

Diabetes knowledge, risk perception, and quality of life among South Asian caregivers in young adulthood

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ABSTRACT

Introduction Persons of South Asian descent have a higher prevalence of type 2 diabetes mellitus (T2DM). The management of T2DM in the South Asian community has required the support of adult children, potentially impacting the quality of life, diabetes-related knowledge, and risk perception among these caregivers.

Research design and methods To investigate diabetes-related knowledge, quality of life, risk perception, and actual risk of developing diabetes among South Asian young adults whose parents are living with T2DM. A cross-sectional study was conducted (n=150). An online survey was administered. Data were analyzed with descriptive and inferential statistics.

Results There was a statistically significant difference in diabetes-related knowledge between males and females ($p<0.001$). Males (in comparison to females) had a lower risk perception of developing diabetes ($p=0.06$). Further, risk perception and diabetes-related knowledge were positively associated with caregiver's physical health ($p=0.002$).

Conclusion Findings highlight the importance of providing gender-specific and culturally tailored diabetes educational interventions.

BACKGROUND

Type 2 diabetes mellitus (T2DM) is a chronic illness, which may have debilitating complications impacting millions of persons globally.¹ Evidence suggests that T2DM disproportionately affects persons of South Asian descent, including those from Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka.^{2–4} In fact, South Asians are three to five times more likely to develop T2DM than the general population due to genetic predisposition, anthropometry (eg, having greater central obesity), and sedentary lifestyle.^{5–7} The majority of the South Asian population (SAP) resides in the province of Ontario and is one of the fastest growing immigrant populations in Canada, comprising 25.1% of Canada's visible minority.^{4 6 7}

To manage diabetes, people are required to adhere to a myriad of treatment recommendations, including dietary modifications, adherence to medication, routine physical

Significance of this study

What is already known about this subject?

- ▶ Individuals of South Asian background (descent) are at great risk of developing type 2 diabetes.

What are the new findings?

- ▶ Although young South Asian female caregivers reported higher diabetes knowledge and risk perception of developing diabetes, male participants had lower diabetes knowledge and were actually at greater risk for developing diabetes.

How might these results change the focus of research or clinical practice?

- ▶ The findings provide preliminary insight into young South Asian caregivers and highlight opportunities for further education and support.

activity or exercise, and monitoring of blood glucose levels.⁸ Social supports such as family members may promote medication adherence and minimize the stress of managing diabetes.⁸ South Asian households are typically multigenerational, where grandparents or older adults live in the same household as their children and grandchildren. This may result in an increased dependency on adult children for the provision of care to their parent within the same household.⁹

Empirical evidence has shown that the caregiving responsibilities for persons living with chronic diseases such as diabetes are often assumed by young adults between 18 and 25 years of age.¹⁰ In addition to age, culture, and gender also influence caregiving.^{11 12} For example, South Asian countries have strong patriarchal norms, suggesting a greater reliance on women to take on caregiver responsibilities within households.^{12 13} As such, immigrant South Asian women are often faced with the challenges of balancing cultural expectations with the demands of their work, resulting in an increase in caregiver burden relative to their male counterparts.¹² Although the family caregiving



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literature has significantly expanded over the years, there is limited empirical evidence specific to young adult caregivers from diverse racial and/or ethnic backgrounds,^{10 11} representing an understudied population. Further exacerbating the gap in evidence is the dearth of research pertaining to young adult caregivers of adults (ie, parents) living with diabetes; the majority of existing evidence focuses on caregiving for older adults living with dementia, Alzheimer's disease, and/or mental health illnesses. The focus on caregiving for older adults may not be applicable to the younger adult caregiver of parents with T2DM, as adults are generally diagnosed with T2DM at a younger age and live with T2DM for a longer period of time,¹⁴ require ongoing self-management support for behavior modification to increase physical activity and adhere to nutritional and medication guidance, while navigating family dynamics and culture.^{5-7 9}

There is also a paucity of research examining the role of young adult South Asians caregivers of parent(s) living with T2DM, and the impact that caregiving has on their own health.^{9 10} Examining young adult caregivers who may be at greater risk of developing T2DM and providing support to their parent(s) with T2DM may inform health promotion initiatives within this population, improve quality of life (QoL) as well as inform targeted diabetes screening and prevention programs. Therefore, the purpose of this study was to explore diabetes-related knowledge, risk perception, actual estimated diabetes risk, and QoL among young adult South Asian caregivers.

METHODS

Design

A cross-sectional study design was used to explore young adult South Asian caregivers' diabetes-related knowledge, QoL, and risk perception of developing diabetes compared with their actual risk of developing diabetes. An online survey was constructed and administered, using the Tailored Design Method.¹⁵

Sample

Participants were eligible to take part in the study if they met the following inclusion criteria: (1) adults between 18 and 29 years of age and whose parent(s) have been diagnosed with T2DM for at least 1 year; (2) their parent(s) must have immigrated to Canada; (3) self-identified as South Asian (defined as persons from Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka;^{2 3} (4) self-reported as able to speak and read English; (5) residing in Canada; and (6) providing unpaid or arranged for paid or unpaid help to manage their parents' diabetes (eg, driving to appointments, checking blood glucose, promoting exercise, helping adhere to a healthy lifestyle).¹⁶ Participants were excluded from the study if they had diabetes themselves, as these individuals were no longer at risk for T2DM.

The sample size calculation for conducting t-tests to compare diabetes knowledge between males and females

(the primary outcome) was done. It was determined that a sample size of 63 males and 63 females (a total of 126 participants) was necessary to conduct a t-test according to an alpha level of 0.05, power of 0.80, and a medium effect size of $R=0.5$ (17, 18). A sample size calculation was also completed for multiple regression (to examine relationships) using the following formula: $n>50+8m$ (where m is the number of independent variables).¹⁷ Therefore, accounting for two independent variables, 132 participants were needed, with 66 male and 66 female participants. After incorporating oversampling by 10% for any incomplete data, $n=146$ was obtained, where approximately 73 male and 73 female participants were required.¹⁸ To have enough power to detect differences and to enhance the rigor of the study, we used the larger sample size of 73 male and 73 female participants.

Participant recruitment

To attain a sample of the target population that were willing to participate and easily accessible, a convenience sampling method was employed. Evidence suggests that the recruitment of ethnic minorities including those of South Asian descent for research can be challenging.¹⁹ As such, the researchers employed several modalities to enhance participant recruitment including posting advertisements at community centers and religious organizations (eg, churches and temples), emailing members of different cultural groups (eg, local youth groups), and the creation of social media profiles and posts (ie, Facebook, Instagram and Twitter). For recommendations of online surveys, the researchers contacted members of the South Asian social groups a total of four times over the course of 6 weeks.¹⁵ The emails outlined the purpose of the study, how data would be used, 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 on completion of the survey. The online survey was made available using LimeSurvey, a Canadian open survey application. Completion of the online survey took approximately 20–30 min and implied informed consent.

Data collection

Participant characteristics

The following participant characteristics were collected: (1) age; (2) gender; (3) self-identified ethnic background; (4) religion; (5) level of education; (6) body mass index (BMI) classification calculated from self-reported height and weight; (7) employment status; (8) whether participant is cohabitating with parent(s) living with diabetes; and (9) average hours spent (per week) caregiving and various caregiving support completed (ie, insulin administration, meal preparation and driving parent to medical appointments, and so on).

Instruments

The main study variables were diabetes-related knowledge, risk perception, actual risk for developing diabetes,

and QoL. Four instruments were used to measure these variables and are described below.

The 24-item Diabetes Knowledge Questionnaire (DKQ)

The DKQ was designed to measure diabetes-related knowledge among populations at high risk for developing diabetes. This tool has been used to evaluate diabetes-related knowledge of caregivers providing care to family member living with diabetes and for persons living with diabetes.²⁰ The DKQ-24 has previously been used in ethnic minority populations including Latino population and SAP.^{20 21} Each correct answer was given two points, an answer of “I don’t know” was scaled at one point and an incorrect answer equated to zero points. The 24-item DKQ has demonstrated good construct validity and reliability (Cronbach’s alpha coefficient: 0.78).²¹

The Risk Perception of Developing Diabetes Survey (RP-DD)

The RP-DD has 33 questions and evaluates personal control (4 questions), worry (2 questions), optimistic bias (2 questions), personal disease risk (related to participant’s perceived development of specific disease such as heart disease, cancer, and asthma) (15 questions), and comparative environmental risk (related to related to participant’s perceived environmental risk such as violent crimes, air pollutions, and household chemicals) (9 questions).²² The raw scores from each question were converted into transformed scores, with higher scores reflecting perceived higher risk. To minimize any redundancies in the questions asked, the diabetes risk knowledge portion 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 questions were not included in the composite score calculation (E. Walker, personal communication, 22 December 2016).

Canadian Diabetes Risk Assessment Questionnaire (CANRISC)

The CANRISC was used to evaluate actual risk for developing diabetes based on risk factors.²³ The CANRISC was based on the original Finnish Diabetes Risk Score (FIND-RISC). The CANRISC questionnaire consist of multiple-choice questions about (1) ethnicity; (2) health behaviors such as the consumption of fruits and vegetables, participation in physical activity for 30 min per day; and (3) body weight, specifically BMI and waist size. The response to each question was attributed to a specific number of points, with higher scores representing greater risk for the development of diabetes.

The World Health Organization Quality of Life (WHOQOL-Brief) instrument

The WHOQOL-Brief was used to measure QoL of young South Asian adults. The WHOQOL-Brief consists of four domains: physical health, psychological health, social relationships, and environment.²⁴ The questionnaire is anchored on a five-point Likert scale with response options ranging from one to five, with higher values representing better QoL. The WHOQOL-BREF has been

used among South Asians persons and in 23 different countries. Further, the instrument has shown to have cross-cultural competency ensuring congruency and consistency among the SAP (Cronbach’s $\alpha > 0.70$).^{25 26}

Data analyses

All statistical analysis was completed using IBM Statistical Package for the Social Sciences (SPSS) V.20.0 Statistical Software. Descriptive statistics were conducted to describe the study sample. Inferential statistics were conducted to examine the outcomes of interest. More specifically: (1) an unpaired t-test was employed to compare gender differences of diabetes-related knowledge; (2) parametric (unpaired t-test) and non-parametric tests (Mann-Whitney U) were employed to compare QoL scores and determine actual risk of diabetes between males and females; (3) χ^2 tests were performed to compare gender differences regarding perceived risk in developing diabetes as well as diabetes-related knowledge and the engagement in high-risk behaviors; (4) bivariate linear regression analysis was performed to examine the relationship between diabetes-related knowledge and perceived risk for developing diabetes as well as actual risk of developing diabetes and one’s risk perception of developing diabetes; and (5) a multivariate regression analysis was conducted to examine how risk perception and diabetes-related knowledge influence young caregiver’s QoL.

RESULTS

Participant characteristics

A total of 150 participants aged 18–29 years (77 females, 73 males) completed the survey; however, only 149 surveys (76 females, 73 males) were fully completed, totaling 149 participants comprising the study sample. 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, with 18.2% females and 20.5% males reported being of Sri Lankan descent. A total of 79.2% of females and 64.4% of males reported to living in the same household as their parent(s) living with T2DM (table 1).

When examining the different caregiving tasks completed by both male and female caregivers, a gender-based division was noted (table 2). The results indicated that 32.5% of females and 11% of males took part in administering insulin for parents ($p < 0.05$). Further, a greater proportion of females (55.3%), relative to males (17.8%), manage their parents’ diabetes-related complications (ie, wound care, low blood sugar, kidney disease, loss of limb, and nerve damage) ($p < 0.001$). Female caregivers prepared the majority of meals for their parents(s) more often than male caregivers (30.1%) ($p < 0.001$). Conversely, managing diabetes-associated finances was primarily performed by male caregivers (49.30%)

Table 1 Characteristics of study participants (n=150)

Characteristic	Characteristics of participants N (%)		P value*
	Females	Males	
Age (years)			
18–20	11 (14.5)	9 (12.3)	0.28
21–23	16 (21.1)	16 (21.9)	
24–26	29 (38.2)	19 (26)	
27–29	20 (26.3)	29 (39.7)	
Background			
India	52 (68.4)	47 (64.4)	0.75
Pakistan	8 (10.5)	5 (6.8)	
Sri Lanka	13 (17.1)	15 (20.5)	
Nepal	2 (2.6)	2 (2.7)	
Bangladesh	1 (1.3)	3 (4.1)	
Other	–	1 (1.40)	
Education			
Some high school or less	12 (15.8)	19 (26)	0.2820
Some college or university	26 (34.2)	24 (32.9)	
University or college degree	38 (50)	30 (41.1)	
Religion			
Buddhist	1 (1.3)	5 (6.8)	0.70
Christian	27 (35.5)	24 (32.9)	
Hindu	27 (35.5)	25 (34.2)	
Muslim	9 (11.8)	7 (9.6)	
Sikh	9 (11.8)	8 (11)	
Other	3 (3.9)	3 (4.1)	
Live in the same household as parent(s) with diabetes			
Yes	60 (78.9)	47 (64.4)	0.05
No	15 (19.7)	25 (34.2)	
Employment status			
Full-time	29 (38.2)	35 (47.9)	0.14
Part-time	36 (47.4)	29 (39.7)	
Unemployed	8.00 (10.5)	3.00 (4.1)	
Other	–	2.00 (2.7)	
Hours spent on caregiving in an average week			
Less than 1 hour	14 (18.2)	9 (12.3)	0.23
1–5 hours	40 (51.9)	49 (67.1)	
6–10 hours	20 (26)	15 (20.5)	
11–15 hours	1 (1.3)	–	
16–25 hours	1 (1.3)	–	
Body mass index classification (kg/m ²)			
Less than 25	38 (5)	20 (27.4)	0.21
25–29	31 (40.8)	40 (54.8)	
30–34	6 (7.9)	12 (16.)	
35 and over	1 (1.3)	1 (1.4)	

*The p values were obtained using the χ^2 test or Fisher's exact test.

Table 2 Association between gender and caregiving tasks (n=150)

Caregiving tasks	Participants (%)		P value
	Female	Males	
Monitoring your parent's blood sugar levels	52 (68.4)	41 (56.2)	0.12
Managing your parent's medications	47 (61)	41 (56.2)	0.48
Help or administer insulin for your parent(s)	25 (32.5)	8.00 (11)	0.05
Picking up medications	62 (81.6)	64 (87.7)	0.30
Ensuring parent(s) with diabetes get(s) some exercise	47 (61.8)	56 (76.7)	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 (55.3)	13 (17.8)	0.001
Drive your parent(s) to their diabetes appointments	50 (64.9)	62 (84.9)	0.001
Involved in grocery shopping for parent(s)	61 (80.3)	49 (67.1)	0.07
Participating in meal preparation for your parent(s)	55 (72.4)	22 (30.1)	0.001
Managing finances associated with diabetes	7 (9.2)	36 (49.3)	0.001–
Other	74 (97.4)	72 (98.6)	

compared with female caregivers (9.20%) ($p<0.001$). Finally, driving one's parent(s) to diabetes appointments was performed by male caregivers (84.9%) compared with female caregivers (64.9%) ($p<0.05$).

Diabetes-related knowledge, risk perception, actual risk, and quality of life

Males had statistically significantly less diabetes-related knowledge (respectively, males— $M=30.16$, $SD=4.87$ and females— $M=34.31$, $SD=4.41$; $p<0.001$, 95% CI -5.64 to 2.65). However, there was no statistically significant difference between males and females in QoL. Specific to participants' risk-perception of developing diabetes, it was found that 20.5% ($n=73$) of male and 34.2% ($n=76$) of females had a high-risk perception of developing diabetes. Interestingly, although females had a higher-risk perception of developing diabetes, male participants were actually at greater risk for developing diabetes (male— $M=27.68$, $SD=4.87$; female— $M=20.05$, $SD=6.93$; $p<0.001$).

Specific to the relationship between diabetes-related knowledge and perceived risk for developing T2DM, there was no relationship found ($F(1,146)=2.52$, $p=0.12$). Similarly, there was no association found between actual risk of developing diabetes and risk perception of developing diabetes ($F(1,147)=0.687$, $p=0.41$). Additionally, there was no association found between young adult South Asian's diabetes-related knowledge and exercising habits ($\chi^2(1)=3.00$, $p=0.08$). Contrarily, among young adult South Asian caregivers, risk perception score had a negative association over physical health, indicating that for every unit that the risk perception score increased, physical health scores decreased by 4.03 units. Further, multiple regression analyses revealed statistically significant associations between caregiver's risk perception, diabetes-related knowledge, and physical health. More specifically, there was a 2.2% variation in caregiver's

QoL (physical health) scores that may be explained by diabetes-related knowledge and risk perception.

DISCUSSION

Given the paucity of literature examining young adult South Asian caregivers, the findings from this study provide preliminary insight and perspective of diabetes-related knowledge, risk perception, actual risk, and QoL in young South Asian adults. First, this study highlighted differences between male and female South Asian caregivers and their knowledge related to day-to-day diabetes management. Although there was a statistically significant difference of diabetes-related knowledge ($p<0.001$), it is important to note that 18.2% of females and 35.6% of males in this study believed that diabetes could be cured, reflecting the incorrect belief that once one's blood glucose levels are controlled then diabetes is cured.²⁷ The gender-related findings pertaining to diabetes-related knowledge is in alignment with a cross-sectional study conducted by Dos Santos *et al*²⁸ which found that women had greater knowledge regarding diabetes foot care and diabetes associated complications (eg, blindness, impaired wound healing and male sexual dysfunction) and obtained better knowledge scores relative to males.²⁸

Gender differences were also noted on task-related caregiving between females and males although the same amount of time was noted. The majority of female caregivers took part in tasks including meal preparation, being involved in grocery shopping for their parent(s), and administering insulin and being responsible for the management of diabetes complications. In contrast, male caregivers primarily dealt with tasks such as driving their parent(s) to their diabetes appointments and managing finances associated with diabetes. The differences in caregiver tasks may be related to the differences

in diabetes-related knowledge. For example, the type of tasks female caregivers took part in often required more knowledge of the disease process and/or treatment. Although this study noted gender differences in diabetes-related knowledge and overall caregiving descriptively, this was not further explored due to limited participant data to explain gender differences, such as socioeconomic data (eg, type of education, income, housing, postal code/address, and occupation).^{28–30}

An interesting finding in this study is that overall QoL scores were lower in all domains for both male and female caregivers relative to the established norms for each domain of the WHO-BREF.³¹ This finding is consistent to that of the literature. For example, Anaforoğlu *et al*³² noted that caregivers of patients living with diabetes experienced depression and their social function was negatively impacted.³²

There was also no association found between gender and risk perception of developing diabetes in this study. This finding may be clinically meaningful because changes to health perception may act as a catalyst to uptake positive health behaviors. Empirical evidence has shown that females tend to perceive themselves to be more at risk of developing diabetes and other chronic illness (eg, cardiovascular disease and cancer) relative to males.³³ This finding is consistent with our present study as it was found that more female (32.4%) caregivers perceived themselves to be at high risk of developing diabetes relative to males (20.5%). Further, it was found that male caregivers (26%) were more likely than female caregivers (3.9%) to engage in risky health behaviors such as tobacco usage. This is particularly noteworthy considering that in 2013, with 14 million more males diagnosed with diabetes than females worldwide.^{34 35} A potential explanation to the low-risk perception is the optimistic bias whereby this population of young caregivers' underestimate or have misconceptions regarding their risks of developing T2DM relative to their peers.³⁶ Another explanation may be due to the young age of the caregivers (18–29 years) and that they may not be concerned about the development of diabetes. The lack of concern may have detrimental health consequences in the future because young adults are more prone to engage in 'risky-health behaviors' (ie, drinking, sedentary lifestyle, and smoking).³⁷

Implications

The findings from this study have several noteworthy implications for clinical practice and research. Specific to clinical practice, findings from the present study highlight the importance for the following strategies/approaches. First is for healthcare providers to aim to attain an understanding of the culture, family dynamic and determine who is the caregiver of the respective patient, fostering a patient centered care approach, and building a rapport founded on trust and respect. Second is the provision of culturally tailored and gender-specific education in young South Asians caregivers. Tailoring diabetes educational

interventions (particularly related to risk-perception) to the gender of caregivers may help the respective caregivers be more adept at helping manage their parent's diabetes as well as understand their own personal risk for developing diabetes and important lifestyle modifications (ie, smoking cessation, physical activity, improving dietary habits) that may be implemented. Through such interventions, this may dampen some of the effects of optimistic bias that they may have on their own risk perception of developing diabetes. Third, because of the increase in prevalence rates of T2DM and associated complications seen among the SAP, it may be valuable for training initiatives offered to healthcare providers on how to deliver culturally tailored diabetes-related education and "communicating cross-culturally."¹¹ Through culturally tailored education and communication, this may improve the delivery and quality of patient care and meet the unique needs of this young adult caregiver population. Finally, because of the inaccurate risk perceptions of T2DM and inadequate knowledge regarding the cause of diabetes, it may be beneficial to formulate diabetes screening tools and screening procedures for this young population at a much a younger age for health promotion and prevention purposes.

Specific to research, additional research is warranted focusing on: (1) the intersection of gender, socioeconomic status with diabetes-related knowledge and caregiving role/tasks; (2) determining the causal relationship between diabetes-related knowledge and health behaviors as well as one's risk perception and the development of diabetes; and (3) prospectively follow this caregiver population to attain a more comprehensive understanding of the current risk perception, behavior and diabetes-related knowledge, and the association with the onset of diabetes. Further, there is a current gap in the literature exploring this high-risk population in Canada, which may have serious medical/clinical implications. As such, future research should assess variables such as level of education, income and employment, to further understand how such variables are associated with gender and one's diabetes knowledge and their caregiver roles.^{28–30} Additional research may focus on developing/tailoring tools to support Health Care Providers (HCPs) (ie, registered nurses, physicians, diabetes educators, and so on) to accurately quantify diabetes risk within this population.

Limitations

This study has several noteworthy limitations. First, a cross-sectional design was used, and data were collected from participants at a single point in time. Second, a convenience sampling method was employed, potentially limiting the representative of the entire Canadian SAP. Third, participants were volunteers and their experience and perspective may differ to South Asian caregivers that did not take part in the study. Fourth, the cross-sectional survey had limited socioeconomic data on participants, thus limiting further statistical analyses to explore relations (ie, gender) identified in the data. Finally, an online

self-administered questionnaire was used, potentially increasing the possibility of duplicate responses and social desirability bias although the survey was anonymous.

CONCLUSION

Empirical evidence has shown that caregiving responsibilities for persons living with chronic diseases such as diabetes is often assumed by young adults. However, young adult caregivers are an understudied population. The SAP is at a high risk of developing T2DM, highlighting the importance of examining this population. The purpose of this cross-sectional study was to explore diabetes-related knowledge, risk perception, actual diabetes risk and QoL among young adult South Asian caregivers. In our sample, diabetes-related knowledge and risk perception were higher among female caregivers. Moreover, there was gender-based division in caregiving tasks. Although our participant caregivers reported taking part in different caregiving tasks for their parents, the findings suggest there was no difference in QoL between males and females. Further, despite having a family history of diabetes and taking on the role of a caregiver, there was a general lack of diabetes-related knowledge. These results suggest a need to equip these young adult caregivers with diabetes-related knowledge to support them in their caregiving role and to promote health awareness among this high-risk population. The results of the study have implications for improving diabetes-related education and risk perception among this young adult population who are at risk for developing this chronic illness.

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