proportion of females (55.3%) relative to males (17.8%) manage their parents' diabetes related complications (i.e. wound care, low blood sugar,

kidney disease, loss of limb and nerve damage) (p<0.001) (Table 6). The results

demonstrated that 72.4% of females and only 30.1% males participate in meal preparation

for their parents (p<0.001) (Table 6). Interestingly, managing finances associated with

diabetes was primarily done by male caregivers (49.30%) compared to (9.20%) females

(p<0.001) (Table 6). It was also noted that 67.1% of male caregivers and 51.9% of female

caregivers reported spending one to five hours in an average week completing these

caregiving tasks.

Table 5

*Frequency of Demographic Characteristics of Study Participants*

| Characteristic | Characteristics of Participants n (%) | | p-value [a] |
|---|---|---|---|
| | Females | Males | |
| **Age (years)** | | | 0.28 |
| 18-20 | 11(14.50) | 9 (12.30) | |
| 21-23 | 16 (21.10) | 16 (21.90) | |
| 24-26 | 29 (38.20) | 19 (26) | |
| 27-29 | 20 (26.30) | 29 (39.70) | |
| **Background** | | | 0.75 |
| India | 52 (68.40) | 47 (64.40) | |
| Pakistan | 8 (10.50) | 5 (6.80) | |
| Sri Lanka | 13 (17.10) | 15 (20.50) | |
| Nepal | 2 (2.60) | 2 (2.70) | |
| Bangladesh | 1 (1.30) | 3 (4.10) | |
| Other | --- | 1 (1.40) | |
| **Education** | | | 0.28 |
| Some high school or less | 12 (15.80) | 19 (26) | |
| Some college or university | 26 (34.20) | 24 (32.90) | |
| University or college degree | 38 (50) | 30 (41.10) | |
| **Religion** | | | 0.70 |
| Buddhist | 1 (1.30) | 5 (6.80) | |
| Christian | 27 (35.50) | 24 (32.90) | |
| Hindu | 27 (35.50) | 25 (34.20) | |
| Muslim | 9 (11.80) | 7 (9.60) | |
| Sikh | 9 (11.80) | 8 (11) | |
| Other | 3 (3.90) | 3 (4.10) | |
| **Live in the same household as parent(s) with diabetes** | | | 0.05 |
| Yes | 60 (78.90) | 47 (64.40) | |
| No | 15 (19.70) | 25 (34.20) | |

| | | | |
|---|---|---|---|
| **Employment status** | | | 0.14 |
| Full-time | 29 (38.20) | 35 (47.90) | |
| Part-time | 36 (47.40) | 29 (39.70) | |
| Unemployed | 8.00 (10.50) | 3.00 (4.10) | |
| Other | --- | 2.00 (2.70) | |
| **Hours Spent on Caregiving in an average week** | | | 0.23 |
| Less than 1 hour | 14(18.20) | 9 (12.30) | |
| 1-5 hours | 40 (51.90) | 49 (67.10) | |
| 6-10 hours | 20 (26) | 15 (20.50) | |
| 11-15 hours | 1 (1.30) | -- | |
| 16-25 hours | 1(1.30) | -- | |
| **Body Mass Index Classification (kg/m$^2$)** | | | 0.21 |
| Less than 25 | 38 (50) | 20 (27.4) | |
| 25-29 | 31 (40.80) | 40 (54.80) | |
| 30-34 | 6 (7.90) | 12 (16.4) | |
| 35 and over | 1 (1.30) | 1 (1.40) | |

[a] The p-values were obtained using the Chi-square test or Fisher's exact test.

Table 6

*A Chi-Square Test Examining the Association Between Gender and Caregiving Tasks*

| Caregiving tasks | Participants (%) | | p-value |
|---|---|---|---|
| | **Female** | **Males** | |
| Monitoring your parent's blood sugar levels | 52(68.40) | 41(56.20) | 0.12 |
| Managing your parent's medications | 47 (61) | 41(56.20) | 0.48 |
| Help or administer insulin for your parent(s) | 25 (32.50) | 8.00 (11) | * |
| Picking up medications | 62 (81.60) | 64 (87.70) | 0.30 |
| Ensuring parent(s) with diabetes get(s) some exercise | 47 (61.80) | 56 (76.70) | 0.05 |
| Manage complications associated with diabetes (such as mobility, heart-related problems, vision loss, wound care, low blood sugar, kidney disease, loss of limb, and nerve damage) | 43 (55.30) | 13 (17.80) | ** |
| Drive your parent(s) to their diabetes appointments | 50 (64.90) | 62 (84.90) | * |
| Involved in grocery shopping for parent(s) | 61 (80.30) | 49 (67.10) | 0.07 |
| Participating in meal preparation for your parent(s) | 55 (72.40) | 22 (30.10) | ** |
| Managing finances associated with diabetes | 7 (9.20) | 36 (49.30) | ** |
| Other | 74 (97.40) | 72 (98.60) | -- |

All expected cell frequencies were greater than five. **Significant at a $p<0.001$ * Significant at a $p<0.05$.

**Research Questions and Results**

*1. What is the diabetes related knowledge of South Asian males compared to females?*

The groups that were compared were: Females (77 female participants); and

Males (73 male participants) (n=150). Diabetes knowledge was measured using the DKQ

was the dependent variable in this statistical test. The mean total diabetes knowledge

score of participants was 32.29 (SD=5.07), range (18 to 44), skewness (-0.58), and

kurtosis (-0.29). Total diabetes knowledge score was normally distributed as assessed by

Shapiro-Wilk's test (p >0.05). The DKQ is primarily made of questions regarding diabetes management and complications (Table 7). When assessing the DKQ responses, differences were noted between genders (Table 7).

An independent t-test was employed to examine whether there is a difference in diabetes knowledge between males and females. Based on the Levene's test, which assesses for homogeneity of variances a p-value of 0.741 was obtained. Therefore, equal variances were assumed. The results indicated that there was statistically significant difference in diabetes knowledge between males (M=30.16, SD=4.87) and females (M=34.31, SD=4.41); t (148) = -5.47, p<0.001, 95% CI [-5.64, -2.65] (Table 7). This highlights how diabetes knowledge is lower amongst male participants compared to females.

Because the diabetes knowledge scores, were slightly skewed (-0.58) a non-parametric test (Mann-Whitney U Test) was used to corroborate the results from the t-test. A box plot indicated that no outliers were present (Appendix Q). Results demonstrated that there was a statistically significant difference between median diabetes knowledge between males and females. Distribution of diabetes knowledge scores for male and female were similar, which was obtained by visual inspection (Appendix Q). Median diabetes knowledge scores were higher in females (35) compared to males (30) U=1473 z=-5.04, p<0.001.

Table 7

*Comparison of Correct Female and Male Responses from the DKQ*

| DKQ question | Female n (%) | Male n (%) |
|---|---|---|
| Eating too much sugar and other sweet foods is a cause of diabetes. | 52 (67.50) | 54 (74) |
| The usual cause of diabetes is a lack of effective insulin in the body. | 29 (37.70) | 24 (32.90) |
| Diabetes is caused by a failure of the kidneys to keep sugar out of the urine. | 53 (68.80) | 44 (60.30) |
| Kidneys produce insulin. | 53 (68.80) | 44 (60.30) |
| In untreated diabetes, the amount of sugar in the blood usually increases. | 42 (54.50) | 20 (27.40) |
| If I am diabetic, my children have a higher chance of being diabetic. | 68 (88.30) | 62 (84.90) |
| Diabetes can be cured. | 63 (81.80) | 47 (64.40) |
| A fasting blood sugar level of 11.5mmol/ is too high. | 55 (71.40) | 44 (60.30) |
| The best way to check my diabetes is by testing my urine. | 60 (77.90) | 56 (76.70) |
| Regular exercise will increase the need for insulin or other diabetic medication. | 41 (53.20) | 29 (39.70) |
| There are two main types of diabetes: Type 1 (insulin-dependent) and Type 2 (non-insulin-dependent). | 68 (88.30) | 61 (83.60) |
| An insulin reaction caused by too much food. | 33 (42.90) | 18 (24.70) |

| | | |
|---|---|---|
| Medication is more important than diet and exercise to control diabetes. | 45 (58.40) | 24 (32.90) |
| Diabetes often causes poor circulation. | 57 (74) | 28 (38.40) |
| Cuts and abrasions on diabetics heal more slowly. | 64 (83.10) | 30 (41.10) |
| Diabetics should take extra care when cutting their toenails. | 52 (67.50) | 17 (23.30) |
| A person with diabetes should cleanse a cut with iodine and alcohol. | 13 (16.90) | 15 (20.50) |
| The way I prepare my food is as important as the foods I eat. | 62 (80.50) | 39 (53.40) |
| Diabetes can damage my kidneys. | 52 (67.50) | 32 (43.80) |
| Diabetes can cause loss of feeling in my hands, fingers and feet. | 59 (76.60) | 26 (35.60) |
| Shaking and sweating are signs of high blood sugar. | 42 (54.50) | 24 (32.90) |
| Frequent urination and thirst are signs of low blood sugar. | 16 (20.80) | 10 (13.70) |
| Tight elastic hose or socks are not bad for diabetics. | 29 (37.70) | 19 (26) |
| A diabetic diet consists of mostly special foods. | 39 (50.60) | 23 (31.50) |

*2. What is the quality of life of males compared to females?*

When examining QoL transformed scores of participants across all four domains of the WHOQoL –BREF were examined (n=149). The results remonstrated that domain 1 (Physical health) participants had scores that ranged from 18 to 44, (M=32.32, SD=5.07),

Skewness of -0.71, and kurtosis of -0.286. In domain 2 (Psychological) participants

scores ranged from 25 to 81, (M=57.34, SD=8.41), Skewness of 0.111, and kurtosis of

1.643. Moreover, the findings demonstrated that Domain 3 (Social relationships) had

scores that ranged from 19 to 100, (M=64.71, SD =8.41), Skewness of -0.28, and kurtosis

of -0.06. Lastly, domain 4 (Environment) scores ranged from 31 to 100, (M=63.77,

SD=16.69), skewness of 0.51, and kurtosis of -0.053.

Independent t-tests were employed to examine whether there was a difference in

each QoL domain scores between male and female participants (Table 8). The results

indicated that there was not a statistically significant difference across any domain of

QoL scores between males and females.  In order to corroborate the results of the

independent t-test a non-parametric test was conducted. The results of the Mann-Whitney

U test corroborated the results of the t-test, indicating that there was not a statistically

significant difference in the median across domains between genders. Distribution of all

the WHO QoL domain scores for male and female were similar, which was obtained by

visual inspection. Results demonstrated that there was no statistically significant

difference between any median WHO QoL domain scores between males and females.

Median QoL domain one scores were the same for females (Score 69) compared to males

(Score 69) U=2709, Z=-0.25, $p$=0.80. Median QoL domain two scores were the same

amongst females (Score 56) and males (Score 56) U=2525.5, Z=-1.014, $p$=0.31.

 Median QoL domain three scores were the same for females (Score 11) and males (Score

11) U=2588, Z=-.716, $p$=0.474. Median QoL domain 4 scores were the same for females

(Score 63) and males (Score 63) U=2515.5, Z=-0.993, $p$=0.32.

Table 8

*Questionnaire Scoring of Study Participants*

| Questionnaire scores | Characteristics of Participants n (%) | | Mean (SD) | | p-value |
| --- | --- | --- | --- | --- | --- |
| | Female | Male | Female | Male | |
| **Diabetes knowledge scores** | | | 34.31 (4.41) | 30.16 (4.87) | ** |
| Low knowledge level | 42 (55.30) | 59 (80.80) | | | |
| High knowledge level | 34 (44.70) | 14 (19.20) | | | |
| **CANRISK scores** | | | 20.05 (6.93) | 27.68 (5.90) | ** |
| Low to moderate risk | 70 (92.10) | 60 (82.20) | | | |
| High risk | 6.00 (7.90) | 12 (16.40) | | | |
| Very high risk | -- | 1.00(1.40) | | | |
| **WHOQoL BREF** | | | | | |
| **Transformed scores** | | | | | |
| Domain 1- Physical health | | | 69.86 (11.59) | 69.21 (13.05) | 0.75 |
| Domain 2- Psychological | | | 58.05 (8.142) | 56.59 (8.68) | 0.29 |
| Domain 3- Social Relationships | | | 65.67 (18.03) | 63.71 (18.88) | 0.52 |
| Domain 4- Environment | | | 65.28 (18.21) | 62.21 (14.92) | 0.26 |
| **Risk Perception of developing diabetes scores** | | | | | |
| Personal Control | | | 1.96 (0.70) | 1.79 (0.60) | 0.10 |
| Worry | | | 2.79 (0.56) | 2.84 (0.56) | 0.56 |
| Optimistic Bias | | | 1.41 (0.57) | 1.47 (0.47) | 0.55 |
| Personal Disease Risk | | | | | |
| Low risk perception of diabetes | 50 (65.80) | 58(79.50) | | | |
| High risk perception of diabetes | 26 (34.20) | 15 (20.50) | | | |
| Comparative environmental Risk | | | 1.33 (0.50) | 1.20 (0.34) | 0.06 |

The p-value indicates the difference in male and female participants. **Significant at a p<0.001 *Significant at a p<0.05

*3. What is the risk perception of males compared to females in developing diabetes?*

A Pearson chi-squared test was selected to evaluate if there was an association between gender and risk perception of developing diabetes (n=149). The variables chosen were both categorical measurements and had at least two or more independent groups. The results demonstrated that 20.5% of male participants (n=73) and 34.2% of females (n=76) had a high-risk perception of developing diabetes. Similarly, 79.5% of males and 65.8% of females had a low risk perception of developing diabetes. The Pearson chi-squared (test of independence) test found that $\chi^2(1)=3.49$, *p=0.06*; a non-statistically significant association between gender and risk perception of developing diabetes. The clustered bar graph highlights the gender groups and the frequency of high and low risk perceptions in those groups (Figure 1).
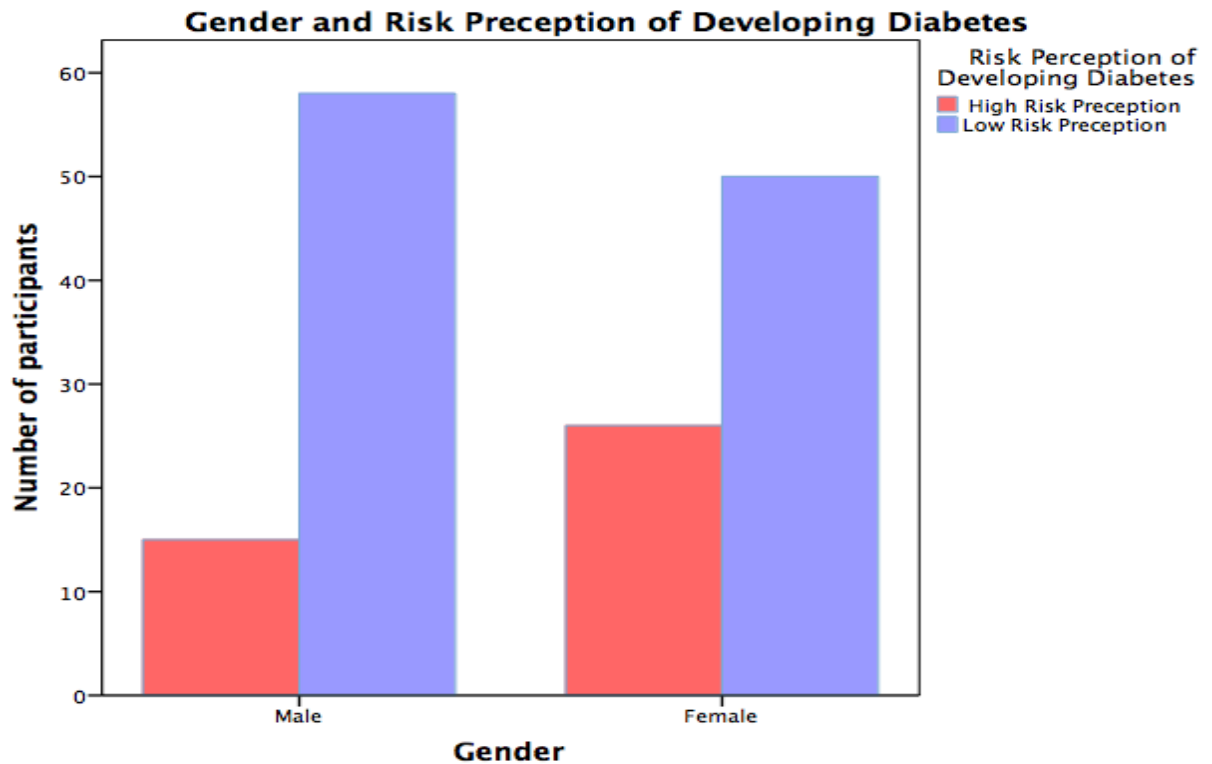
Figure 1. *Comparison of risk perceptions of developing diabetes between genders*

*4. What is the 'actual risk' of developing diabetes of males compared to females?*

Independent t-tests were employed to examine whether there was a difference in each QoL domain scores between male and female participants (Table 8). Female CANRISK scores were lower (M=20.05, SD=6.93) than males (M=27.68, SD=5.90). Based on the Levene's test, which assesses for homogeneity of variances a p-value of 0.15 was obtained. Therefore, equal variances were assumed. The results indicated that there was a statistically significant difference in CANRISK scores between males and females t (147)=7.22, p<0.001, 95% CI [5.54, 9.72] (Table 8). In order to corroborate the results of the independent t-test a non-parametric test was conducted. The results of the Mann-Whitney U test corroborated the results of the t-test, indicating that there was

statistically significant difference in the median CANRISK scores between males (27) and females (18). Distributions of CANRISK score for males and females were not similar, as assessed by visual inspection. There was a statistically significantly difference in CANRISK scores between males and females, U=1051, z=-6.55, p<0.001. The results indicated that male participants were at greater risk of developing diabetes relative to female participants.

When examining actual risk categories, 82.2% of male participants (n=73) and 92.1% female participants (n=76) had low to moderate risk of developing diabetes and 16.4% of males and 7.9% of females had a high-risk of developing diabetes. When examining the very high-risk category 1.4% of males and 0% of females fell into this category. Diabetes Canada recommends screening for those at the high and very high-risk category for screening for T2DM. As such we grouped these categories together and examined the association between gender and one' actual risk category (low to moderate risk versus high risk to very high risk), using the chi-square test. The Pearson chi-squared (test of independence) test revealed that $\chi^2$ (1)=3.29, p=0.07. Therefore, a non-statistically significant association between gender and actual risk categories of developing diabetes. Figure 2 highlights the gender groups and the frequency of actual risk in those groups.
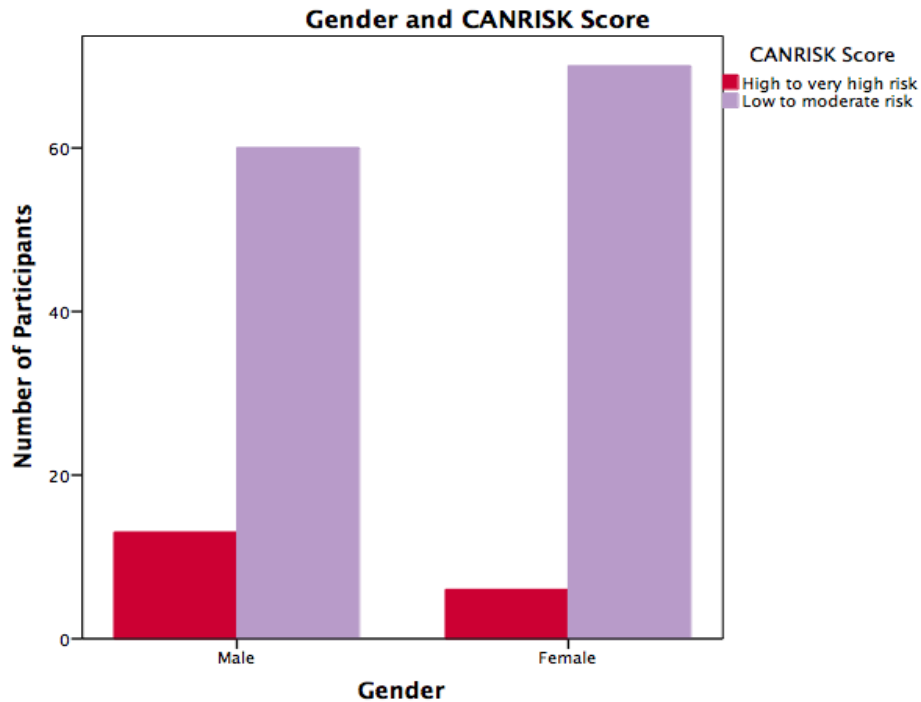
*Figure* 2. Comparison of actual risk of developing diabetes between genders.

*5. Is there a relationship between knowledge of T2DM and perceived risk for developing T2DM?*

A linear correlation and regression analysis was completed to determine if there was an association between diabetes related knowledge and perceived risk of developing diabetes and the strength of the association. In order to conduct a linear regression there are five assumptions that cannot be violated which include: (1) A linear relationship between two continuous variables, (2) no significant outliers, (3) independence of errors (residuals), (4) homoscedasticity of residuals (equal error variances), (5) residuals are normally distributed (Daniel & Cross, 2012).

Both diabetes related knowledge and perceived risk of developing diabetes are continuous variables, which permit the use of the linear correlation and regression test.

Although these two variables do not have a linear relationship, it does not fail the assumption of linearity. Linearity was established by visual inspection of a scatterplot (Figure 3). Homoscedasticity, refers to the variance or errors being the same for all values of the independent variables. Homoscedasticity was assessed using a plot of standardized residuals versus standardized predicted values. Residuals were normally distributed as assessed by visual inspection of the P-P plot (Appendix R). Case wise diagnostics were utilized to identify any outliers one outlier was identified. The participant who was considered the outlier in the dataset had a total risk perception score of 2.69. According to Weisberg (2014) both approaches with and without the outlier should be reported. When the outlier was not included in the regression analysis results demonstrated that diabetes knowledge accounted for 1.7% of the variation in diabetes risk perception with adjusted $R^2$ of 0.010. The adjusted $R^2$ value accounts for any positive bias to explain the variation in the dependent variable that can be explained by the independent variable. Independence of residuals is assessed by a Durbin-Watson statistic which can range from 0-4. A value of approximately 2 indicates no correlation between residuals. A Durbin-Watson statistic of 1.515 was obtained; therefore, there was an independence of residuals. Diabetes knowledge did not significantly predict risk perception $F_{(1,146)}=2.52$, $p=0.12$. Similarly, a regression including the outlier was conducted. There was an independence of residuals, as assessed by a Durbin-Watson statistic of 1.601. Results demonstrated that diabetes knowledge accounted for only 1.5% of the variation in diabetes risk perception with adjusted $R^2$ of 0.008. Diabetes knowledge did not significantly predict risk

perception F (1,147) = 2.211, p=0.14. This suggests that one's diabetes related knowledge does not predict their risk perception of developing diabetes.
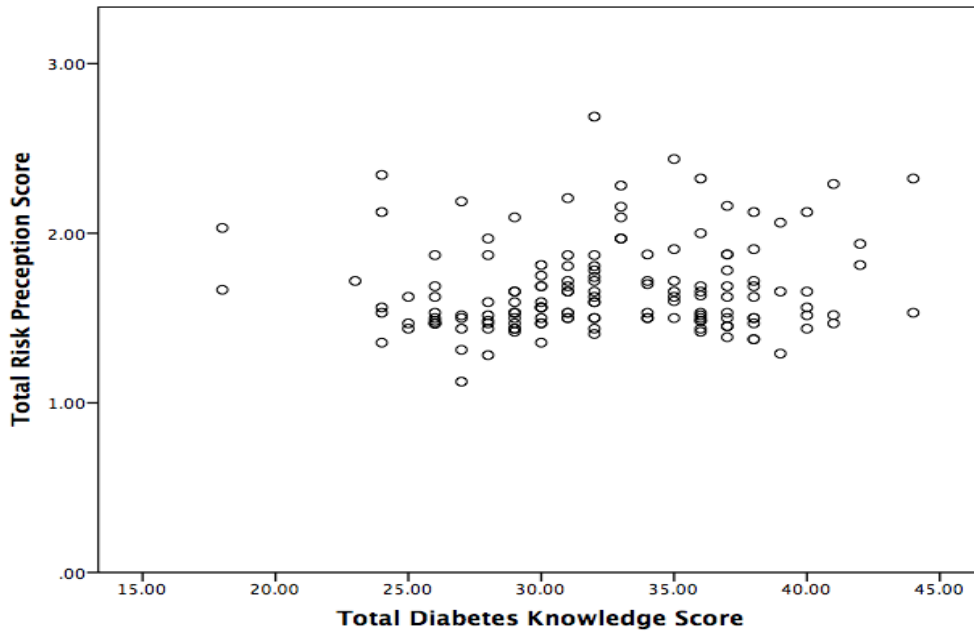


*Figure* 3. Relationship between diabetes related knowledge and perceived risk of developing diabetes.

*6. Is actual risk of developing diabetes associated with risk perception of developing diabetes?*

When examining the domain personal control a higher score indicates greater perceived personal control over developing diabetes in this sample. The mean score for females (1.96±0.70) and males (1.79± 0.60) indicated a perception of poor personal control. The mean subscale score for environmental risk (Females=1.33±0.50; Males= 1.20±0.34) indicated, on average, low perceived personal risk from the environment. When examining the domain worry, males (2.84±0.56) and females (2.79±0.56) had relative had the same level of worry. When examining males (1.47±0.47) and females (1.42±0.57); it was noted that they had similar level of optimistic bias.

A linear regression was conducted to determine if there was an association between one's actual risk of developing diabetes and one's risk perception of diabetes. Linearity was determined by visual assessment of the scatterplot (Figure 4). There was an independence of residuals, as assessed by a Durbin-Watson statistic of 1.61. Homoscedasticity was as assessed using a plot of standardized residuals versus standardized predicted values. Residuals were normally distributed as assessed by visual inspection of the P-P plot. Case wise diagnostics were utilized to identify any outliers and as such two outliers were identified. The participants who were considered the outliers in the dataset had a total risk perception score of 2.44 and 2.69. When the outliers were included in the regression analysis results demonstrated that actual risk accounted for 0.5% of the variation in diabetes risk perception with $R^2$ of 0.005. There was an independence of residuals, as assessed by a Durbin-Watson statistic of 1.61 ($\beta$ = -0.068; CI [-0.008 to 0.003]). Actual risk of developing diabetes did not significantly predict risk perception F (1,147) = 0.687, $p$=0.41. Similarly, a regression without the outliers was conducted. There was an independence of residuals, as assessed by a Durbin-Watson statistic of 1.623 and actual risk accounted for 0.5% of the variation in diabetes risk perception with $R^2$ of 0.005. The results from a regression between total risk perception scores and CANRISK scores showed no significant results (F (1, 145) = 0.706, $p$=0.40) ($\beta$ = -0.07; CI[-0.008 to 0.003]).

To determine if the domain scores of risk perception could be predicted by actual risk, a linear regression was done with each domain of the RP-DD survey. A linear regression was calculated to predict risk perception based on actual risk. The independent

variable of interest to be included in the regression model was the CANRISK total scores and the dependent variable was the personal control domain scores from the RP-DD survey. Results demonstrated that only 6.9% of variation in personal control scores can be explained by CANRISK scores. Moreover, findings indicated that a majority of male (80%) and female (67%) caregivers felt they had low personal control over the development of T2DM. A significant regression equation was found ($F_{(1, 147)}=10.84$, $p=0.001$) with an $R^2$ of 0.069 (adjusted $R^2 =0.062$). Results demonstrate that one's actual risk of developing diabetes can statistically significantly predict one's feelings of personal control of developing diabetes. A linear regression was calculated to predict comparative environmental risk based on actual risk of developing diabetes. There was an independence of residuals, as assessed by a Durbin-Watson statistic of 1.63. The independent variable of interest to be included in the regression model was CANRISK total scores and dependent variable was the total comparative environmental risk domain score. Results demonstrated that only 2.6% of variation in comparative environmental risk can be predicted by CANRISK scores. A significant regression equation was found ($F_{(1, 147)}=3.99$, $p=0.048$) with an $R^2$ of 0.026 (adjusted $R^2 =0.02$). Although one's actual risk for diabetes can significantly predict one's comparative environmental risk it is not clinically relevant as a variation of 2.6% is minimal. Lastly, the results from a regression between worry and CANRISK scores showed no significant results ($F_{(1, 147)}$ $=2.96$, $p=0.09$) with an $R^2$ of 0.020 (adjusted $R^2 =0.13$). Results demonstrated that only 2.0% of variation in worry can be predicted by CANRISK scores.
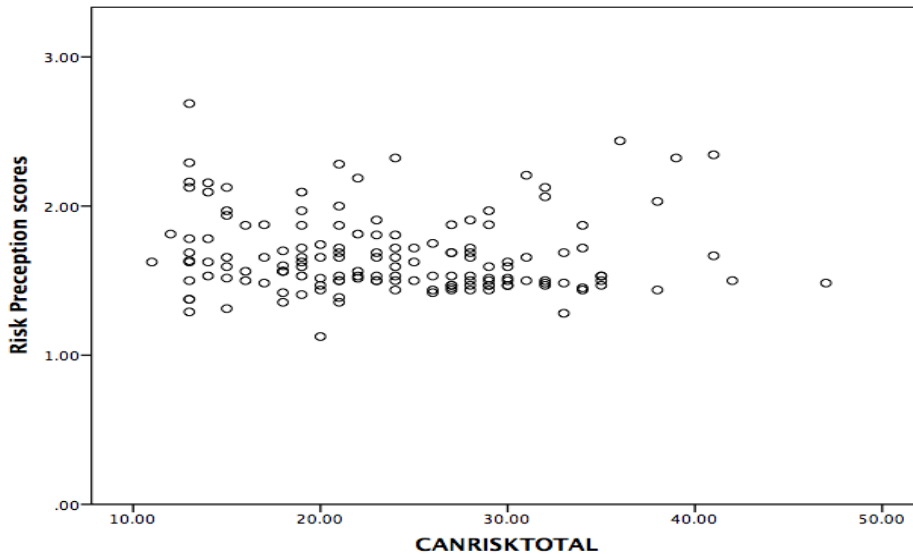
*Figure 4*. Relationship between perceived risk of developing diabetes and actual risk of developing diabetes.

7.  *Does their diabetes knowledge impact their adoption of exercise habits?*

Previous literature using the DKQ utilized 50% and higher as a benchmark for satisfactory knowledge level and a score of less than 50% was rated as poor knowledge levels (Parimalakrishnan, Dussa, & Sahay, 2015). However, this was based on a modified version of the questionnaire and as such it cannot be directly transferred to the current study. Moreover, there was no mention of the tool's reliability (Parimalakrishnan et al., 2015). Based on the normal distribution of the diabetes knowledge scores the median was used as our cut off value.  A score of 0 to 32 on the DKQ indicated low/poor knowledge, and score of 33 to 34 was indicative of satisfactory/high knowledge. Exercising habit was assessed using the CANRISK question which had dichotomized responses of 'yes' and 'no'. This research question was assessed using a Chi-squared approach and all expected

cell frequencies were greater than five. The Pearson chi-squared (test of independence) test revealed that $\chi^2$ (1) = 3.00, $p$=0.08, indicating a non-statistically significant association between diabetes knowledge and exercising habits.

*8. Does their risk perception and diabetes knowledge impact their quality of life?*

The WHO QoL scale has no composite score and is composed of four domains. When examining the QoL scores, there are no norms specifically for this caregiver population; however general cut points and norms have been established based on age and gender (Hawthrone, Herrman, Murphy, 2006). The norm scores for males for each domain are as follows: Physical (M=88.70, SD=9.80); Psychological (M=74.30, SD=16.80); Social (M=68.10, SD=23.40); Environment (M=77.20, SD=10.60) (Hawthrone et al., 2006). The norm scores for females for each domain are as follows: Physical (M=83.60, SD=11.30); Psychological (M=69.70, SD=17.90); Social (M=75.60, SD=15.30); Environment (M=72.70, SD=15.60) (Hawthrone et al., 2006). When examining the domain of physical health in this study, it was noted that both female (M=69.86, SD=11.59) and male (M=69.21, SD=13.05) participants scored less than the norm. When examining the domain of psychological health both female (M=58.05, SD=8.14) and male (M= 56.59, SD=8.68) were less than the norms; indicating poor psychological health. Additionally, it was noted that female (M=65.67, SD=18.03) and male (M=63.71, SD=18.88) participants scored less than the social domain norm. Lastly, female (M=65.28, SD=18.21) and male (M=62.21, SD=14.92) participants scored less than the norm.

This research question was assessed using a multiple regression approach. A multiple regression analysis was done with each domain of WHO QoL to determine if risk perception and diabetes knowledge influence QoL. In order to conduct a multiple regression, the following assumptions must be met: (1) a dependent variable that is measured on a continuous scale and two or more independent variables that are measured on continuous or nominal scale, (2) there should be an independence of residuals, (3) a linear relationship should exist between the dependent variable and each independent variable and between the dependent and both the independent variable, (4) data needs to show homoscedasticity of residuals, (5) there should be no multicollinearity between independent variables, (6) no significant outliers/leverage points/ highly influential points, and (7) there should be a normal distribution of residuals.

WHO QoL Domain 1 (Physical health)

There was an independence of residuals, which was assessed by a Durbin-Watson statistic of 1.805. Homoscedastcity was assessed by visual inspection of a plot of studentized residuals versus unstandardized residuals. Multicollinearity occurs when the independent variables are correlated with each other. There was no evidence of multicollinearity as assessed by variance inflation factor (VIF's) less than 10. There were no leverage values greater than 0.2 and Cooks distance above 1 (Cook and Weisberg, 1982). A large Cooks distance (greater than one) is an indicator of influential points. No significant outliers were present (standard residual ±3 standard deviations, a common classification of an outlier was utilized). Normality was assessed by a Q-Q plot. $R^2$ for the overall model was 2.2% with adjusted $R^2$ of 0.08%. Risk perception and diabetes

knowledge statistically significantly predicted physical health F (2, 146)=6.751, $p$ = 0.002. However, only the diabetes knowledge scores added statistically significantly to the prediction p=0.002. Based on the results, the following is the regression equation to calculate domain 1 (physical health) QoL scores:

Predicted domain 1 QoL scores = 53.66- (4.03 risk perception score) + (0.70 diabetes knowledge score)

Based on the regression equation, risk perception score had a negative association over physical health where for each unit that the risk perception score increases the domain1 scores will decrease in 4.03 units. Diabetes knowledge has a positive effect and for each unit that the knowledge score increases, the domain1 scores will increase in 0.70 units. These results highlight that amongst young adult caregivers, greater diabetes knowledge can improve their physical health.

WHO QoL Domain 2 (Psychological)

There was an independence of residuals, which was assessed by a Durbin-Watson statistic of 1.71. Homoscedastcity was assessed by visual inspection of a plot of studentized residuals versus unstandardized residuals. There was no evidence of multicollineraity as assessed by VIF's less than 10. There were no leverage values greater than 0.2 and Cooks distance above 1 (Cook and Weisberg, 1982). Normality was assessed by a Q-Q plot. $R^2$ for the overall model was 2.2% with adjusted $R^2$ of 0.9%. Risk perception and diabetes knowledge did not significantly predict psychological health F (2, 146) = 1.65, $p$= 0.20.

Predicted domain 2 QoL scores = 52.43 -(1.72 risk perception score) + (0.240 diabetes knowledge score)

WHO QoL Domain 3 (Social relationships)

There was an independence of residuals, which was assessed by a Durbin-Watson statistic of 1.969. Homoscedastcity was assessed by visual inspection of a plot of studentized residuals versus predictive values. There were no studentized deleted residuals greater than ±3 standard deviations. There was no evidence of multicollineraity as assessed by VIF's less than 10. There were no leverage values greater than 0.2 and Cooks distance above 1(Cook and Weisberg, 1982). Normality was assessed by a P-P plot. $R^2$ for the overall model was 1.9% with adjusted $R^2$ of 0.06%. Risk perception and diabetes knowledge did not significantly predict social relationships $F(2, 146) = 1.42$, $p = 0.25$.

Predicted domain 3QoL scores = 43.24+ (5.75 risk perception score) + (0.37 diabetes knowledge score)

WHO QoL Domain 4 (Environment)

There was an independence of residuals, which was assessed by a Durbin-Watson statistic of 1.71. Linearity was assessed by visual inspection of the partial regression plots. There were no studentized deleted residuals greater than ±3 standard deviations. There was no evidence of multicollineraity as assessed by VIF's less than 10. There were no leverage values greater than 0.2 and Cooks distance above 1 (Cook and Weisberg, 1982). Normality was assessed by a P-P plot. $R^2$ for the overall model was 12.4% with adjusted $R^2$ of 11.2%, which is classified as a small effect size (Cohen, 1988). Risk

perception and diabetes knowledge significantly predicted the Environmental domain of QoL scores F $(2, 146)$=10.30, $p< 0.001$. Only the diabetes knowledge scores added statistically significantly to the prediction ($p<0.001$). Participants who believed that they were at higher risk of developing diabetes and had higher knowledge scores had better environmental domain scores.

Predicted domain 4 QoL scores = 15.65+ (10.02 risk perception score)+ (0.96 diabetes knowledge score)

**Summary of Results**

In this study, more than half the participants were of Indian descent. Additionally, 78.9% of females and 64.4% of males lived with their parent(s) with diabetes. When examining the caregiving tasks completed by male and female caregivers, findings suggested that more than 80% of male and female caregivers pickup their parent's medications. The findings highlighted a gender based division of caregiving roles. A greater percentage of males reported taking part in driving their parent(s) to their appointments, managing finances associated with diabetes, and ensuring their parents get some exercise. In contrast, a greater percentage of female caregivers reported taking part in managing diabetes associated complications, grocery shopping for parent(s), monitoring blood glucose, managing medications and administering insulin. Diabetes knowledge was statistically significantly higher amongst young adult female caregivers compared to males. This highlights a potentially clinically significant difference in diabetes knowledge between male and female caregivers. Moreover, the individual DKQ questions highlights differences in responses between genders and areas where there is a

lack of knowledge amongst caregivers (Table 7). Additionally, findings demonstrated that there was not a statistically significant difference between any median WHO QoL domain scores between male and female caregivers. Clinically, these results demonstrate that male and female caregivers have similar QoL scores despite taking part in different caregiving tasks.

When examining actual risk there was statistically significant difference in the CANRISK scores between genders, where a greater proportion of males where in the high-risk/very high-risk category (Table 8). Despite being at greater risk of developing diabetes, a larger proportion of male relative to female caregivers perceived themselves to be at low risk of developing diabetes (Table 8). Based on the linear regression analysis, diabetes knowledge did not predict risk perception. It could be postulated that there are other factors at play a greater role in the formulation of one's risk perception of diabetes development. Furthermore, results of the regression analysis indicated that a 6.9% of variation in personal control can explained by one's actual risk of developing diabetes. Multiple regression analyses revealed statistically significant associations between caregiver's risk perception, diabetes knowledge and physical health.  There was a 2.2% of the variation in caregiver's QoL (physical health) scores which could be explained by diabetes related knowledge and risk perception. Additionally, findings demonstrated that caregivers who had greater diabetes knowledge scores had better environmental domain scores.

## CHAPTER 5: DISCUSSION

### Overview of Chapter

The findings of this research will be discussed in three sections. The first section discusses the key findings of the study's research questions and compares findings to previous studies. The second section addresses the strengths and limitations of the present study. The third section discusses the possible contributions and implications the findings may have on nursing practice, education and policy.

**Key Findings**

Given the paucity of literature examining young SAP adult caregivers, the findings from this study provide initial insight and perspective of diabetes related knowledge, risk perception, actual risk and quality of life amongst young adult South Asian caregivers.

Education is intrinsic in the management of diabetes and health promotion. The results suggested that there was a potential clinical significance in the difference in the diabetes knowledge level between genders. This could be attributed to the fact that a greater percentage of females compared to males completed a university degree (50% versus 41.1% respectively). Previous research has suggested that greater diabetes knowledge was associated with one's SES and higher education level (Rani et al., 2008). Based on our findings, more female caregivers tended to predominately physical caregiving tasks that required education (i.e. managing diabetes associated complications, administration of insulin, monitoring parent's glucose levels) (Table 6). The results highlight a lack of the knowledge regarding the cause diabetes between males (60.3%)

and females (55.8%). Moreover, 18.2% of females and 35.6% of males believed that diabetes could be cured (Table 7). These responses may reflect the incorrect belief that once one's blood glucose levels are controlled then diabetes is cured (Gulabani, John & Isaac, 2008). The importance of providing knowledge regarding diabetes prevention and management amongst this young population is vital for health promotion. Moreover, when examining the current study, approximately 42% of the DKQ centers around some of the complications of diabetes. The results demonstrated that 55.8 % of female caregiver whereas only 17.8% male caregivers reported managing complications associated with diabetes. Moreover, only 32.9% of males and 54.5% of females were able to correctly identify signs of high blood glucose. Also, 13.7% of males and 20.8% of females were able to identify signs of low blood glucose. Despite reporting managing diabetes complications more than half of the female participants were unable to identify signs of low blood glucose. This highlights a knowledge gap in this group of caregivers. Additionally, when examining the amount of time spent on caregiving activities in an average week, it was noted that a greater proportion female caregivers spent a greater amount time relative to males (Table 5). These findings are similar to a cross-sectional study conducted by dos Santos et al., (2014) which demonstrated that women had greater knowledge regarding diabetes foot care and diabetes associated complications (e.g. blindness, impaired wound healing, and male sexual dysfunction). Moreover, the study highlighted that females were more likely to obtain better knowledge scores relative to males (dos Santos et al., 2014). In contrast, Gulabani, John & Isaac, (2008) examined the level of diabetes related knowledge amongst Indian patients with diabetes and

demonstrated lower knowledge levels amongst women. This inconsistency may be, in part, the result of differences in educational levels between the different sample populations. Nonetheless, differences in knowledge between genders highlights the need for gender-specific health promotion amongst this young population of caregivers.

There is a large body of literature that has documented how caregiving can have physical and psychological impacts on the caregiver's life, due to the increased responsibilities and time commitment required (Lim & Zebrack, 2004; Northouse, Katapodi, Schafenacker, & Weiss, 2012; Pinquart & Sorensen, 2003; Schulz & Sherwood, 2008). In the present study, the majority of female caregivers took part in tasks including: taking part in meal preparation, being involved in grocery shopping for their parent(s), administering insulin and being responsible for the management of diabetes complications (Table 6). In contrast, male caregivers primarily dealt with tasks such as: driving their parent(s) to their diabetes appointments (84.9%) and managing finances associated with diabetes (49.30%) (Table 6). Providing assistance with daily living activities such as meal preparation, diabetes complication management and grocery shopping may be more time consuming and labour intensive on a routine basis. This is further supported by the fact that a majority of female participants spent a greater amount of time completing caregiving tasks. Moreover, Literature has also shown that South Asian immigrants (especially second-generational) tend to adopt the predominant culture of society (Talbani & Hasanli, 2000). In the current study, although there was a difference in the tasks they take part in, and the amount of time spent on caregiving; there was no statistical difference in QoL between genders (Table 8). There is some evidence that

suggests that this can be attributed to appraisal of stressors which varies between genders (Schulz & Sherwood, 2008). Literature evaluating the QoL and social functioning among caregivers of patients with diabetes has demonstrated that caregivers were depressed and social function was impacted negatively (Anaforoglu, Ramazanogullari, Algün, Kutanis, 2012). Similarly, in the current study, QoL was sharply lower in all domains for both male and female caregivers relative to the norms established for each domain of the WHO-BREF (Hawthrone et al., 2006). This highlights the need to support this population in their caregiving role.

Although there was no statistically significant association between gender and risk perception of developing diabetes ($p=0.062$) found in this study, findings may be clinically meaningful. As changes to health perception can act as a catalyst to uptake positive health behaviours. Historically, literature has shown that women tend to perceive themselves to be more at risk of developing diabetes and other chronic illness relative to men (Montgomery, Erblich, DiLorenzo, & Bovbjerg, 2003). This was demonstrated in a population of male and female participants who had a family history or a friend with diagnosis of chronic illness (i.e. diabetes, heart condition, colon cancer, prostate cancer breast cancer etc.). The sample population had a mean age of 40 and consisted of 56% Caucasian, 15% African American, 12% Hispanic, 8% Asian, 4% Asian/Pacific Islander and 6% other (Montgomery, Erblich, DiLorenzo, & Bovbjerg, 2003). A diabetes diagnosis amongst family and friends resulted in an increased perceived risk amongst women. This is consistent with our findings as a greater proportion of female caregivers (32.4%) perceived themselves to be at high risk of developing diabetes relative to males

(20.5%). Moreover, our findings suggest that male caregivers (26%) were more likely

than female caregivers (3.9%) to engage in risky health behaviors such as using tobacco.

Despite differences in engaging in risky health behaviours, previous research has shown

that women have a greater level of fear of developing diseases due to differences in

cognitive processing (Harris, Jenkins & Glaser, 2006). This may result in a decrease in

engaging in health risk behaviors amongst females. Additionally, it has been postulated

that due the role socialization of males they are more likely to engage in risky healthy

behaviours which can impede health promotion initiatives (Griffith, Gilbert, Bruce, &

Thorpe, 2016).

It is important to note that previous studies found that men are more likely to

develop diabetes and in 2013 there were 14 million more men diagnosed with DM than

women globally (Guariguata et al., 2014; Kautzky-Willer, Harreiter & Pacini, 2016).

However, gender differences in diabetes risk have not been adequately explored among

South Asian Canadians. This study found that a majority of male (82.2%) and female

(90.9%) caregivers were considered to have 'low to moderate risk' of developing

diabetes. A total of 16.4% of male caregivers and 7.8% of female caregivers were

considered to be at 'high risk' of developing diabetes. According to the Canadian Task

Force on Preventative Health Care (CTFPHC) 'high risk' is considered the stage at which

screening with A1C should be conducted every three to five years (CTFPHC, 2018). The

current study found a statistical significance in difference in male and female in actual

risk scores (p<0.001). However, there was no statistically significant association between

gender and actual risk category of developing diabetes ($p$=0.070) (Table 8).  According to

study conducted by Agarwal et al., (2018) the use of the CANRISK tool is not as sensitive when used amongst South Asians who are under the age of 40. The findings suggested that lowering CANRISK thresholds for the risk categories increases the sensitivity of the tool amongst this young adult SAP (Agarwal et al., 2018). Therefore, despite statistically significant differences in actual risk scores between genders the use of risk category may not accurately capture diabetes risk in this population. Additionally, in the current study a large proportion of male (27.40%) and female caregivers (50%) had a BMI that were under 25; this category includes individuals who are considered to be healthy weight. Although, BMI is a strong predictor of the development of T2DM, it fails to consider body fat distribution, particularly in the abdomen (Hsu et al., 2015). Amongst South Asians diabetes risk begins at lower BMI levels compared to Caucasians. This can be attributed to the fact that those of South Asian descent typically have a greater likelihood to develop visceral fat which can lead to insulin resistance and development of diabetes (Chan et al., 2009). Although the CANRISK questionnaire does ask respondents to measure and report their waist circumference it is possible that individuals did not accurately assess their waist circumference or accurately report their most recent measurement.

The development of T2DM involves an interplay of both environmental and genetic factors. Based on our findings, diabetes knowledge did not statistically significantly predict risk perception amongst this population of caregivers. This can be attributed to the fact despite knowledge levels these caregivers felt that were not at high risk of T2DM development. Additionally, based on our findings, only 20.5% of males

and 33.8% of females perceived themselves to be at high risk of developing T2DM. Interestingly, based on the DKQ scoring 84.9% of males and 88.3% of females were aware that having a parent with T2DM places them at greater risk for development of T2DM. There are various possible explanations for lower levels of risk perception despite knowledge of genetic component of T2DM amongst this population of caregivers. One explanation is attributed to optimistic bias, whereby this population of young caregivers underestimates or has misconceptions regarding their risks of developing T2DM relative to their peers (Rouyard et al., 2017). Another explanation is that due to the young age of caregivers; they may not be concerned about the development of diabetes. This lack of concern could have detrimental health consequences in the future. This is because as young adults they are more prone to engage in 'risky-health behaviours' (i.e. drinking, engaging in sedentary lifestyle, smoking etc.) (Rolison, Hanoch, Wood, & Liu, 2013). The current study found that of the participants who were found to be at high/very high risk of developing diabetes, 68.4% of participants perceived themselves to be at low risk. Moreover, this study demonstrated that actual risk did not significantly reflect risk perception. In contrast, previous literature has demonstrated that patients who perceived themselves to be at higher risk of developing diabetes were in fact at higher risk (Hivert et al., 2009). The incongruency between risk perception and actual risk may be attributed to one's optimistic bias. Our findings suggest that 35% of participants had high levels of optimistic bias regarding their likelihood of developing T2DM, meaning they did not perceive a risk of developing diabetes. Existing literature has shown that these inaccurate beliefs increase as young adults transition into adulthood (Brnstrm & Brandberg, 2010).

Additionally, our findings indicated that a majority of male (80%) and female (67%) caregivers felt they had low personal control over the development of T2DM. This is a small amount but it signals the fact that personal control may be influenced by one actual risk of developing diabetes. This highlights an area to consider educating these young adults regarding the effects of exercise and diet on diabetes prevention and delaying onset to help change perceptions of low personal control. Also, when examining their worry about developing diabetes, it was noted that a majority of male (87%) and female (83%) caregivers reported having high levels of worry of developing T2DM based on the RPS-DD survey. Research suggests that those who perceive themselves to be at high risk and are worried about a particular outcome are less motivated to engage in health promoting behaviours (Ferrer, Portnoy, & Klein, 2013; Persoskie, Ferrer & Klein, 2014).

When examining diabetes knowledge level and exercising habits no statistically significant association was found. It is important to note that the CANRISK tool dichotomizes whether participants exercise 30 minutes every day into 'yes' and 'no' which is not sufficient to capture the intensity, frequency and type of exercise (Van Draanen et al.,2014). More research is needed to examine association between knowledge level and exercise behaviours in this population. Additionally, the current study found risk perception and diabetes knowledge positively predicted the environmental domain of QoL. Participants who had higher risk perception scores and diabetes knowledge scores had higher environmental domains scores. The environmental domain of QoL measures access to health care services, and availability of information needed in their day-to-day life and opportunity for leisure and recreation. Greater diabetes knowledge may act as a

form of increased informational support and result in better quality of life. Diabetes

knowledge positively predicted the domain of physical health of QoL. This may be

attributed to the fact that a greater knowledge can mediate caregiver level of fatigue

which is one of the constructs measured within this domain). Literature has demonstrated

that family caregivers feel unprepared to provide care due to inadequate knowledge on

how to deliver care (Reinhard, Given, Petlick & Bemis, 2008). This may place caregivers

at risk of caregiver fatigue (Reinhard et al., 2008).

 **Strengths and Limitations**

A strength of the present study is that the instruments utilized for the study were

all valid and reliable. Also, the study had a large sample size which had sufficient

statistical validity. The use of social media (Facebook, Twitter, Instagram) provided a

cost-effective and efficient method to recruit potential participants. For example, the first

study post on Facebook reached 400 people (Appendix B). The use of social media as a

platform for recruitment allowed researchers to engage with young adults by providing

them with interesting facts about diabetes, resources on diabetes management and interact

with other diabetes related accounts (i.e. Diabetes Canada). Additionally, this study is

novel in that it examined a unique population of South Asian caregivers who are at high-

risk of developing T2DM.

The study was limited in that a convenience sample utilized. Therefore, the

sample population may not have been representative of the entire Canadian SAP (Quach

et al., 2013). The use of the online self-administered questionnaire is a limitation of this

study, due to the possibility of duplicate responses and reporting bias. Specific questions

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in the questionnaire were mandatory in order to complete the study. This may have

resulted in selection bias, as participants who did not answer these questions were unable

to submit their responses. Also, the online survey prevents researchers from controlling

the environment in which participants access the survey. As such, it is possible for

participants to simultaneously engage in other activities while completing the survey,

which may impact the quality of responses (Quach et al., 2013). Additionally, due to the

online nature of the questionnaire, participants may feel a lack of accountability due to

the increased distance between participants and researchers which can increase the

likelihood of response-bias (Quach et al., 2013). Moreover, due to the use of a cross-

sectional approach causation cannot be implied. Also, findings would have been more

accurate if clinical assessments of: BMI, weight, and waist circumference were obtained;

as it may have minimized the effect of response bias. Previous studies have demonstrated

that self-reported data such as height and weight are unreliable relative to clinical

assessments; as females were more likely to underreport their weight and overweight

individuals and females had more pronounced differences in their actual weight and

height relative to their self-reported measurements (Bowring et al., 2012; Rowland,

1990). Lastly, it is important to consider some confounding factors when interpreting the

findings. For instance, factors such as level of education, age, and employment can

impact one's risk perception of developing diabetes and QoL.

**Implications for Nursing**

**Evidence for Nursing Practice/ Clinical Care**

In order to improve clinical practice and patient care, it is vital that research findings become translated into the clinical setting. Findings from the present study highlight the importance of examining the South Asian family milieu when providing care to those affected by T2DM. Gaining awareness of the diabetes associated tasks male and female caregivers complete allows health professionals to gain insight into the caregiving role and understand the different challenges each group may encounter. Moreover, examining the family culture and role dynamics can enhance the quality of care provided to those affected by T2DM, and those at high-risk of developing T2DM. Clinicians should take the opportunity to initiate dialogue regarding T2DM prevention and increase awareness regarding these caregiver's risk (e.g. providing risk counselling) of developing diabetes. This will create an opportunity to implement early lifestyle modification interventions such as promotion of physical activity, improving dietary habits, minimizing exposure to risky health behaviour (i.e. smoking, drinking etc.) to prevent/ delay onset of T2DM. This in turn can facilitate a decrease in the diabetes burden seen among this population. Additionally, when caring for patients with diabetes nurses ought to consider taking the opportunity to provide health teaching regarding diabetes risk factors to their family members who may be at risk of developing this chronic illness. Also, due to the fact that these caregivers help manage their parent's diabetes, it would be valuable to equip them with information on diabetes management (i.e. signs of hypo/hyperglycemia, cause of diabetes, diabetes associated complications etc.) so they

can provide better care for their parents. Furthermore, nurses could utilize the findings from the study to explore the knowledge gaps, and quality of life of these caregivers and plan interventions accordingly. Increasing awareness amongst healthcare practitioners about this group of caregivers enhances the likelihood of engaging this population in early preventative measures. This would act as a form of upstream prevention given that this population of caregivers are at risk for developing T2DM.

Due to the increase in prevalence rates of T2DM seen amongst the SAP and its associated complications; it may be valuable to train nurses in a variety of clinical settings (i.e. primary care, diabetes clinics, hospitals etc.) and nursing students on how to effectively provide education regarding diabetes causes, medication, and management to both care recipient and this young adult caregiver population. This may improve the delivery and quality of patient care as education can enhance the knowledge and skill of nurses providing care and minimize any discomfort they may feel. This can be achieved by incorporating diabetes education for high-risk populations into nursing school curriculums and in hospital in-service education. These educational initiatives can help nurses to tailor diabetes educational strategies to the unique needs of the young adult caregiver population.

**Policy**

The findings can inform health policies to ensure interventions are available to support young caregivers, not only in their role as caregivers but also as a population at risk of developing T2DM. Although the findings from a single study may not be able to change practice, the findings can be used to examine interventions currently used in

practice and identify gaps in patient care and policy guidelines. These study findings highlight the importance of gender-specific education for this young population of caregivers. Tailoring diabetes educational interventions to the gender of caregivers, may help these caregivers to be more adept at helping manage their parent's diabetes. This may also dampen some of the effects of 'optimistic' bias they may have on their own risk perception of developing diabetes. With the increasing prevalence of social media, it may be beneficial to utilize social media as a platform to deliver educational campaigns. These campaigns can be used to enhance awareness about risk of T2DM development and target the knowledge gaps identified amongst the young adult SAP. Moreover, due to the inaccurate risk perceptions of T2DM and inadequate knowledge regarding the cause of diabetes, it may be beneficial to formulate screening tools and screen this young population for diabetes at a much a younger age. This may facilitate better perceptions of risk amongst this high-risk population. Based on this study it was noted that a large proportion of these South Asian caregivers had BMI's that were within normal range. However, due their differences in their body fat composition, the use of BMI may not accurately capture their risk for developing diabetes. This highlights the need for the development of tools that are ethnically tailored to accurately quantify T2DM risk for this population. One way this can be achieved is by utilizing lower BMI cut-offs for what constitutes as being within normal range, 'overweight' and 'obese' as suggested in pervious literature (Van Draanen et al., 2014; Tillin et al., 2015). Although this change would cause an increase in the incidence of obesity, it can also create a heightened awareness and facilitate more accurate perceptions of T2DM risk amongst this population

(Van Draanen et al., 2014). Although international organizations such as WHO have had consultations regarding the need for ethnic specific BMI cut-offs, no consensus has been reached (Misra, 2015). Further research is needed to support the creation of lower BMI cut-offs. Overall, these policy changes may help curtail the diabetes epidemic.

**Future Research**

More research is needed to establish any causal relationships between one's diabetes related knowledge and health behaviours as well as one's risk perception and development of diabetes. It would be insightful to prospectively follow this caregiver population to gain insight into how their current risk perception, behaviour and knowledge of diabetes are directly associated with the onset of diabetes. The current gap in literature in exploring this high-risk population in Canada is problematic as it can have serious medical/clinical implications downstream. Future projects could focus on developing/tailoring tools to help healthcare professionals (i.e. Nurses, physicians, diabetes educators etc.) to accurately quantify diabetes risk within this population. Moreover, utilizing a qualitative approach to explore some of the challenges of providing diabetes care and further explore their risk perception will provide valuable insight and add to the breadth of knowledge about this population. This can help create effective support strategies for this young adult caregiver population.

## CHAPTER 6: CONCLUSION

Canada is a multicultural nation with immigrants from all over the world. Due to the greater incidence of T2DM amongst the SAP and the life-long complications associated with T2DM; it is vital to further to explore this high-risk population. The purpose of this cross-sectional study was to explore diabetes related knowledge, risk perception, actual diabetes risk and QoL amongst young adult South Asian caregivers. Diabetes related knowledge and risk perception was found to be significantly higher amongst female caregivers. Moreover, there was gender based division in caregiving tasks. Although caregivers take part in different caregiving tasks for their parents, the findings suggest there was no difference in QoL between males and females. Despite having a family history of diabetes and taking on the role of a caregiver the findings indicate that there was a lack of diabetes related knowledge regarding wound care and identifying signs of hyper/hypoglycemia. The results suggest a need to equip these young adults with diabetes knowledge in order to support them in their caregiving role and to promote health awareness amongst this high-risk population. The results of the study have implications for improving diabetes education, and risk perception amongst this young adult population. These findings also highlight a group of caregivers who are at risk for developing a chronic illness that they help manage. We hope that this research can also help raise awareness about the importance of diabetes risk perception, QoL and diabetes knowledge amongst other high-risk populations and diabetes caregivers.

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**APPENDICES**

## Appendix A –Literature Review

Table 9

*Key Concepts from Literature Review*

| Study: Author (Country, year) | Study Design | Population | Objective/Aim of study | Findings | Implication for current study |
|---|---|---|---|---|---|
| **CAREGIVER** | | | | | |
| **Awadalla et al., (Sudan, 2006)** | Cross-sectional study | Sudaneese caregivers of type1 and T2DM were recruited (N=240). The caregiver group or participants consisted of 39% men with a mean age of 38.7. 61% women with a mean age of 34.6. The non-caregiver group consisted of 62.6% men and 37.4%women (N= 139). | To examine the QoL of caregivers of patients with diabetes compared to the general population | Patients age, illness duration was found to be positively associated with caregiver QoL scores. Moreover, caregivers of type 1 diabetics had lower QoL score relative to caregivers of those with T2DM. | The study highlights the importance of promoting awareness of family caregivers and their role in diabetes management and the impact caregiving can have one QoL. To effectively support caregivers in their role it is imperative to understand the impact of their role on their QoL. |
| **Katbamna et al., (UK, 2004)** | Qualitative (phenomenology) | 105 South Asian caregivers (aged 20-72; 68% female and 31% males) | Explore the experiences and needs of South Asian carers to develop guidelines for primary healthcare teams | Findings suggest that the main source of support was their immediate family members. However, this form of support was not dependable because it was sporadic. | The study suggests that due to cultural expectations and role socialization the nature of caregiving experience and tasks completed by caregivers differs based on gender. This study emphasizes the need to explore difference |

| | | | | Moreover, the quality of care provided was influenced by a multitude of factors, including employment, housing, strength of social networks and the nature of care needed. The study also noted a gender-based division of caregiving roles. | between male and female caregivers. |
|---|---|---|---|---|---|
| **Scarton et al., (2016)** | Integrated Review | A convenience sample of American Indians, African American and Caucasian family. 68.8% of participants were females and 31.2% of participants were males. | To identify the needs and concerns of family caregivers of persons with T2DM. | Findings suggest that caregivers required more information on T2DM (i.e. the signs of diabetes complications-hypoglycemia. Additionally, Caregivers with T2DM exhibited depressive and behavioral symptoms. | These results underscore the importance of examining diabetes related knowledge and the mental health of T2DM caregivers. |
| **DIABETES KNOWLEDGE AND RISK PRECPETION** | | | | | |
| **Kueh et al., (Australia, 2015)** | Cross-sectional study | There were 291 participants with T2DM (192 males, 99 females) and ranged in age from 21-71. | To examine a model describing the inter-relationship between diabetes knowledge, attitudes, | The results demonstrated that a higher level of knowledge was associated with an increase in the level of | The study highlights the importance of examining the inter-relationship between diabetes knowledge and its influence on health related |

| | | | | | |
|---|---|---|---|---|---|
| | | | self-management, and QoL of people with T2DM | positive attitude and more frequent self-management with regards to blood glucose testing. Additionally, the findings indicated that knowledge was indirectly associated with QoL. | behaviour (i.e. diet, exercise etc.) and quality of life when targeting diabetes prevention. |
| **Hivert et al., (US, 2009)** | Cross-sectional study | A total of 150 participants who were non-diabetic were recruited. | Examine perceived risk of developing diabetes amongst primary care patients. | Patients with high-perceived risk of developing diabetes were at a greater risk of developing diabetes and were more likely women. Yet, these patients did not plan to change their lifestyle more than patients with a low perceived risk. | These results highlight differences in risk perception between genders. It also highlights how accurate perceptions of risk may not translate to adoption of health preventative behavior. |

| Joiner et al., (US,2016) | Cross-sectional study | The study had a total of 146 participants. 74% of participants were females. 82% of participants reported being of Mexican or Guatemalan descent. Additionally, 35% a family history of diabetes. | The purpose of this study was to describe risk perception of developing diabetes among foreign-born U.S. Latinos. | 31.5% of the participants perceived themselves to be at moderate/high risk for developing diabetes. The study highlights several factors that influenced the prediction of moderate/high risk vs. lower risk for developing diabetes. This included having a history of gestational diabetes, being a high-school graduate, having less optimistic bias, greater degree of worry or concern, and having perception of greater risk for developing other chronic diseases and health conditions. | Overall, the findings from the study provide insight into some of the predictors of diabetes risk perception in another high-risk population. Utilizing one's perception of risk in prevention strategies can help create targeted interventions. |

**Appendix A1 –Literature Search Strategy**

```
┌─────────────────────────────────┐        ┌─────────────────────────────────┐
│   Potential Relevant articles   │        │ Additional articles were        │
│         (N=12587)               │        │ identified through other        │
│     PubMed (n =350)             │        │ sources/snowball                │
│    EBSCOhost (n=1555)           │        │ approach                        │
│       Ovid (n=969)              │        │ (n =6)                          │
│    Google Scholar= 2300         │        │                                 │
│   Scholar Portal (n=7413)       │        │                                 │
└─────────────────────────────────┘        └─────────────────────────────────┘
                │                                           │
                └─────────────────┬─────────────────────────┘
                                  ▼
              ┌─────────────────────────────────────┐
              │  Duplicate articles were removed    │
              │           (n = 8366)                │
              └─────────────────────────────────────┘
                                  │
                                  ▼
                    ┌──────────────────────────┐
                    │  4227 potential articles │
                    │    were identified       │
                    └──────────────────────────┘
                                  │
                                  ▼
```

Articles excluded by title and abstracts (n =4165)
- Focused on T1DM
- Children with diabetes
- Caring for children with DM
- Gestational DM
- Managing diabetes complications

Full-text articles assessed for eligibility (n = 62)

Articles included in Literature Review (n = 60)

Full-text articles excluded, with reasons (n = 2)
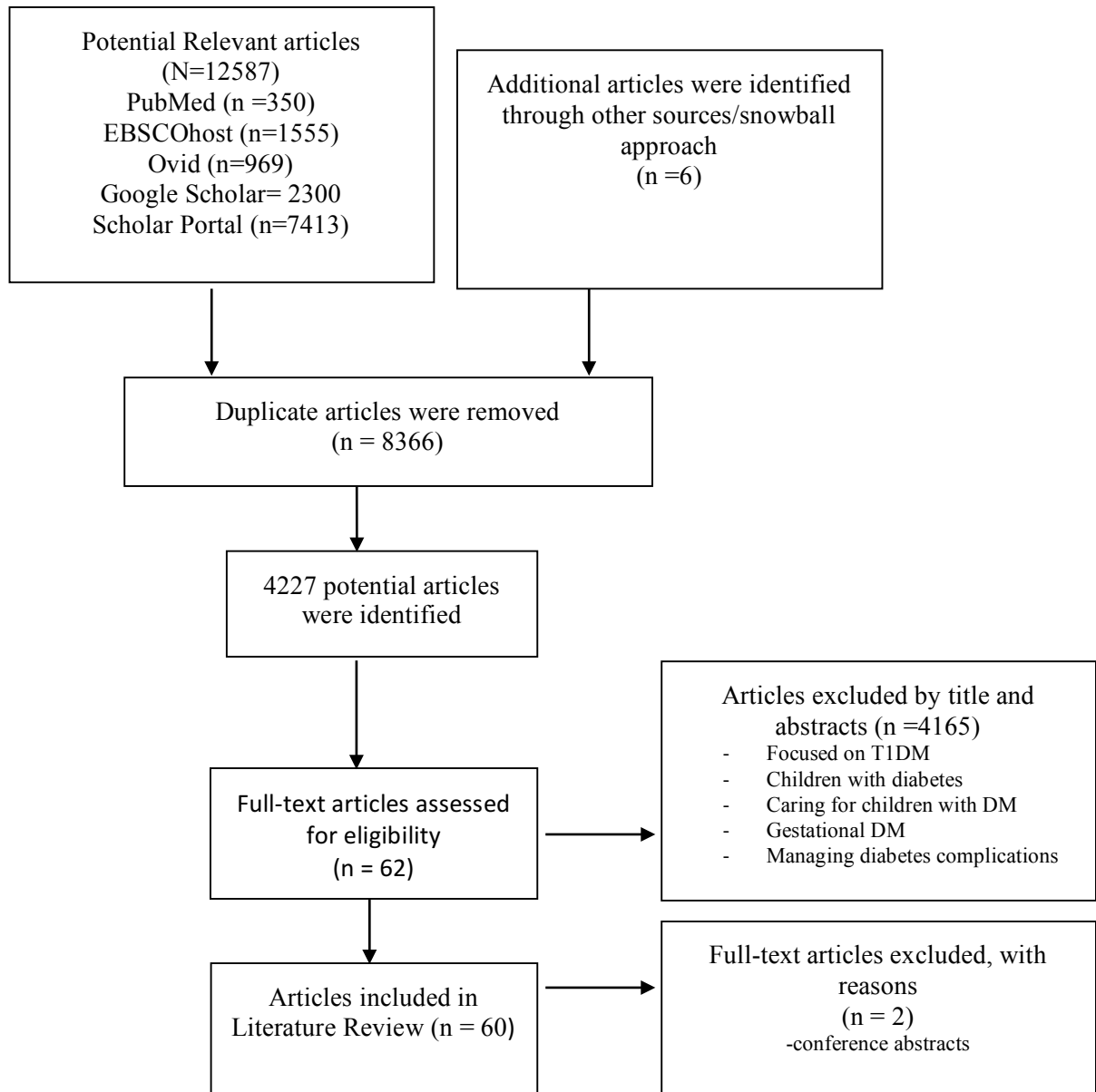-conference abstracts

*Figure 1*. PRISMA flow diagram outlining the identification and screening of literature search results. Adapted from "Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement," by D. Moher, A. Liberati, J. Tetzlaff, D. G. Altman, and The PRISMA Group, 2010, PLoS Med, 8(8), doi:10.1016/j.ijsu.2010.02.007

**Appendix A2- Literature Search: Duplicates Found using Google Scholar**

| Author/ Year/ Country | Objective | Study Design | Intervention /Control or exposure/ob servation | Findings | Conclusions |
|---|---|---|---|---|---|
| (Awadall a et al., 2006) Sudan | To examine the QoL of caregivers of patients with diabetes compared to the general populatio n | A cross-sectiona l study design | Use of the WHOQOL-BREF tool on caregivers for type1 and type 2 diabetics in Sudan | Patients age, illness duration was positively associated with caregiver Qol scores. Moreover, caregivers of type 1 diabetics had lower QoL score relative to caregivers of those with T2DM. Lastly caregiver QoL was directly related to caregivers | Highlights the importance of promoting awareness of family caregivers and their role in diabetes management as this can  enhance QoL and diabetes management |
| (Lesser et al., 2014) Canada | To gain insight into the impact of dietary acculturat ion to effectivel y formulate nutritional programin g  for South Asian immigrant s | Sub-study of the Multi-Cultural Commu nity Health Assess ment Trial (M-CHAT) . Cross-sectiona l study method | Questionnair e addressing perceived changes in dietary patterns, food preparation, and nutrition knowledge and awareness since immigration. Length of stay was used as a proxy for measuring acculturation . | Results demonstrated that dietary practices were improved after immigration as seen by lower BMIs. However, participants reported a greater consumption of convenience foods | Provided insight into the impact acculturation has on dietary practices. It underscores a need to provide cultural sensitivity when promoting positive dietary practices. |
| (Katbam na et al., 2004) | Explore the experienc | A qualitati ve | Focus groups and in-depth interviews | The finding suggests that the main source of | The results strengthen the importance of family dynamics in |

123

| | | | | | |
|---|---|---|---|---|---|
| United Kingdom | es and needs of South Asian carers to develop guidelines for primary healthcare teams | study was conducted. However, there was no mention of what the study's philosophical underpinnings were | were used to collect data from participants | support was their immediate family members. However, this form of support was unreliable because it was sporadic. Moreover, the quality of care provided is influenced by a multitude of factors, including employment, housing, strength of social networks and the nature of care needed. The study also noted a gender-based division of caregiving roles. | caregiving. It also emphasizes that when the needs of this of caregivers get overlooked it acts as barrier to the quality of care they provide. |
| Sinclair et al., 2010 United Kingdom | To investigate the role of informal caregivers in diabetes management and the burden of care experienced by them. | Cross-sectional Study. Participants were recruited from specialist hospital-based outpatient clinics. | Patients and careres completed an interview and the following questionnaires the Diabetes Knowledge Questionnaire EuroQol, Caregiver Strain Scale and General Health Questionnaire. | Majority of participants had low diabetes knowledge and reported feeling overwhelmed by their caregiving responsibilities and lacked support. Their care responsibilities included: testing glucose, help medication administration, shopping, housework, transportation etc. | To effectively support this population of carers, healthcare professionals need to recognize the needs of carers to equip them with the knowledge and skills for effective management of diabetes. |

**Appendix A3- Literature Search: Terminology Used in the Search Strategy**

Search strategy using Ovid Database(s): OVID Medline Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

| # | Searches | Results |
|---|----------|---------|
| 1 | (care* and diabetes).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] | 64112 |
| 2 | Adult/ or Diabetes Mellitus, Type 2/ or Diabetes Mellitus/ or "Quality of Life"/ or Caregivers/ | 4785169 |
| 3 | 1 and 2 | 40140 |
| 4 | Risk Factors/ or Metabolic Syndrome/ or Asian Continental Ancestry Group/ or Diabetes Mellitus, Type 2/ or Insulin/ | 1011622 |
| 5 | 3 and 4 | 20693 |
| 6 | (south asian caregiver and quality of life).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] | 0 |
| 7 | Attitude to Health/ and Diabetes Mellitus, Type 2/ and Diabetes Mellitus/ and Health Knowledge, Attitudes, Practice/ and Perception/ and Risk Factors/ | 0 |
| 8 | Attitude to Health/ or Diabetes Mellitus, Type 2/ or Diabetes Mellitus/ or Health Knowledge, Attitudes, Practice/ or Perception/ or Risk Factors/ | 1068732 |
| 9 | (diabetes risk perception and south Asian).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] | 0 |
| 10 | 2 and 8 | 573683 |
| 12 | (diabetes knowledge and south Asian).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading | 1 |

| | | |
|---|---|---|
| | word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] | |
| 13 | (diabetes knowledge and caregiver).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] | 5 |
| 14 | (diabetes risk perception and knowledge).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] | 6 |
| 15 | 1 and 2 and 4 and 8 | 19949 |
| 16 | Diabetes Mellitus, Type 2/ and Diabetes Mellitus/ and Chronic Disease/ and Caregivers/ | 0 |
| 17 | Diabetes Mellitus, Type 2/ or Diabetes Mellitus/ or Chronic Disease/ or Caregivers/ | 484859 |
| 18 | 6 and 17 | 0 |
| 19 | (young adult caregiver and diabetes).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] | 0 |
| 20 | Caregivers/cl and Caregivers/ed and Caregivers/px and Caregivers/sn and Caregivers/td [Classification,Education,Psychology,Statistics & Numerical Data,Trends] | 0 |
| 21 | (type 2 diabetes and health promotion).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] | 820 |
| 22 | (RISK PERCEPTION or KNOWLEDGE or QUALITY OF LIFE).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] | 893814 |

| 23 | Diabetes Mellitus, Type 2/ or Diabetes Mellitus/ | 214592 |
|----|---|---|
| 24 | DIABET*.mp. | 600570 |
| 25 | 23 or 24 | 600570 |
| 26 | SOUTH ASIAN.mp. | 4089 |
| 27 | Caregivers/ | 29232 |
| 28 | (Care GIVER* or caregiver* or carer*).mp. | 70896 |
| 29 | 26 and 27 and 28 | 23 |
| 30 | 24 and 26 and 27 | 0 |
| 31 | 13 and 26 | 0 |
| 32 | Health Promotion/ or Diabetes Mellitus/ or diabetes health promotion.mp. or Diabetes Mellitus, Type 2/ | 278265 |
| 33 | 26 and 32 | 497 |
| 34 | 26 and 28 and 32 | 2 |
| 35 | 22 and 26 | 470 |

Search strategy using PubMed Database(s)

| Search | Query | Items found |
|---|---|---|
| #43 | Search ((Care GIVER* or caregiver* or carer*)) AND (SOUTH ASIAN AND DIABETES) | 7 |
| #37 | Search DIABETES CAREGIVERS AND quality of life | 164 |
| #42 | Search (diabet*) AND informal caregiver | 48 |
| #41 | Search ((diabetes) AND informal caregiver) OR south asian | 15388 |
| #40 | Search ((south Asian) AND diabetes) AND (Care GIVER* or caregiver* or carer*) | 7 |
| #39 | Search ((south asian) AND diabetes) AND (care GIVER* OR caregiver* OR carer*) | 7 |
| #38 | Search ((south asain) AND diabetes) AND (Care GIVER* or caregiver* or carer*) | 0 |
| #14 | Search (south asian caregivers) AND quality of life | 8 |
| #36 | Search ((diabetes caregiver) AND ((type 2 diabetes) AND health promotion)) AND SOUTH ASIAN Schema: all | 0 |
| #35 | Search ((diabetes caregiver) AND ((type 2 diabetes) AND health promotion)) AND SOUTH ASIAN | 0 |
| #32 | Search Care GIVER* or caregiver* or carer* | 71539 |
| #31 | Search SOUTH ASIAN AND DIABETES | 1703 |
| #30 | Search SOUTH ASIAN | 15341 |
| #29 | Search DIABET* | 652094 |
| #28 | Search ((Diabetes Mellitus) OR Diabetes Mellitus) AND Type 2 | 163941 |
| #27 | Search diabetes RISK PERCEPTION or KNOWLEDGE or QUALITY OF LIFE | 939222 |
| #26 | Search RISK PERCEPTION or KNOWLEDGE or QUALITY OF LIFE AND diabetes | 32523 |
| #25 | Search RISK PERCEPTION or KNOWLEDGE or QUALITY OF LIFE | 964439 |
| #24 | Search (type 2 diabetes) AND health promotion | 2068 |
| #23 | Search young adult caregivers and diabetes | 92 |
| #22 | Search young adult caregiver and diabetes | 98 |
| #21 | Search diabetes knowledge AND caregiver | 140 |
| #20 | Search (diabetes knowledge) AND caregiver | 140 |
| #19 | Search (diabetes knowledge) AND south Asian | 132 |
| #17 | Search diabetes risk perception and south Asian | 15 |

| #16 | Search south asian caregivers AND quality of life OR DIABETES | 616696 |
|------|------|------|
| #15 | Search south asian caregivers AND quality of life | 8 |
| #13 | Search (south asian caregiver) AND quality of life | 10 |
| #12 | Search (Diabetes Mellitus, Type 2 OR Diabetes Mellitus OR "Quality of Life" OR Caregivers) | 742787 |
| #8 | Search Adv Exp Med Biol[JOUR] AND 2018/2/27[EDAT] | 2 |
| #4 | Search diabetes caregiver | 1064 |
| #1 | Search (care*) AND diabetes | 93936 |

Table 10: Search strategy using CINAHL

| # | Query | Results |
|------|------|------|
| S80 | S42 AND S71 | 0 |
| S79 | S51 AND S71 | 8 |
| S78 | S53 AND S71 | 2 |
| S77 | S64 AND S71 | 4 |
| S76 | S53 AND S71 | 2 |
| S75 | S65 AND S71 | 4 |
| S74 | S66 AND S71 | 0 |
| S73 | S66 AND S71 | 0 |
| S72 | S70 AND S71 | 2 |
| S71 | "south asian" | 1,179 |
| S70 | (MH "Diabetes Mellitus, Type 2/NU") OR "diabetes risk perception AND knowledge" OR (MH "Risk Taking Behavior/FG") | 322 |
| S69 | (MH "Diabetes Mellitus, Type 2/PF") OR "health belief model AND ( type 2 diabetes or type 2 diabetes mellitus or t2dm )" | 1,075 |
| S68 | (MH "Diabetes Mellitus, Type 2/NU") OR "health belief model AND diabetes type 2" | 319 |

| S67 | "( risk perception or perceived risk ) AND ( diabetes type 2 or mellitus ) AND health belief" | 0 |
|---|---|---|
| S66 | "diabetes AND risk perception" | 4 |
| S65 | (MM "Diabetes Mellitus, Type 2/ED/NU") OR "diabetes type 2 or diabetes mellitus type 2 or diabetes 2" | 411 |
| S64 | (MM "Diabetes Mellitus, Type 2/ED/NU") OR "diabetes type 2 or diabetes mellitus type 2 or diabetes 2" | 450 |
| S63 | "diabetes type 2 or diabetes mellitus type 2 or diabetes 2" | 0 |
| S62 | "( diabetes type 2 or diabetes mellitus type 2 or diabetes 2 or t2dm or non insulin dependent diabetes mellitus or niddm ) AND ( risk perception or perceived risk )" | 0 |
| S61 | "type 2 diabetes AND diabetes knowledge" | Display |
| S60 | "south asian AND type 2 diabetes" | 0 |
| S59 | "south asian AND diabetes" | Display |
| S58 | "south asian AND diabet* AND management" | 0 |
| S57 | (MH "Diabetes Mellitus, Type 2/FG/HI/ET") OR "diabetes AND south asians" OR (MH "Diabetes UK/ED") | 1,188 |
| S56 | "diabetes mellitus AND ( carers or caregivers or family members )" | 0 |
| S55 | "type 2 diabetes AND management AND SOUTH ASIAN" | 0 |
| S54 | S51 AND S53 | 31 |
| S53 | "diabetes knowledge" | 360 |
| S52 | "diabetes mellitus type 2 AND diabetes knowledge AND caregiver" | 0 |

| S51 | (MH "Diabetes Mellitus, Type 2/PF/ED") OR "( caregivers or family members or relatives or informal caregivers ) AND diabetes type 2" | 1,361 |
|---|---|---|
| S50 | (MH "Caregivers/PF") OR "diabetes knowledge AND ( caregivers or family members or relatives or informal caregivers )" | 7,121 |
| S49 | "diabetes type 2 AND ( risk perception or perceived risk )" | 0 |
| S48 | (MH "Attitude to Risk/HI/ED") OR (MH "Diabetic Patients/PF") OR "diabetes risk perception AND south asian" OR (MH "Diabetes Mellitus, Type 2") | 31,673 |
| S47 | "SOUTH ASIAN AND diabetes type 2" | 0 |
| S46 | "south asian AND immigrants AND DIABET*" | 0 |
| S45 | (MM "Diabetes Mellitus, Type 2/PF") | 755 |
| S44 | "diabetes type 2 AND caregiver" | 0 |
| S43 | "south asian immigrants AND diabetes type 2" | 0 |
| S42 | "care* AND diabetes" | 608 |
| S41 | "immigrant AND south asian AND DIABET*" | 0 |
| S40 | S2 AND S31 | 0 |
| S39 | S11 AND S31 | 8 |
| S38 | S13 AND S31 | 2 |
| S37 | S24 AND S31 | 4 |
| S36 | S13 AND S31 | 2 |
| S35 | S25 AND S31 | 4 |
| S34 | S26 AND S31 | 0 |
| S33 | S26 AND S31 | 0 |

| S32 | S30 AND S31 | 2 |
|-----|-------------|---|
| S31 | "south asian" | 1,179 |
| S30 | (MH "Diabetes Mellitus, Type 2/NU") OR "diabetes risk perception AND knowledge" OR (MH "Risk Taking Behavior/FG") | 322 |
| S29 | (MH "Diabetes Mellitus, Type 2/PF") OR "health belief model AND ( type 2 diabetes or type 2 diabetes mellitus or t2dm )" | 1,075 |
| S28 | (MH "Diabetes Mellitus, Type 2/NU") OR "health belief model AND diabetes type 2" | 319 |
| S27 | "( risk perception or perceived risk ) AND ( diabetes type 2 or mellitus ) AND health belief" | 0 |
| S26 | "diabetes AND risk perception" | 4 |
| S25 | (MM "Diabetes Mellitus, Type 2/ED/NU") OR "diabetes type 2 or diabetes mellitus type 2 or diabetes 2" | 411 |
| S24 | (MM "Diabetes Mellitus, Type 2/ED/NU") OR "diabetes type 2 or diabetes mellitus type 2 or diabetes 2" | 450 |
| S23 | "diabetes type 2 or diabetes mellitus type 2 or diabetes 2" | 0 |
| S22 | "( diabetes type 2 or diabetes mellitus type 2 or diabetes 2 or t2dm or non insulin dependent diabetes mellitus or niddm ) AND ( risk perception or perceived risk )" | 0 |
| S21 | "type 2 diabetes AND diabetes knowledge" | 0 |
| S20 | "south asian AND type 2 diabetes" | 0 |
| S19 | "south asian AND diabetes" | 1 |
| S18 | "south asian AND diabet* AND management" | 0 |
| S17 | (MH "Diabetes Mellitus, Type 2/FG/HI/ET") OR "diabetes AND south asians" OR (MH "Diabetes UK/ED") | 1,188 |

| S16 | "diabetes mellitus AND ( carers or caregivers or family members )" | 0 |
|---|---|---|
| S15 | "type 2 diabetes AND management AND SOUTH ASIAN" | 0 |
| S14 | S11 AND S13 | 31 |
| S13 | "diabetes knowledge" | 360 |
| S12 | "diabetes mellitus type 2 AND diabetes knowledge AND caregiver" | 0 |
| S11 | (MH "Diabetes Mellitus, Type 2/PF/ED") OR "( caregivers or family members or relatives or informal caregivers ) AND diabetes type 2" | 1,361 |
| S10 | (MH "Caregivers/PF") OR "diabetes knowledge AND ( caregivers or family members or relatives or informal caregivers )" | 7,121 |
| S9 | "diabetes type 2 AND ( risk perception or perceived risk )" | 0 |
| S8 | (MH "Attitude to Risk/HI/ED") OR (MH "Diabetic Patients/PF") OR "diabetes risk perception AND south asian" OR (MH "Diabetes Mellitus, Type 2") | 31,673 |
| S7 | "SOUTH ASIAN AND diabetes type 2" | 0 |
| S6 | "south asian AND immigrants AND DIABET*" | 0 |
| S5 | (MM "Diabetes Mellitus, Type 2/PF") | 755 |
| S4 | "diabetes type 2 AND caregiver" | 0 |
| S3 | "south asian immigrants AND diabetes type 2" | 0 |
| S2 | "care* AND diabetes" | 608 |
| S1 | "immigrant AND south asian AND DIABET*" | |

Table 11:Search strategy using Scholars Portal

| Searches | Results |
|---|---|
| 1.   1. type 2 diabetes caregiver | 7011 |
| 2.   type 2 diabetes caregiver and quality of life | 4700 |
| 3.   diabetes and young south Asians | 2713 |

## Appendix B - Facebook Posting and Reach

| | Posts | Reach | Clicks/Actions |
|---|---|---|---|
| ☐ | **YSAC Study** Fun Fact....did you know that it was only in 1936 did scientists realize that... | 43 | 0 |
| ☐ | **YSAC Study** Did you know that "depression is more common in people with diabetes... | 29 | 2 |
| ☐ | Check out this video of Dr. Peter Attia speaking about diabetes ❤️... | 28 | 1 |
| ☐ | Food for thought .... what are you're thoughts on taxing sugary drinks to... | 58 | 3 |
| ☐ | Hope you're enjoying your weekend! #YSAC #diabetesresearch... | 352 | 2 |
| ☐ | Happy Friday!! https://surveys.mcmaster.ca/limesurv... | 12 | 1 |

| | Posts | | Reach | Clicks/Actions |
|---|---|---|---|---|
| ☐ | **YSAC Study** | Fun Fact....did you know that it was only in 1936 did scientists realize that... | 43 | 0 |
| ☐ | **YSAC Study** | Did you know that "depression is more common in people with diabetes... | 29 | 2 |
| ☐ | | Check out this video of Dr. Peter Attia speaking about diabetes ❤️ ... | 28 | 1 |
| ☐ | | Food for thought .... what are you're thoughts on taxing sugary drinks to... | 58 | 3 |
| ☐ | | Hope you're enjoying your weekend! #YSAC #diabetesresearch... | 352 | 2 |
| ☐ | | Happy Friday!! https://surveys.mcmaster.ca/limesurv... | 12 | 1 |
| ☐ | | An inside look on living with diabetes amongst South Asian... | 14 | 2 |
| ☐ | | Fun fact "Canada's new food guide comes out sometime in 2018"!!... | 24 | 1 |
| ☐ | **IIS DAY ISTOR** | Lets celebrate this ingenuity!! #YSAC #T2DM #Diabetes | 13 | 1 |
| ☐ | | Support is a superpower!! Here are some ways to support someone in yo... | 34 | 2 |

| | | | |
|---|---|---|---|
| ☐ | Diabetes Canada recommends at least 30mins of exercise 5 days a week! So... | 37 | 4 |
| ☐ | YSAC Study — Fun Fact: Canadian Diabetes Association has changed it's name to... | 28 | 5 |
| ☐ | YSAC Study — Ask us more about #YSAC! https://surveys.mcmaster.ca/limesurv... | 4 | 3 |
| ☐ | YSAC Study — Hey everyone! My name is Angela and I am a Masters student at McMaster... | 473 | 27 |
| ☐ | YSAC Study — YSAC study updated their profile picture. | 2 | 7 |
| ☐ | YSAC Study — Its MONDAY ! Here's a great post on some positive ways to motivated abo... | 34 | 3 |
| ☐ | Happy Friday Everyone!! I hope you get to enjoy the warm weather and get to... | 52 | 4 |
| ☐ | YSAC Study — Happy Canada Day everyone! :) Heres a bit of Canadian history and the... | 28 | 2 |
| ☐ | YSAC Study — Myth vs. Fact "Myth : Fruit is a healthy food. Therefore, it is ok to eat as muc... | 53 | 5 |
| ☐ | Let's spread the word #Repost @amdiabetesassn · · · Diabetes is... | 52 | 3 |
| ☐ | Check out this inspiring story !! #ysac #diabetes | 12 | 1 |
| ☐ | YSAC Study — We've almost reached study goal! Hurry and participate today!... | 15 | 1 |
| ☐ | YSAC Study — It's FINALLY FRIDAY! Happy Friday everyone! Kick start your weekend wi... | 56 | 3 |
| ☐ | YSAC Study — According to Diabetes Canada diabetes prevalence is estimated to... | 16 | 2 |
| ☐ | YSAC Study — Hurry and participate soon for your chance to be entered in the draw!! | 17 | 2 |

**Appendix B1 - List of South Asian Recruitment Groups**

Student associations/ Cultural groups: Canadian Tamil Youth Alliance (CTYA), Indian Student Association McGill - Indian Students Association, Laurier University Tamil Students' Association (LUTSA), McMaster Hindu Students' Association (HSA), McMaster Tamil Student Association (MACTSA), Punjabi Cultural Association of Saskatchewan (PCAS), University of Ottawa Punjabi Association (U.O.P.A.), PSA McGill - Pakistani Students' Association, Pakistan's Students Association (PSA) Simon Fraser University (SFU), University of Ottawa Tamil Students' Union, University of Ottawa- South Asian Law Student Association (SALSA), York University Malayalee Student Association (YUMSA),Tamil Students' Association of University of British Colombia, QBSA-Queen's Bangladeshi Students' Association, South Asian Alliance (SAA)- University of Toronto, South Asian Association –Ryerson, South Asian Association-York University, McMaster Malyalalee Student Association (MALSA)

**Religious Institutions:** Syro Malabar Catholic Church Toronto, Sanatan Mandir,

**Community:** Durham Tamil association, Toronto Malayalee association (TMS), Brampton Tamil Association, Malayalee Nursing Association, Seva Food Bank, Brampton Library - Chinguacousy Branch, Muslim Community Services

**Appendix C- Sample Facebook Post**

Hey everyone! My name is Angela and I am conducting a study on South Asian young adults whose parent(s) have Type 2 Diabetes Mellitus.

Eligible participants will complete a survey, which will take approximately 20-30 minutes to complete. Upon completion, you can provide your email if you wish to be entered in a draw for a $50 gift card.

To be eligible the following criteria should be met:

1.  You must be between the ages 18-29; your parent(s) must have been diagnosed with type 2 diabetes mellitus
2.  Your parent(s) must have immigrated to Canada
3.  You are of South Asian descent (i.e. Bangladesh, India, Pakistan, Sri Lanka, Bhutan, Nepal, or Maldives)
4.  You must speak English.
5.  You must live in Canada
6.  You must provide unpaid or arrange for paid or unpaid help to help manage your parents' diabetes (i.e. driving to appointments, checking blood sugars, promoting exercise, helping adhere to a diabetic diet etc.)

The link to the survey is provided here: [*LIMESURVEY HYPERLINK HERE*]. All information collected in this study shall be kept strictly confidential and any information that could identify you will not be published. If at any point you have any questions, please contact me at koipura@mcmaster.ca.

Thank you once again for your participation!!

**Appendix D- Recruitment Poster**

**PARTICIPANTS NEEDED FOR**
**RESEARCH ON SOUTH ASIAN YOUNG ADULTS CARING FOR PARENTS**
**WITH TYPE 2 DIABETES MELLITUS (T2DM).**

We are looking for volunteers to take part in a study exploring diabetes knowledge, risk perception of developing diabetes and quality of life.

You would be asked to complete an online-questionnaire, which will take approximately 20-30 minutes to complete.

To be eligible for the study:
1. You must be between the ages 18-29 whose parent(s) have been diagnosed with type 2 diabetes mellitus
2. Your parent(s) must have immigrated to Canada
3. You must be of South Asian descent (i.e. Bangladesh, India, Pakistan, Sri Lanka, Bhutan, Nepal, or Maldives)
4. You must be able to speak English.
5. You must live in Canada
6. You must provide unpaid or arrange for paid or unpaid help to help manage your parents' diabetes (i.e. driving to appointments, checking blood sugars, promoting exercise, helping adhere to a diabetic diet etc.)

To participate simply go to [LIMEWIRE *URL*]

Upon completion, you can provide your email if you wish to be entered in a draw for a $50 gift card.

For more information about this study, or to volunteer for this study, please contact: Angela Koipuram RN, BScN, MScN (candidate)

School of Nursing
McMaster University
Hamilton, Ontario, Canada

**This study has been reviewed by, and received ethics clearance by the McMaster Research Ethics Board**

**Appendix E- Email Recruitment**

 Dear members of [insert name of South Asian community group]

We invite South Asian young adults (18-29) who provide care to their parent(s) with Type 2 Diabetes (T2DM) to become a volunteer for the young South Asian caregiver study.

This study is led by **Angela Koipuram**, RN, BScN, MScN Student and **Diana Sherifali** RN, PhD, CDE, at McMaster University's School of Nursing.

As a volunteer, we ask you **to complete a questionnaire that takes a maximum of 20-30 minutes**.

 **The purpose of the study** is to explore South Asian second generational immigrant's knowledge of diabetes, their quality of life, and risk perception of developing diabetes compared to actual risk of developing diabetes.

All we ask is that you follow this link: (Insert hyperlink). By completing the questionnaire, you can be eligible to win one of three **$50 gift cards!!**
If you have any technological concerns, don't hesitate to contact koipura@mcmaster.ca for assistance.

This study has been reviewed by the Hamilton Health Sciences/McMaster Faculty of Health Sciences Research Ethics Board (HHS/FHS REB). The REB is responsible for ensuring that respondents are informed of the risks associated with the research, and that respondents are free to decide if participation is right for them. If you have any questions about your rights as a research respondent, please call The Office of the Chair, HHS/FHS REB at 905.521.2100 x 42013.

We value your input and time
Sincerely,

Angela Koipuram  RN, BScN, MScN student
School of Nursing, McMaster University
1280 Main St. West
Hamilton, Ontario, L8N 3Z5

**Appendix E1- First Reminder email**

Dear members of [insert name of South Asian community group]

A big thank you to all members that have already participated in South
Asian young adult study! It is wonderful to have received so much input!
Your input will provide a rich understanding of the diabetes knowledge, quality of life,
and risk perception of developing diabetes. We greatly encourage all who have not yet
volunteered for this study to participate, by following the link below. This questionnaire
will close on (**insert date here**), so we ask you to complete it as soon as possible.

Just as a reminder, this research study is led by **Angela Koipuram**, RN, BScN, MScN
Student and **Diana Sherifali** RN, PhD, CDE, at McMaster University's School of
Nursing. With the support of **(insert South Asian community group)**, we invite young
adult South Asians to become a volunteer for study. As a volunteer, we ask you **to
complete a questionnaire that takes a maximum of 20-30 minutes. The purpose of
the study** is to explore South Asian second generational immigrant's knowledge of
diabetes, their quality of life, and risk perception of developing diabetes compared to
actual risk of developing diabetes. We hope that the findings from the proposed study will
help highlight key element in facilitating health promoting behaviours amongst young
adult South Asians.

All we ask is that you follow this link **(insert hyperlink to questionnaire**)! By
completing the questionnaire, you can be eligible to win one of (three) **$50 gift cards**!!

If you have any technological concerns, don't hesitate to contact koipura@mcmaster.ca
for assistance.

This study has been reviewed by the Hamilton Health Sciences/ McMaster Faculty of
Health Sciences Research Ethics Board (HHS/FHS REB). The REB is responsible for
ensuring that respondents are informed of the risks associated with the research, and that
respondents are free to decide if participation is right for them. If you have any questions
about your rights as a research respondent, please call The Office of the Chair, HHS/FHS
REB at 905.521.2100 x 42013.

We value your input and appreciate your dedication to diabetes education in Ontario

Sincerely,

Angela Koipuram RN, BScN, MScN student
School of Nursing, McMaster University
1280 Main St. West
Hamilton, Ontario, L8N 3Z5

**Appendix E2- Second Reminder email**

Dear members of  [insert name of South Asian community group]

The research on South Asian young adults caring for parents with type 2 diabetes mellitus (T2DM) is coming to a close. Many thanks to all of you who participated! Your input will provide a rich description of diabetes educators across Ontario. To all of you who have not yet volunteered, good news! This questionnaire is still open! We strongly encourage you to volunteer as soon as possible. All we ask is that **you follow the link below and complete the Questionnaire**. The closing date of this study is (**insert date here**). Following this deadline, we will be in contact with the lucky winners who participated in our draw for a **$50 gift card**.

Just as a reminder, this research study is led by **Angela Koipuram**, RN, BScN, MScN student and **Diana Sherifali** RN, PhD, CDE, at McMaster University's School of Nursing. With the support of **(insert South Asian community group)**, we invite young adult South Asians to become a volunteer for study. As a volunteer, we ask you to **complete a questionnaire that takes a maximum 20-30 minutes**. **The purpose of the study** is to explore South Asian second generational immigrant's knowledge of diabetes, their quality of life, and risk perception of developing diabetes compared to actual risk of developing diabetes.

All we ask is that you follow this link   **(insert hyperlink to questionnaire**)! By completing the questionnaire, you can be eligible to win one of (three/seven) **$50 gift cards**!
If you have any technological concerns, don't hesitate to contact    ██████    for assistance.

This study has been reviewed by the Hamilton Health Sciences/McMaster Faculty of Health Sciences Research Ethics Board (HHS/FHS REB). The REB is responsible for ensuring that respondents are informed of the risks associated with the research, and that respondents are free to decide if participation is right for them. If you have any questions about your rights as a research respondent, please call The Office of the Chair, HHS/FHS REB at 905.521.2100 x 42013.

We value your input and appreciate your dedication to diabetes education in Ontario
Sincerely,

Angela Koipuram RN, BScN, MScN student
Primary Investigator
School of Nursing, McMaster University
1280 Main St. West
Hamilton, Ontario, L8N 3Z5

**Appendix E3- Email confirmation for the Dillman Approach**

Good Morning Angela,
A good update, finally got approval from the board. There was a bit of back and forth happening but finally got approved. It is a first time for our association to get involved in something like this. Sorry for the delay.
Let me know what the next steps would be,
Best Regards

███████████

Koipuram > wrote:

 Hi,

I'm Masters student working in collaboration with Dr. Diana Sherifali in conducting a research study on young South Asian whose parents have type 2 diabetes. I'm writing to invite members of the SOPCA (Screen of Peel Community Association) to participate in the research the study. The purpose of the study is to explore second generational immigrant South Asian's knowledge of diabetes, their quality of life, and risk perception of developing diabetes compared to their actual risk of developing diabetes.
 Involvement of the study would require you to send invitational emails to members based on a modified Dillman approach and having a copy of the email sent to myself.  Dr. Diana Sherifali and I will draft the emails. A modified Dillman approach entails sending an invitational email outlining the purpose of the study, how the data obtained will be utilized, and the hyperlink for the online questionnaire. After the initial email, reminder emails will be sent every two weeks for a total of six weeks. Those who are eligible and wish to participate in the study would click a hyperlink to the online survey that would take them to the online survey. It would take approximately 20-30 minutes to complete. By completing the questionnaire, participants can be eligible to win one of three $50 gift cards! Please let me know if you would be interested in this opportunity.

**Angela Koipuram**

RN, BScN, MScN Candidate
School of Nursing, McMaster University
1280 Main St. West
Hamilton, Ontario, L8N3Z5

**Appendix F- Demographic Data Questionnaire**

*For the purposes of this study a "caregiver" will be defined as someone who provides unpaid or arranges for paid or unpaid help to help manage their parents' diabetes (i.e. driving to appointments, checking blood sugars, promoting exercise, helping adhere to a diabetic diet etc.)*

\* = Will be excluded from the study if they select this option (will exit from survey)

1.      How old are you (please circle one)?

**18—20               21—23               24—26               27— 29      30— or more  \***

2.      Sex:  **Male               Female**

3.      Did your parent(s) immigrate to Canada (select one)?  **Yes      No\***

4.      Are you of South Asian descent (select one)?  **Yes      No\***

Which part of South Asia are you from?
- **a)      India**
- **b)      Pakistan**
- **c)      Sri Lanka**
- **d)      Nepal**
- **e)      Bangladesh**
- **f)      Maldives**
- **g)      Bhutan**

5.      Have you been diagnosed with diabetes  (select one)?     **Yes \*      No**

6.      Do you have any disabilities, chronic illness or mental illness, which inhibited them from acting as a caregiver  (select one)?         **Yes \*      No**

7.      Which of the following statements is most applicable (select one)
- **One of my parents has been diagnosed with Type 2 Diabetes Mellitus (T2DM) for at least 1 year**
- **Both of my parents have been diagnosed with Type 2 Diabetes Mellitus (T2DM) for at least 1 year**
- **None of the above statements apply\***

8. Which of the following caregiving task(s) do you take part in (select all that apply)?

- **Monitoring sugar levels**

- **Managing medications**

- **Help administer insulin**

- **Picking up medications**

- **Ensuring parent(s) with diabetes gets some exercise**

- **Manage complications associated with diabetes (such as mobility, heart-related problems, vision loss, wound care, hypoglycaemia, kidney disease, loss of limb, and neuropathy)**

- **Drive your parent(s) to their diabetes appointments**

- **Involved in grocery shopping**

- **Participating in meal preparation**

- **Managing finances associated with diabetes**

- **Other ___**

- **None of the above \***

9. How many years have you lived in Canada (select one)?

- **Less than a year to 1 year**
- **2-4 years**
- **5-7 years**
- **8-10 years**
- **11-19 years**
- **20+ years**

10. Marital status (please circle one):

**Single        Married            Widowed            Divorced        Other (please specify): _____**

11.     Which one of the following best describes your employment status?

      **a)**      **Full-Time, 35 hours or more a week**
      **b)**      **Part time, less than 32 hours a week**
      **c)**      **Casual**
      **d)**      **Unemployed or laid off, and looking for work**
      **e)**      **Unemployed and not looking for work**
      **f)**      **Homemaker**
      **g)**      **Disabled, not able to work**
      **h)**      **Other (please specify) _____**

**12.**     Do you currently have health insurance (please circle one):  **Yes    No**

13.     What is your religion (please circle one)?

**Christian       Sikh         Hindu          Muslim     Buddhist**

**Other (please specify): _____**

14.      Are you currently a student (select one)?  **Yes      No**

If you are a student, are you completing your studies…..(select one)

- **Full-time**

- **Part-time**

15.     Do you have anyone available to you for support in managing your parent's diabetes (please select one)?     **Yes      No**

If yes, what is their relationship to you? _____

16.     Do you currently live in the same household as your parent (s) who is affected by diabetes (please select one)?    **Yes      No**

If you live in a separate household than parent(s) with diabetes, how often do you visit (please select one)?

   **a)   More than once a week**

   **b)   Once a week**

   **c)   A few times a month**

   **d)   Once a month**

   **e)   A few times a year**

17.      Which of the following statements best describes you today (select one)?

   **a)   I actively search out information about caring for someone with diabetes**

   **b)   If I see or hear something of interest related to caring for someone with diabetes, I read it or listen to it, but I don't search it out**

   **c)   I am too busy or not interested in finding more information about caring for someone with diabetes.**

18.     As a caregiver, do you have . . . (select all that apply)

   - **Less time for your friends or other family members than before?**
   - **To give up vacations, hobbies, or your own social activities?**
   - **Less time for exercise than before**
   - **Worse personal physical health than before**
   - **Worse personal mental health**
   - **None of the above**

19.     Thinking now of all the kinds of help you provide for the person in your care, about how many hours do you spend in **an average week** doing these things (select one)?
   **a)  Less than 1 hour**

   **b)  1-5 hours**

   **c)  6-10 hours**

    **d) 11-15 hours**

    **e) 16-25 hours**

    **f) 26+ hours**

**20.** What is your total annual household income in 2016 from all sources, before taxes?

- **Under $30K**

- **$30-50K**

- **$50-75K**

- **$75-100K**

- **$100K+**

## Assessing Current behaviour

21. Do you exercise regularly (select one)? **Yes     No**

If you do exercise, how times a week do you exercise (select one)?

- **Once a week or less**
- **Twice / week**
- **3-4 times/week**
- **5 or more times / week**

22. Do you use tobacco (select all that apply)? **Yes     No**

If you do use tobacco, which ones apply (select which ones apply)?
- **Cigarette**
- **Pipe**
- **Chewing**
- **Other**

23. Do you drink alcohol (select one)? **Yes     No**

If you do consume alcohol, how many times a week do you drink (select one)?
- **Once a week or less**
- **Twice / week**
- **3-4 times/week**
- **5 or more times / week**

**Appendix G- Patient's Diabetes Knowledge Questionnaire**

| | Questions | Yes | No | Don't Know |
|---|---|---|---|---|
| 1 | Eating too much sugar and other sweet foods is a cause of diabetes. | | | |
| 2 | The usual cause of diabetes is lack of effective insulin in the body. | | | |
| 3 | Diabetes is caused by failure of the kidneys to keep sugar out of the urine. | | | |
| 4 | Kidneys produce insulin. | | | |
| 5 | In untreated diabetes, the amount of sugar in the blood usually increases. | | | |
| 6 | If I am diabetic, my children have a higher chance of being diabetic. | | | |
| 7 | Diabetes can be cured. | | | |
| 8 | A fasting blood sugar level of 210 is too high. | | | |
| 9 | The best way to check my diabetes is by testing my urine. | | | |
| 10 | Regular exercise will increase the need for insulin or other diabetic medication. | | | |
| 11 | There are two main types of diabetes: Type 1 (insulin-dependent) and Type 2 (non-insulin dependent). | | | |
| 12 | An insulin reaction is caused by too much food. | | | |
| 13 | Medication is more important than diet and exercise to control my diabetes. | | | |
| 14 | Diabetes often causes poor circulation. | | | |
| 15 | Cuts and abrasions on diabetes heal more slowly. | | | |
| 16 | Diabetics should take extra care when cutting their toenails. | | | |
| 17 | A person with diabetes should cleanse a cut with iodine and alcohol. | | | |
| 18 | The way I prepare my food is as important as the foods I eat. | | | |
| 19 | Diabetes can damage my kidneys. | | | |
| 20 | Diabetes can cause loss of feeling in my hands, fingers and feet. | | | |
| 21 | Shaking and sweating are signs of high blood sugar. | | | |
| 22 | Frequent urination and thirst are signs of low blood sugar. | | | |
| 23 | Tight elastic hose or socks are not bad for diabetics. | | | |
| 24 | A diabetic diet consists mostly of special foods. | | | |

**Appendix H- Patient's Diabetes Knowledge Questionnaire Scoring**

| Questions |
|---|
| Eating too much sugar and other sweet foods is a cause of diabetes. (False) |
| The usual cause of diabetes is lack of effective insulin in the body. (True) |
| Diabetes is caused by failure of the kidneys to keep sugar out of the urine. (False) |
| Kidneys produce insulin. (False) |
| In untreated diabetes, the amount of sugar in the blood usually increases. (True) |
| If I am diabetic, my children have a higher chance of being diabetic. (True) |
| Diabetes can be cured. (False) |
| A fasting blood sugar level of 11.5 mmol/l is too high. (True) |
| The best way to check my diabetes is by testing my urine. (False) |
| Regular exercise will increase the need for insulin or other diabetic medication. (False) |
| There are two main types of diabetes:  Type 1 (insulin-dependent) and Type 2 (non-insulin-dependent). (True) |
| An insulin reaction is caused by too much food. (False) |
| Medication is more important than diet and exercise to control diabetes. (False) |
| Diabetes often causes poor circulation. (True) |
| Cuts and abrasions on diabetics heal more slowly. (True) |
| Diabetics should take extra care when cutting their toenails. (True) |
| A person with diabetes should cleanse a cut with iodine and alcohol. (False) |
| The way I prepare my food is as important as the foods I eat. (True) |
| Diabetes can damage my kidneys. (True) |
| Diabetes can cause loss of feeling in my hands, fingers, and feet. (True) |
| Shaking and sweating are signs of high blood sugar. (True) |
| Frequent urination and thirst are signs of low blood sugar. (False) |
| Tight elastic hose or socks are not bad for diabetics. (False) |
| A diabetic diet consists mostly of special foods. (False) |

A total of 48 points are possible on the DKQ-24 as each correct answer was scaled at 2 points. An answer of I Don't Know is scaled at 1 point. An incorrect answer is 0 points.

**Appendix I- Risk Perception of Developing Diabetes Survey (RP-DD)**
**General Attitudes**

For each item, please select the number below the response that BEST DESCRIBES YOUR OPINION

| | Strongly Agree | Agree | Disagree | Strongly Disagree |
|---|---|---|---|---|
| 1. I feel that I have little control over risks to my health. | 1 | 2 | 3 | 4 |
| 2. If I am going to get diabetes there is not much I can do about it. | 1 | 2 | 3 | 4 |
| 3. I think that my personal effort will help control my risks of getting diabetes. | 1 | 2 | 3 | 4 |
| 4. People who make a good effort to control the risks of getting diabetes are much less likely to get diabetes. | 1 | 2 | 3 | 4 |
| 5. I worry about getting diabetes. | 1 | 2 | 3 | 4 |
| 6. Compared to other people of my same age and sex (gender), I am less likely than they are to get diabetes. | 1 | 2 | 3 | 4 |
| 7. Compared to other people of my same age and sex (gender), I am less likely than they are to get diabetes. | 1 | 2 | 3 | 4 |
| 8. Worrying about getting diabetes is very upsetting. | 1 | 2 | 3 | 4 |

**Your Attitudes about Health Risks**

Below is a list of health problems and diseases. For each one, please circle the number below the words to tell us if you think **your own personal health** is at "almost no risk," "slight risk," "moderate risk" or "high risk" from these problems.

| | **Almost no Risk** | **Slight Risk** | **Moderate Risk** | **High Risk** |
|---|---|---|---|---|
| 9. Arthritis | 1 | 2 | 3 | 4 |
| 10. Heart Disease | 1 | 2 | 3 | 4 |
| 11. Cancer | 1 | 2 | 3 | 4 |
| 12. High Blood Pressure | 1 | 2 | 3 | 4 |
| 13. Hearing loss | 1 | 2 | 3 | 4 |
| 14. Asthma | 1 | 2 | 3 | 4 |
| 15. Diabetes | 1 | 2 | 3 | 4 |
| 16. Osteoporosis (bone disease) | 1 | 2 | 3 | 4 |
| 17. Stroke | 1 | 2 | 3 | 4 |
| 18. Blindness | 1 | 2 | 3 | 4 |
| 19. Foot Amputation | 1 | 2 | 3 | 4 |
| 20. Infections needing treatment by a doctor | 1 | 2 | 3 | 4 |
| 21. Impotence (only in men) | 1 | 2 | 3 | 4 |
| 22. Kidney Failure | 1 | 2 | 3 | 4 |
| 23. AIDS | 1 | 2 | 3 | 4 |

**Environmental Health Risks**

Below is a list of possible hazards or dangerous conditions in the environment around most of us. For each one, please circle the number below the words to tell us if your **own personal health** is at "almost no risk," "slight risk," "moderate risk" or "high risk" from each of the following hazards or conditions.

| | **Almost No Risk** | **Slight Risk** | **Moderate Risk** | **High Risk** |
|---|---|---|---|---|
| 24. Medical X-rays (radiation) | 1 | 2 | 3 | 4 |
| 25. Violent Crime | 1 | 2 | 3 | 4 |
| 26. Extreme weather (hot or cold) | 1 | 2 | 3 | 4 |
| 27. Diving/ riding in an automobile | 1 | 2 | 3 | 4 |
| 28. "Street" drugs (illegal drugs) | 1 | 2 | 3 | 4 |
| 29. Air pollution | 1 | 2 | 3 | 4 |
| 30. Pesticides | 1 | 2 | 3 | 4 |
| 31. Household chemicals | 1 | 2 | 3 | 4 |
| 32. Cigarette smoke from people around you | 1 | 2 | 3 | 4 |

**Appendix J- Risk Perception of Developing Diabetes Survey (RP-DD) Scoring**

| SUBSCALE | ITEMS | CODING | ALPHA COEFFICIENT |
|---|---|---|---|
| Personal Control | Average Q1, Q2, Q3R*, Q4R* (4 items) | Higher score = more personal control | .68 |
| Worry | Average Q5R & Q8R (2 items) | Higher score = more worry (better as individual items) | .50 |
| Optimistic Bias | Average Q6R & Q7R (2 items) | Higher score = more optimistic bias | .71 |
| Personal Disease Risk | Likert score plus 1 for either *myself or/and* family member having disease, then averaged across Q9-Q23 (15 items) | Higher score = higher perceived comparative personal disease risk | .80 |
| Comparative Environmental Risk | Average Q24-Q32 (9 items) | Higher score = higher perceived comparative environmental risk | .81 |
| COMPOSITE RISK SCORE | Average Q1R, Q2R, Q3, Q4, Q5R, Q6, Q7, Q8R, Q9-Q32 (32 items) | Higher score = more perceived risk (Some are reversed differently from individual scale scoring) | .84 |

| | | | |
|---|---|---|---|
| Diabetes Risk Knowledge – Risk of developing diabetes | Sum of correct responses to Q33-Q43 Correct: Score = 1, Incorrect or Don't Know: Score = 0 (11 items) | High score = more knowledgeable/ more correct answers Correct Answers: 33-1  37-1  41-3 34-2  38-1  42-1 35-3  39-1  43-3 36-1  40-1 | Use as descriptor of level of knowledge |

*R and bolding on items means scoring is reversed to conform to conceptual direction of subscales.

**Appendix K- Canadian Diabetes Risk Assessment Questionnaire (CANRISC)**

How tall are you and how much do you weigh? Use Select your
BMI group from the following choices:

| White (BMI less than 25) | 0 points |
|---|---|
| Light grey (BMI 25 to 29) | 4 points |
| Dark grey (BMI 30 to 34) | 9 points |
| Black (BMI 35 and over) | 14 points |

HEIGHT

| feet/inches | cm | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 6'4" | 192.5 | 12 | 13 | 13 | 14 | 15 | 16 | 17 | 18 | 18 | 19 | 20 | 21 | 22 | 22 | 23 | 24 | 24 | 26 | 26 | 27 | 28 | 29 | 29 | 30 | 31 | 32 | 33 | 34 |
| 6'3" | 190 | 12 | 13 | 14 | 15 | 16 | 16 | 17 | 18 | 19 | 20 | 20 | 21 | 22 | 23 | 24 | 24 | 25 | 26 | 27 | 28 | 29 | 29 | 30 | 31 | 32 | 33 | 34 | 34 |
| 6'2" | 187.5 | 13 | 13 | 14 | 15 | 16 | 17 | 18 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 24 | 25 | 26 | 27 | 28 | 29 | 29 | 30 | 31 | 32 | 33 | 34 | 34 | 36 |
| 6'1" | 185 | 13 | 14 | 15 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 29 | 30 | 31 | 32 | 33 | 34 | 34 | 36 | 37 |
| 6'0" | 182.5 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 20 | 21 | 22 | 23 | 24 | 24 | 26 | 27 | 28 | 29 | 29 | 30 | 31 | 32 | 33 | 34 | 34 | 36 | 37 | 38 |
| 5'11" | 180 | 14 | 15 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 22 | 23 | 24 | 24 | 26 | 27 | 28 | 29 | 30 | 31 | 32 | 33 | 34 | 34 | 36 | 37 | 38 | 39 |
| 5'10" | 177.5 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | 31 | 32 | 33 | 34 | 34 | 36 | 37 | 38 | 39 | 40 |
| 5'9" | 175 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | 31 | 32 | 33 | 34 | 34 | 36 | 37 | 38 | 39 | 40 | 41 |
| 5'8" | 172.5 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 24 | 26 | 27 | 28 | 29 | 29 | 31 | 32 | 33 | 34 | 34 | 36 | 37 | 38 | 39 | 40 | 41 | 42 |
| 5'7" | 170 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 24 | 24 | 26 | 27 | 28 | 29 | 29 | 31 | 32 | 33 | 34 | 34 | 36 | 37 | 38 | 39 | 40 | 41 | 42 | 43 |
| 5'6" | 167.5 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 29 | 29 | 31 | 32 | 33 | 34 | 34 | 36 | 37 | 38 | 39 | 40 | 41 | 42 | 43 | 45 |
| 5'5" | 165 | 16 | 17 | 18 | 19 | 21 | 22 | 23 | 24 | 24 | 26 | 27 | 28 | 29 | 30 | 32 | 33 | 34 | 34 | 36 | 37 | 38 | 39 | 40 | 42 | 43 | 44 | 45 | 46 |
| 5'4" | 162.5 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 26 | 27 | 28 | 29 | 30 | 31 | 33 | 34 | 34 | 36 | 37 | 38 | 39 | 41 | 42 | 43 | 44 | 45 | 46 | 47 |
| 5'3" | 160 | 17 | 18 | 20 | 21 | 22 | 23 | 24 | 25 | 27 | 28 | 29 | 30 | 31 | 32 | 34 | 34 | 36 | 37 | 38 | 39 | 41 | 42 | 43 | 44 | 45 | 46 | 48 | 49 |
| 5'2" | 157.5 | 18 | 19 | 20 | 21 | 23 | 24 | 24 | 26 | 27 | 29 | 29 | 31 | 32 | 33 | 34 | 36 | 37 | 38 | 40 | 41 | 42 | 43 | 44 | 46 | 47 | 48 | 49 | 50 |
| 5'1" | 155 | 18 | 20 | 21 | 22 | 23 | 24 | 26 | 27 | 28 | 29 | 31 | 32 | 33 | 34 | 36 | 37 | 38 | 40 | 41 | 42 | 43 | 45 | 46 | 47 | 48 | 50 | 51 | 52 |
| 5'0" | 152.5 | 19 | 20 | 21 | 23 | 24 | 25 | 27 | 28 | 29 | 31 | 32 | 33 | 34 | 36 | 37 | 38 | 40 | 41 | 42 | 43 | 45 | 46 | 47 | 49 | 50 | 51 | 52 | 54 |
| 4'11" | 150 | 20 | 21 | 22 | 24 | 24 | 26 | 28 | 29 | 30 | 32 | 33 | 34 | 36 | 37 | 38 | 40 | 41 | 42 | 44 | 45 | 46 | 48 | 49 | 50 | 52 | 53 | 54 | 56 |
| 4'10" | 147.5 | 20 | 22 | 23 | 24 | 26 | 27 | 28 | 29 | 31 | 33 | 34 | 35 | 37 | 38 | 40 | 41 | 42 | 44 | 45 | 46 | 48 | 49 | 51 | 52 | 53 | 55 | 56 | 57 |
| 4'9" | 145 | 21 | 22 | 24 | 25 | 27 | 28 | 29 | 31 | 32 | 34 | 35 | 37 | 38 | 39 | 41 | 42 | 44 | 45 | 47 | 48 | 49 | 51 | 52 | 54 | 55 | 57 | 58 | 59 |
| 4'8" | 142.5 | 22 | 23 | 24 | 26 | 28 | 29 | 31 | 32 | 33 | 34 | 36 | 38 | 39 | 41 | 42 | 44 | 45 | 47 | 48 | 50 | 51 | 53 | 54 | 56 | 57 | 59 | 60 | 62 |
| **WEIGHT (kg)** | | 44 | 47 | 50 | 53 | 56 | 59 | 62 | 65 | 68 | 71 | 74 | 77 | 80 | 83 | 86 | 89 | 92 | 95 | 98 | 101 | 104 | 107 | 110 | 113 | 116 | 119 | 122 | 125 |
| **WEIGHT (lbs)** | | 97 | 103 | 110 | 117 | 123 | 130 | 136 | 143 | 150 | 156 | 163 | 169 | 176 | 183 | 189 | 196 | 202 | 209 | 216 | 222 | 229 | 235 | 242 | 249 | 255 | 262 | 268 | 275 |

Using a tape measure, place it around your waist at the level of your belly button. Measure after breathing out (do not hold your breath). Then check the box that contains your measurement (note: this is not the same as the "waist size" on your pants).

**MEN**

| Less than 94 cm or 37 inches | 0 points |
|---|---|
| Between 94-102 cm or 37-40 inches | 4 points |
| Over 102 cm or 40 inches | 6 points |

**WOMEN**

| Less than 80 cm or 31.5 inches | 0 points |
|---|---|
| Between 80-88 cm or 31.5-35 inches | 4 points |
| Over 88 cm or 35 inches | 6 points |

Do you usually do some physical activity such as brisk walking for at least 30 minutes each day? This activity can be done while at work or at home.

| Yes | 0 points |
|---|---|
| No | 1 point |

How often do you eat vegetables or fruits?

| Everyday | 0 points |
|---|---|
| Not everyday | 2 points |

Have you ever been told by a doctor or nurse that you have high blood pressure OR have you ever taken high blood pressure pills?

| Yes | 4 points |
|---|---|
| No or don't know | 0 points |

Have you ever been found to have a high blood sugar either from a blood test, during an illness, or during pregnancy?

| Yes | 14 points |
|-----|-----------|
| No or don't know | 0 points |

Have you ever given birth to a large baby weighing 9 pounds (4.1 kg) or more?

| Yes | 1 points |
|-----|----------|
| No or don't know or not applicable | 0 points |

Have any of your blood relatives ever been diagnosed with diabetes? Check ALL that apply.

| Mother | 2 points |
|--------|----------|
| Father | 2 points |
| Brother/Sisters | 2 points |
| Children | 2 points |
| Other | 0 points |
| No/don't know | 0 points |

What is the highest level of education that you have completed?

| Some high school or less | 5 points |
|--------------------------|----------|
| High school diploma | 1 point |
| Some college or university | 0 points |
| University or college degree | 0 points |

**Appendix L- Canadian Diabetes Risk Assessment Questionnaire (CANRISC) Scoring**

| | | |
|---|---|---|
| 0-32 POINTS LOW TO MODERATE RISK | 1-17% chance of being diagnosed with diabetes over the next 10 years* | The CTFPHC recommends not routinely screening for type 2 diabetes. |
| 33-42 POINTS HIGH RISK | 33% chance of being diagnosed with diabetes over the next 10 years* | The CTFPHC recommends screening every 3-5 years with A1C.† |
| 43+ POINTS VERY HIGH RISK | 50% chance of being diagnosed with diabetes over the next 10 years* | The CTFPHC recommends annual screening with A1C.† |

Add up the points from questions to determine total risk score.

**Appendix M- World Health Organization Quality of Life  (WHO 26-item QOL)**

The following questions ask how you feel about your quality of life, health, or other areas of your life. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

|  | Very Poor | Poor | Neither poor nor good | Good | Very Good |
|---|---|---|---|---|---|
| 1.  How would you rate your quality of life? | 1 | 2 | 3 | 4 | 5 |

|  | Very dissatisfied | Dissatisfied | Neither satisfied nor dissatisfied | Satisfied | Very satisfied |
|---|---|---|---|---|---|
| 2.  How satisfied are you with your health? | 1 | 2 | 3 | 4 | 5 |

The following questions ask about how much you have experienced certain things in the last four weeks.

|  | Not at all | A little | A moderate amount | Very much | An extreme amount |
|---|---|---|---|---|---|
| 3.  To what extent do you feel that physical pain prevents you from doing what you need to do? | 5 | 4 | 3 | 2 | 1 |
| 4.  How much do you need any medical treatment to function in you daily life? | 5 | 4 | 3 | 2 | 1 |

| | | | | | |
|---|---|---|---|---|---|
| 5. How much do you enjoy life? | 1 | 2 | 3 | 4 | 5 |
| 6. To what extent do you feel your life to be meaningful? | 1 | 2 | 3 | 4 | 5 |

| | Not at all | A little | A moderate amount | Very much | Extremely |
|---|---|---|---|---|---|
| 7. How well are you able to concentrate? | 1 | 2 | 3 | 4 | 5 |
| 8. How safe do you feel in your daily life? | 1 | 2 | 3 | 4 | 5 |
| 9. How healthy is your physical environment? | 1 | 2 | 3 | 4 | 5 |

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

| | Not at all | A little | Moderately | Mostly | Completely |
|---|---|---|---|---|---|
| 10. Do you have enough energy for everyday life? | 1 | 2 | 3 | 4 | 5 |
| 11. Are you able to accept bodily appearance? | 1 | 2 | 3 | 4 | 5 |
| 12. Have you enough money to meet your needs? | 1 | 2 | 3 | 4 | 5 |
| 13. How available to | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| you is the information that you need in your day-to-day life? | | | | | |
| 14. To what extent do you have the opportunity for leisure activities? | 1 | 2 | 3 | 4 | 5 |

| | Very poor | Poor | Neither poor nor good | Good | Very good |
|---|---|---|---|---|---|
| 15. How well are you able to get around? | 1 | 2 | 3 | 4 | 5 |

| | Very dissatisfied | Dissatisfied | Neither satisfied nor dissatisfied | Satisfied | Very Satisfied |
|---|---|---|---|---|---|
| 16. How satisfied are you with your sleep? | 1 | 2 | 3 | 4 | 5 |
| 17. How satisfied are you with your ability to perform your daily living activities? | 1 | 2 | 3 | 4 | 5 |
| 18. How satisfied are you with your capacity for work? | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| 19. How satisfied are you with yourself? | 1 | 2 | 3 | 4 | 5 |
| 20. How satisfied are you with your personal relationships? | 1 | 2 | 3 | 4 | 5 |
| 21. How satisfied are you with your sex life? | 1 | 2 | 3 | 4 | 5 |
| 22. How satisfied are you with the support you get from your friends? | 1 | 2 | 3 | 4 | 5 |
| 23. How satisfied are you with the conditions of your living place? | 1 | 2 | 3 | 4 | 5 |
| 24. How satisfied are you with your access to health services? | 1 | 2 | 3 | 4 | 5 |
| 25. How satisfied are you with your transport? | 1 | 2 | 3 | 4 | 5 |

The following question refers to how often you have felt or experienced certain things in the last four weeks.

|  | Never | Seldom | Quite often | Very often | Always |
|---|---|---|---|---|---|
| How often do you have negative feelings such as blue mood, despair, anxiety, depression? | 5 | 4 | 3 | 2 | 1 |

**Appendix N- World Health Organization Quality of Life (WHO 26-item QOL) Scoring**

| DOMAIN 1 Raw Score | Transformed scores 4-20 | Transformed scores 0-100 |
|---|---|---|
| 7 | 4 | 0 |
| 8 | 5 | 6 |
| 9 | 5 | 6 |
| 10 | 6 | 13 |
| 11 | 6 | 13 |
| 12 | 7 | 19 |
| 13 | 7 | 19 |
| 14 | 8 | 25 |
| 15 | 9 | 31 |
| 16 | 9 | 31 |
| 17 | 10 | 38 |
| 18 | 10 | 38 |
| 19 | 11 | 44 |
| 20 | 11 | 44 |
| 21 | 12 | 50 |
| 22 | 13 | 56 |
| 23 | 13 | 56 |
| 24 | 14 | 63 |
| 25 | 14 | 63 |
| 26 | 15 | 69 |
| 27 | 15 | 69 |
| 28 | 16 | 75 |
| 29 | 17 | 81 |
| 30 | 17 | 81 |
| 31 | 18 | 88 |
| 32 | 18 | 88 |
| 33 | 19 | 94 |
| 34 | 19 | 94 |
| 35 | 20 | 100 |

| DOMAIN 2 Raw score | Transformed scores 4-20 | Transformed scores 0-100 |
|---|---|---|
| 6 | 4 | 0 |
| 7 | 5 | 6 |
| 8 | 5 | 6 |
| 9 | 6 | 13 |
| 10 | 7 | 19 |
| 11 | 7 | 19 |
| 12 | 8 | 25 |
| 13 | 9 | 31 |
| 14 | 9 | 31 |
| 15 | 10 | 38 |
| 16 | 11 | 44 |
| 17 | 11 | 44 |
| 18 | 12 | 50 |
| 19 | 13 | 56 |
| 20 | 13 | 56 |
| 21 | 14 | 63 |
| 22 | 15 | 69 |
| 23 | 15 | 69 |
| 24 | 16 | 75 |
| 25 | 17 | 81 |
| 26 | 17 | 81 |
| 27 | 18 | 88 |
| 28 | 19 | 94 |
| 29 | 19 | 94 |
| 30 | 20 | 100 |

| DOMAIN 3 Raw score | Transformed scores 4-20 | Transformed scores 0-100 |
|---|---|---|
| 3 | 4 | 0 |
| 4 | 5 | 6 |
| 5 | 7 | 19 |
| 6 | 8 | 25 |
| 7 | 9 | 31 |
| 8 | 11 | 44 |
| 9 | 12 | 50 |
| 10 | 13 | 56 |
| 11 | 15 | 69 |
| 12 | 16 | 75 |
| 13 | 17 | 81 |
| 14 | 19 | 94 |
| 15 | 20 | 100 |

| DOMAIN 4 Raw score | Transformed scores 4-20 | Transformed scores 0-100 |
|---|---|---|
| 8 | 4 | 0 |
| 9 | 5 | 6 |
| 10 | 5 | 6 |
| 11 | 6 | 13 |
| 12 | 6 | 13 |
| 13 | 7 | 19 |
| 14 | 7 | 19 |
| 15 | 8 | 25 |
| 16 | 8 | 25 |
| 17 | 9 | 31 |
| 18 | 9 | 31 |
| 19 | 10 | 38 |
| 20 | 10 | 38 |
| 21 | 11 | 44 |
| 22 | 11 | 44 |
| 23 | 12 | 50 |
| 24 | 12 | 50 |
| 25 | 13 | 56 |
| 26 | 13 | 56 |
| 27 | 14 | 63 |
| 28 | 14 | 63 |
| 29 | 15 | 69 |
| 30 | 15 | 69 |
| 31 | 16 | 75 |
| 32 | 16 | 75 |
| 33 | 17 | 81 |
| 34 | 17 | 81 |
| 35 | 18 | 88 |
| 36 | 18 | 88 |
| 37 | 19 | 94 |
| 38 | 19 | 94 |
| 39 | 20 | 100 |
| 40 | 20 | 100 |

| | Equations for computing domain scores | Raw score | Transformed scores* | |
|---|---|---|---|---|
| | | | 4-20 | 0-100 |
| **Domain 1** | (6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18 | a. = | b: | c: |
| **Domain 2** | Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26) | a. = | b: | c: |
| **Domain 3** | Q20 + Q21 + Q22 | a. = | b: | c: |
| **Domain 4** | Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25 | a. = | b: | c: |

Raw domain scores for the WHOQOL should be converted to a 4-20 score based on guidelines.  The higher domain scores denote higher QOL. The mean score of items within each domain is used to calculate the domain score. After computed the scores, they transformed linearly to a 0-100-scale.

**Appendix O-Data Analysis Plan**

1.  What is the diabetes related knowledge of the adult child who is of immigrant South Asian descent?
    Methods:
    - T- test / Mann-Witney U test comparing total male and female total scores
    - Identify if there are any scoring differences between male and females within the different domains of the questionnaire
    Rationale:
    - Literature demonstrated that females take on a greater percentage and different caregiving responsibilities compared to males (Katbamna et al., (2004). This analysis can highlight the impact of having different caregiving responsibilities and diabetes related knowledge?
    - This question can provide greater insight into their knowledge, which can impact the care they provide their parents, their risk perception of developing diabetes and their quality of life.

2.  What is the quality of life of the males compared to females?
    Methods:
    - T- test/ Mann-Witney U test comparing total male and female total scores
    Rationale:
    - As caregivers males and females typically engage in different caregiving tasks (Katbamna et al., 2004). Their level of engagement and the tasks they complete as part of their caregiving responsibilities can impact their quality of life differently.
    - Moreover, it allows us to determine if there is a positive aspect of caregiving.

3.  What is the risk perception of the males compared to females in developing diabetes?
    Methods:
    - The Chi-Square test (comparing male /female versus risk perception level)
    Rationale:
    - Previous studies have illustrated that familial history of a chronic illness does not change does not change one's perceived ability of developing the disease (Acheson et al., 2010)
    - Due to the fact males and females engage in different caregiving tasks their perception of developing diabetes may differ (Katbamna et al., 2004).

4.  What is the 'actual risk' of developing diabetes of males compared to females?

    Methods:
    - The Chi-Square test Risk category (Low, high, and very high risk) versus gender (Male and female)
    - T- test / Mann-Witney U test comparing total male and female total CANRISK scores

5.  Is there a relationship between knowledge of T2DM and perceived risk for developing T2DM?
    Methods:
    - Regression
    Rationale:
    - Knowledge of a chronic illness' risk factors and ones perceived risk for chronic illness have shown to be associated with health promoting behaviours (Farmer, Levy & Turner, 1999; Kan & Tsai, 2004).
    - Moreover, previous studies have demonstrated that having knowledge about risk factors of diabetes can lead to a better perception of personal risk for developing diabetes (Chilton, Hu & Wallace, 2006; Farmer, Levy & Turner, 1999). However, to date the relationship between knowledge and risk perception of developing diabetes has not been examined within the SAP.

6.  Is actual risk of developing diabetes associated with risk perception of developing diabetes?
    Methods:
    - Regression
    Rationale:
    - Literature highlights how perceived risk can act as a form of protective behaviour (Gerrard et al., 1996; Graham et al., 2006). When ones' risk perception and actual risk of developing a chronic condition are incongruent it is unlikely that they will engage in health promoting behaviours (Graham et al., 2006). Due to the fact that there has been a considerable amount time since these studies have been conducted and perceptions of risk vary among different populations, it is vital to explore the relationship between risk perception and actual risk of developing diabetes amongst the SAP.

7.  Does their diabetes knowledge impact their adoption of exercise habits?
    Methods:
    - High knowledge vs. engaging in high risk behaviours (i.e. smoking/ diet/ alcohol)
    - A chi-square test level of knowledge (high/ low vs. engaging in high risk behaviours)

    Rationale:
    - Literature has shown that knowledge and education can improve glycemic index and self-management behaviours amongst adults with T2DM (Atak, Gurkan, & Kose, 2008, Norris et al., 2001). However, there is a paucity of research the examining diabetes knowledge amongst high-risk populations, specifically South Asians.

8.  Does their risk perception and diabetes knowledge impact their quality of life?
    Methods:
    - Multiple regression

    Rationale:
    - Diabetes knowledge has shown to impact QoL of those with T2DM (Kueh et al., 2015;). However, to date no study has examined this phenomenon amongst caregivers from the SAP who are at high risk of developing diabetes. QoL is multifaceted, and can significantly be impacted by providing care for family members with chronic illnesses, knowledge and ones risk perception

**Appendix P- Hamilton Integrated Research Ethics Board Approval**

**HiREB**

Hamilton Integrated Research Ethics Board

**Amendment Approval**

March 10 2017

**HiREB Project #:** 2017-2884,

**Local Principal Investigator:** Dr. Diana Sherifali

**Project Submission Title:** EXPLORING DIABETES KNOWLEDGE, RISK PERCEPTION OF DEVELOPING DIABETES AND QUALITY OF LIFE AMONGST SECOND GENERATIONAL SOUTH ASIAN YOUNG ADULTS CARING FOR PARENTS WITH TYPE 2 DIABETES MELLITUS (T2DM).

Document(s) Amended with version # and date:

| Document Name | Document Date | Document Version |
| --- | --- | --- |
| Appendix A_1_final edits_clean | Mar-07-2017 | 1 |
| HiREB_CONSENT_clean | Mar-07-2017 | 1 |
| protocol summary+final edits_cleanversion | Mar-07-2017 | 1 |

We have completed our review of your amendment and are pleased to issue our final approval. You may now continue your study as amended.

Kristina Trim, PhD, RSW
Chair, HiREB Student Research Committee
MDCL 3308, McMaster University

The Hamilton Integrated Research Ethics Board (HiREB) represents the institutions of Hamilton Health Sciences, St. Joseph's Healthcare Hamilton, and the Faculty of Health Sciences at McMaster University and operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations; For studies conducted at St. Joseph's Healthcare Hamilton, HiREB complies with the health ethics guide of the Catholic Alliance of Canada

**Appendix P1- Letter of consent**

**Study title:** An exploration of diabetes knowledge, risk perception and quality of life amongst second generational South Asian young adults caring for parents with Type 2 Diabetes Mellitus (T2DM).

**Principal Investigator:**
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**Introduction:**
Before agreeing to take part in this research study, it is important that you read the information in this research consent form. It includes details we think you need to know in order to decide if you wish to take part in the study. If you have any questions, ask a study staff.  You should not provide your consent to this study until you are sure you understand the information. All research is voluntary.

**Purpose of the Study:**
You are invited to complete a questionnaire to help us understand the diabetes knowledge, risk perception of developing diabetes and quality of life of Young South Asian Caregivers (YSAC). This research study is a partial fulfillment of the requirements for the Degree Master of Science in Nursing.

**To be eligible to complete this survey the following criteria must be met:**
You must be between the ages 18-29; your parent(s) must have been diagnosed with type 2 diabetes mellitus (for at least 1 year)
Your parent(s) must have immigrated to Canada
You are of South Asian descent (i.e. Bangladesh, India, Pakistan, Sri Lanka, Bhutan, Nepal, or Maldives)
You must speak English. You must live in Canada
You must not have diabetes You must provide unpaid or arrange for paid/unpaid help to assist with your parents' diabetes (i.e. driving to appointments, checking blood sugars, promoting exercise, helping adhere to a diet etc.)

**Procedures involved in the Research:**
If you agree to be in this study, you will be asked to do the following:
1. Complete questions regarding Demographics and Assessment of current behaviours. The time required to complete will be approximately 2-5 minutes.
2. Complete a survey, the **24-item Diabetes Knowledge Questionnaire (DKQ)** to measure diabetes related knowledge. This will take approximately 5 minutes.
3. Complete the **Risk Perception of Developing Diabetes Questionnaire (RPS-DD)** to evaluate one's risk perception of developing diabetes. The time required to complete this survey will be approximately 5 minutes.
4. Complete the **World Health Organization Quality of Life (WHO 26-item QOL)** questionnaire. The time required to complete this survey will be approximately 10 minutes.
5. Complete the **Canadian Diabetes Risk Assessment Questionnaire (CANRISC)**. The time required to complete this survey will be approximately 2-5 minutes.

Due to the nature of the study, it is imperative that specific questions are answered. As such, you will be required to answer these questions in order to complete the study.

**Potential Harms, Risks or Discomforts:**
There is no potential for physical harm during your participation in this study. Your surveys and questionnaires will be reviewed in this study, and extensive measures will be undertaken to protect your privacy. Also, all results will be anonymous and kept confidential.

**Reimbursement**
In appreciation of the time you have given to this study, you can enter your name in one of 3 draws to win a 50$ gift card. Your odds of winning one of the prizes are based on the number of individuals who participate in the study. Information collected to draw for the prizes will not be linked to the study data in any way, and this identifying information will be stored separately, and then destroyed after the prizes have been provided.

**Confidentiality**
All study staff are committed to respecting your privacy. No other persons will have access to questionnaire information or identifying information without your consent, unless required by law. All information collected in this study shall be kept strictly confidential and any information that could identify you will not be published. All information that identifies you, both paper copy and electronic information, will be kept confidential and stored and locked in a secure place that only the study staff will be able to access. The information obtained from the participant will be kept in a password protected computer file. Electronic files will be stored securely on institutional networks or securely on any portable electronic devices. No information identifying you will be allowed off site in any form.

**Participation:**
Your participation in this study is voluntary. Furthermore, upon your decision to participate you may withdraw from the study at any time. Discontinuation of the study will be of no consequence. *Once* you have submitted your responses for this anonymous survey: your answers will be put into a database and will not be identifiable to you. This means that once you have submitted your survey, your responses cannot be withdrawn from the study because we will not be able to identify which responses are yours.

**Information about the Study Results:**
We expect to have this study completed by approximately September 2017. If you would like a brief summary of the results, please let me know how you would like it sent to you.

**Questions about the Study:**
If you have questions or need more information about the study itself, please contact me at

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

> McMaster Research Ethics Secretariat
> Telephone: (905) 525-9140 ext. 23142
> C/o Research Office for Administrative Development and Support
> E-mail: ethicsoffice@mcmaster.ca

<div align="center">

**CONSENT**
</div>

**By clicking next, I:**
- Have read the information presented in the information letter about a study being conducted by Dr. Diana Sherifali and Angela Koipuram of McMaster University.
- Understand the potential harms and benefits (if any) of participating in this research study
- Understand that investigators may analysis and publish the outcomes of the study academically
- Understand that I will receive a signed copy of this consent form
- Confirm that I have read the above information regarding the study and agree to participate in this study

**Appendix P2-Thank you and Explanation of Study's eligibility criteria**

Thank you for your interest and participation in this study. Based on your response you did not meet the study's eligibility criteria. To be eligible for the study we ask that participants meet the following criteria.

- Participants must be between the ages 18-29
- Participant's parents must have immigrated to Canada
- Participants must be of South Asian descent
- Participants do not have diabetes
- One or both of participant's parents have type 2 diabetes for at least 1year
- Participants must help provide my parents or arrange for paid help to help manage my parent's diabetes (i.e. driving to appointments, checking blood sugars, promoting exercise, helping adhere to a diabetic diet etc.)

If you have any questions or concerns feel free to contact southasianstudy@gmail.com

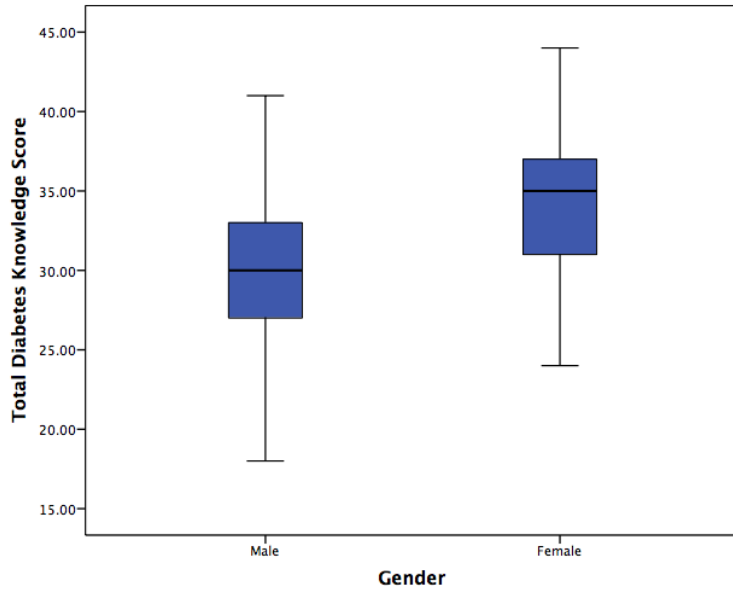**Appendix Q- Findings from Non-parametric test**



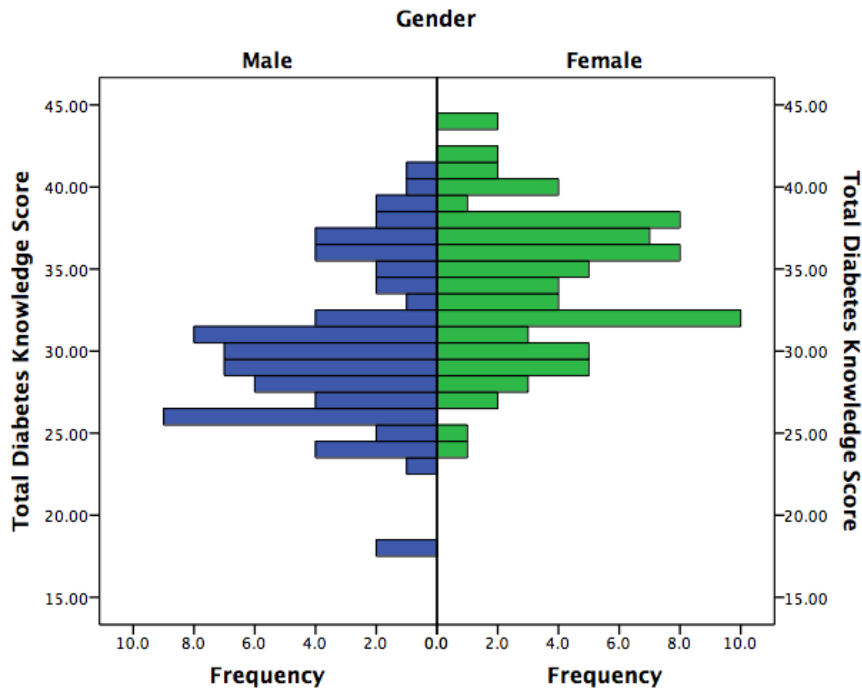*Figure 1.* Boxplot of Diabetes Knowledge scores of male and female participants.



*Figure 2.* Population pyramid of Diabetes Knowledge scores of male and female participants.

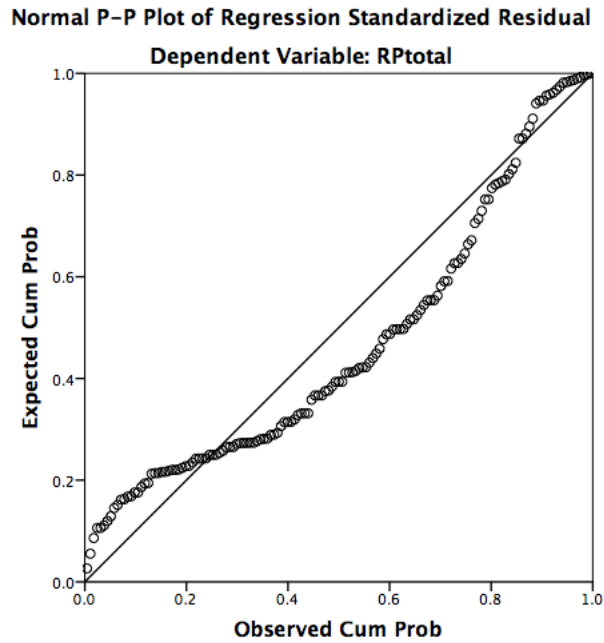**Appendix R-Linear Regression Results**



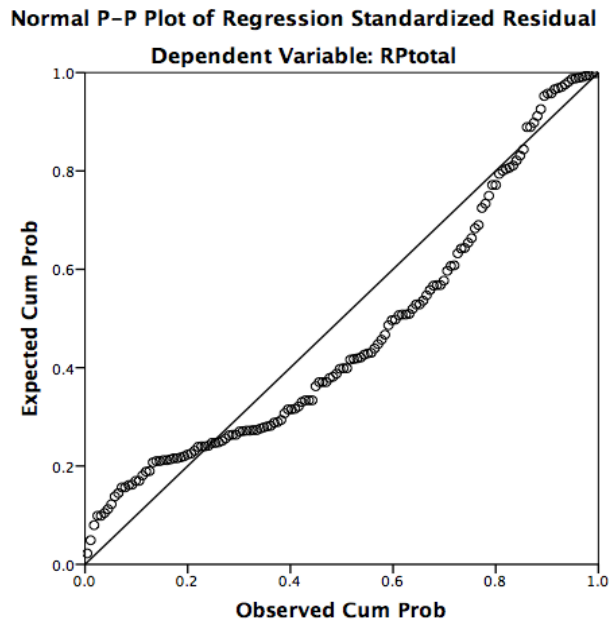*Figure 1.* P-P plot illustrating normality of the residuals when the outlier was included.



*Figure 2.* P-P plot illustrating normality of the residuals when the outlier was included.