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Original Research

Culturally Tailored Resources for South Asian Immigrant Women With Gestational Diabetes: Do They Work and What's Missing? A Qualitative Study

Stephanie de Sequeira MPH^{a,b,*}; Ilana Halperin MD, MSc^{c,d}; Lorraine L. Lipscombe MD, MSc^{a,c,d,e,f}^a Women's College Research Institute, Women's College Hospital, Toronto, Ontario, Canada^b Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada^c Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada^d Department of Medicine, University of Toronto, Toronto, Ontario, Canada^e Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, Ontario, Canada^f Institute for Clinical Evaluative Sciences, Toronto, Ontario, Canada

Key Messages

- South Asian immigrant women have the highest rates of gestational diabetes mellitus in Canada.
- Diabetes Canada has been developing diabetes education material that accounts for the cultural preferences of South Asians.
- It is uncertain whether South Asians are aware of the resources, trust them or have factors influencing the uptake of advice.

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ABSTRACT

Objectives: Gestational diabetes mellitus (GDM) increases the risk of pregnancy complications. South Asian immigrant women have among the highest rates of GDM in Canada and they also have the highest lifelong risk of developing type 2 diabetes after a GDM pregnancy. Diabetes Canada has been developing diabetes education material that accounts for the cultural preferences of South Asians. However, there is uncertainty to whether South Asian immigrants are aware of these resources or trust them, or if other factors influence their uptake of advice.

Methods: In this study, we conducted qualitative interviews to explore, among South Asian immigrant women with GDM: 1) their awareness of diabetes education resources, 2) their attitudes toward information from different resources and varying health-care providers and 3) their barriers and facilitators for GDM management recommendations. Gender theory is embedded in this study, as culturally specific gender roles regarding motherhood have been shown to be important to South Asian immigrant women and their perceptions of health.

Results: There was an emergence of 3 main themes. First, awareness of culturally tailored educational resources is low. Second, there is an overabundance of GDM management information, which leads to variability among participants of how they rank accuracy of informational sources. Finally, there is a gender role reversal present, where women are being taken care of by their families instead of being the providers of care.

Conclusions: These results indicate that better dissemination strategies for GDM educational material are needed for health-care providers and patients, and may require additional consideration of family involvement during GDM education sessions.

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* Address for correspondence: Stephanie de Sequeira MPH, Women's College Research Institute, Women's College Hospital, 76 Grenville Street, Toronto, Ontario M5S 1B2, Canada.

E-mail address: stephanie.desequeira@wchospital.ca

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R É S U M É

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Objectifs : Le diabète sucré gestationnel (DSG) augmente le risque de complications de la grossesse. Les femmes immigrantes sud-asiatiques présentent le taux de DSG le plus élevé au Canada et, de ce fait, elles sont aussi exposées tout au long de leur vie au risque le plus élevé d'être atteintes du diabète de type 2 après avoir eu un DSG. Diabète Canada a conçu du matériel didactique sur le diabète qui tient compte des préférences culturelles des Sud-Asiatiques. Toutefois, on ne sait pas avec certitude si les immigrantes sud-asiatiques connaissent ces ressources et si elles y font confiance, ou encore, si d'autres facteurs influencent l'adoption des conseils.

Méthodes : Dans la présente étude, nous avons mené des entrevues qualitatives auprès de femmes immigrantes sud-asiatiques atteintes du DSG pour explorer : 1) si elles connaissent l'existence des ressources didactiques sur le diabète; 2) leurs attitudes à l'égard des renseignements qui proviennent des différentes ressources et des divers prestataires de soins de santé; 3) les facteurs qui nuisent aux recommandations de prise en charge du DSG et les facteurs qui les facilitent. Nous avons intégré la théorie du genre à cette étude puisqu'il a été démontré que les rôles de genre en matière de maternité sont importants pour les femmes immigrantes sud-asiatiques et leurs perceptions de la santé.

Résultats : Trois thèmes principaux sont apparus. Premièrement, la connaissance de l'existence des ressources didactiques adaptées à la culture est faible. Deuxièmement, le fait que les renseignements sur la prise en charge du DSG surabondent entraîne une variabilité de la valeur que les participantes accordent à l'exactitude des sources d'informations. Finalement, il existe une inversion des rôles de genre où les femmes sont prises en charge par leur famille plutôt que d'être les soignantes.

Conclusions : Ces résultats montrent que de meilleures stratégies de diffusion du matériel didactique sur le DSG sont indispensables aux prestataires de soins de santé et aux patientes, et qu'il convient que l'on prenne de surcroît en considération la participation de la famille durant les séances d'enseignement sur le DSG.

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Introduction

Gestational diabetes mellitus (GDM) is diagnosed when glucose intolerance is detected during pregnancy at 24 to 28 weeks (1). GDM is an increasing public health concern in Canada, with data from Ontario showing a doubling of the incidence from 1996 to 2010 (2). Women with GDM have an increased risk of pregnancy complications, such as macrosomia, preterm labour and pre-eclampsia (3,4). Furthermore, the risk of developing type 2 diabetes mellitus (T2DM) later in life is 7-fold higher for women who had GDM compared to women without GDM (5).

Immigrant women in Ontario have higher incidence rates of GDM compared with their Canadian-born counterparts (6). Among immigrant women in Ontario, South Asians have the highest incidences rates, with a >3-fold greater frequency of GDM than Canadian-born pregnant women (6). In addition, South Asian women with GDM have the highest risk for developing T2DM. About 50% of South Asian women with GDM develop T2DM within 14 years compared with 23.1% for the general population (7).

Management of GDM is similar to that of T2DM, with an emphasis on a healthy diet and increased physical activity to maintain normal glucose levels, and the use of insulin or other medication, if necessary (8). However, there are several sociocultural barriers for South Asians, especially among first-generation immigrants, in managing T2DM. For example, some South Asians believe that diabetes is not a serious disease and, therefore, do not make changes to their diet or physical activity levels (9,10). Furthermore, some South Asians feel that educational resources for diabetes management do not account for culturally appropriate foods and do not consider their need for gender-specific exercise spaces (11–14). Moreover, diabetes-related stigma makes it difficult for some South Asians to follow diabetes treatment and management regimens (15).

South Asian culture also presents some facilitators to diabetes management. First, South Asians believe that their physicians are the best source of knowledge and, therefore, report taking the advice of physicians seriously (16–19). Second, the social networks

of South Asian immigrants contribute to emotional support and exchange of knowledge for individuals managing diabetes (15,16,20). In addition, the power of prayer has been reported by South Asians as being useful in coping with a diabetes diagnosis (15).

More specific to GDM, qualitative studies of South Asian women with GDM indicate that they often feel stressed about a GDM pregnancy, and feel like they do not have control over the condition (21). Moreover, South Asian women often report that increased physical activity and restricting diet during their GDM pregnancy increases negative symptoms, such as tiredness and a general feeling of illness (21), which contradicts culturally held beliefs about diet and exercise during pregnancy (21,22). In addition, because GDM, like T2DM, is increasingly common among South Asian populations, many female peers and relatives offer women advice with how to cope with their GDM diagnosis. However, this advice is not always medically accurate (21).

Because South Asians have one of the highest risks of developing diabetes in Canada (23), there has been an increase in the availability of culturally tailored diabetes management and education resources for South Asian Canadians in the past few years. For example, Diabetes Canada has created culturally tailored Internet-based resources for health-care practitioners as well as Internet-based nutritional resources for the diverse South Asian population groups (24). Moreover, the Heart and Stroke Foundation shares print materials in a variety of South Asian languages, which are available in areas in which South Asian communities gather, such as religious institutions and community health fairs. These print materials detail healthy activity guidelines, culturally adapted versions of Canada's Food Guide, and culturally specific heart healthy recipes (25,26).

Although culturally tailored diabetes management resources have been developed for South Asians, it is unknown whether women with GDM are aware of these resources or find them trustworthy. For example, South Asians who rarely or never speak English at home, which is common among recent immigrants, are >5-fold more likely to get medical information from their families

compared with the Internet or print media (i.e. pamphlets) (24,27). Furthermore, there are important social factors that drive individuals to look for medical advice on the Internet; individuals who lack trust in their health-care professionals are driven to find different informational sources (28), and higher income groups are more likely to use the Internet for health-related queries compared with lower income groups (29).

It is also important to consider gender when studying diabetes management in South Asian immigrant populations, especially South Asian immigrant women embarking on motherhood. Gender refers to the social aspects of being a man or a woman. This includes the development of an identity based on certain roles, tasks and characteristics that society places on males or females (30). Because gender is a social construct, culture can strongly influence the development of culturally specific gender roles. Thus, recent immigrants may be socialized to follow South Asian-specific gender roles more than Canadian ones. Similar to gender roles in Canada (31), women who follow South Asian traditions are expected to stay healthy to keep their family healthy (20). This gendered expectation is especially important in the case of GDM, because the woman's health directly influences the health of the developing fetus. In addition, the familial responsibilities of South Asian women dictate that family life take precedence over self-care. Therefore, women report visiting a physician for health concerns only if they are encouraged to do so by family members (20), or do not partake in self-care activities, such as visiting a physician for health problems, as they devote most of their time to domestic duties (21). Furthermore, South Asian culture prescribes that husbands should take the lead in decision making, including health-related decisions (20). Thus, it is important to assess whether husbands also have access to information and resources on GDM management so that they can help their wives during pregnancy.

In the present study, we used qualitative methodology to explore, among South Asian immigrant women with GDM in Toronto and the Greater Toronto Area: 1) their awareness of diabetes education and management resources (i.e. pamphlets from community fairs, Internet-based resources, recipe cards and educational material for managing diabetes); 2) their trust of information and recommendations from different resources and varying health-care professionals (e.g. nurse vs physician); and 3) their barriers and facilitators for diabetes management resources.

Methods

Study population

South Asian immigrant women with GDM were recruited from the Diabetes in Pregnancy clinic at Sunnybrook Hospital, an academic health centre in Toronto that provides care for approximately 8 to 12 South Asian patients with GDM per month (Figure 1). We purposefully recruited South Asian women who had a diagnosis of GDM; immigrated to Canada within the last 15 years from Afghanistan, Bangladesh, Bhutan, Maldives, Nepal, India, Pakistan or Sri Lanka; were able to provide informed consent; and were able to speak conversational English. Most qualitative studies require around 12 interviews for saturation among a homogeneous population (32).

Semistructured interviews

Semistructured interviews were conducted in English with South Asian immigrant women with GDM. Potential participants were identified from the Diabetes in Pregnancy clinic lists by their surnames. Using surname lists to identify South Asian individuals

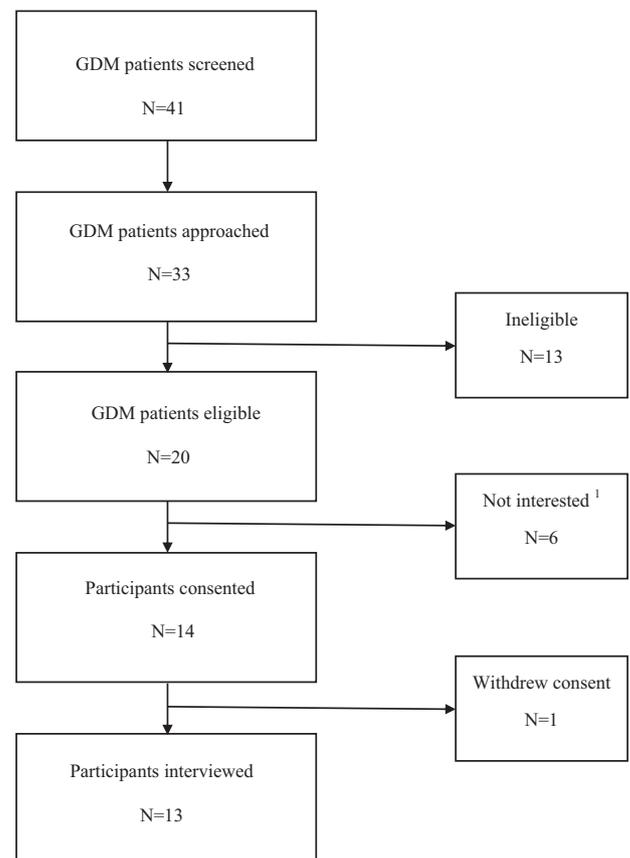


Figure 1. Consort flow diagram of participant selection. ¹Reasons for nonparticipation included not being interested in research and not having time to complete interview. GDM, gestational diabetes mellitus.

has a positive predictive value of 89.3% (33). The health-care team also identified patients who were not identified on the clinic list. Once a potential participant was identified, the interviewer (S.D., a graduate student) approached the patient and explained the study. If the participant agreed to take part in the study, the informed consent process was completed.

Because the aim of the study was to understand how South Asian immigrant women with GDM interact with culturally tailored diabetes education resources, the interview guide was created using an interpretivist approach. An interpretivist approach posits that meaning is created through interactions with the environment (34), which presently translates to the feelings of South Asian immigrant women with GDM toward the GDM clinic staff and diabetes management education. In addition, under the interpretivist paradigm, understanding context is fundamental in understanding reality (34). Therefore, the conceptual framework of the interview guide was based on gender theory, which includes cultural context and family dynamics (30).

The interviews were conducted in person, in a quiet and private clinic room, either before or after their clinical appointment. The interviews were recorded with permission of the participants, and transcribed verbatim (unless identifying information was revealed). The interviewer also took detailed notes during the interview.

Descriptive statistics were also collected in the interview and were self-reported by participants. Descriptive statistics were decided *a priori*, based on items decided by the team that described the social context of participants. Categorical variables are presented as frequency and percent, and continuous variables are presented as median and interquartile range (IQR).

Data analysis

The transcriptions of the interviews underwent thematic content analysis using NVivo version 11 software. Thematic content analysis is useful for answering questions regarding important issues for a specific group of respondents (i.e. GDM management in South Asian immigrant women) (35). The first 5 interview transcripts were read and open coded to establish additional avenues of inquiry. The interview guide was then slightly updated based on these additional avenues of inquiry (35). Interviews were concluded once thematic saturation occurred in the top 3 themes (36).

The interview transcripts were read twice by the interviewer to understand the depth and nuances of the data. Each interview transcript was hand-coded by the interviewer. It was the aim of the study to keep data analysis inductive; therefore, themes emerged from the data rather than from pre-existing theory. This created the emergence of the initial codes from the data, which the graduate student discussed with her supervisor (L.L.). Our next step included axial coding, where the codes were combined into categories. This was completed through discussions with the interviewer and supervisor. The interview transcripts were then analyzed using the refined codes, ensuring that the resulting codes cover the depth of data, with no further codes needed (35,36).

Ethics

Research ethics board approval for this study was obtained from Women's College Hospital and the Sunnybrook Health Sciences Centre. All participants provided written informed consent before taking part in the interview.

Results

We approached 33 women, of whom 20 were eligible. Fourteen women agreed to participate (Figure 1). We conducted 13 interviews over a period of 8 months; participants had a median age of 33 years (standard deviation [SD], 31 to 35 years), a median duration of residence in Canada of 3.5 years (IQR, 0.84 to 13 years) and 12 were at least college/university educated (Table 1). The interviews lasted about 30 to 45 minutes. Thematic saturation was achieved for 3 themes: 1) low awareness of culturally tailored resources, 2) overabundance of GDM information and 3) gendered role reversal.

Awareness of resources

First, in response to our first objective, we found that awareness of culturally tailored resources was low among South Asian immigrant women with GDM. In addition, from the patient perspective, there is some indication of either low awareness of these resources by health-care providers, or there is a barrier in health-care providers communicating these resources to South Asian patients. For example, one participant stated a wish for "recipes for converting like a typical ethnic dish into something that's like a low-carb dish" (participant 8). However, recipes for a variety of low-carbohydrate South Asian dishes are available online and in print, and have been created by reputable organizations, such as Diabetes Canada and the Heart and Stroke Foundation.

Participants not only reported having to convert Canadian recipes given to them by their health-care team into ethnic variations, they also stated that they had to spend extra time explaining cultural foods and their significance to health-care providers:

Table 1

Sociodemographic characteristics of 13 South Asian immigrant women with gestational diabetes mellitus (N=13)

Demographic	
Age	Median, 33 years (IQR, 31–35 years)
Length of stay in Canada	Median, 3.5 years (IQR, 0.84–13 years)
Country of origin	
India	n=9 (69.23%)
Sri Lanka	n=2 (15.38%)
Pakistan	n=1 (7.69%)
Bangladesh	n=1 (7.69%)
Highest level of education	
High school	n=1 (7.69%)
College/university	n=7 (53.85%)
Postgraduate	n=5 (38.46%)
Language spoken most frequently at home	
English	n=2 (15.38%)
English and Hindi	n=1 (7.69%)
English and Tamil	n=1 (7.69%)
Tamil	n=4 (30.77%)
Urdu	n=1 (7.69%)
Marawari	n=1 (7.69%)
Marawathi	n=1 (7.69%)
Bengali	n=1 (7.69%)
Telugu	n=1 (7.69%)

IQR, interquartile range.

I am associated with the dietitian and everything, but there is a slight gap here. So I try to convert everything from my side to present it to her. (participant 3)

Whatever samples [the Diabetes in Pregnancy clinic] gave it is all Canadian like bread, sandwiches, and the grilled foods, which I'm not used to. So, then I have to change it to my things. I think if country-specific patterns, sample diets [were created], that could be better. (participant 11)

So that was like something I kind of had to figure out and explain to her what exactly it meant. Because it was so common in my family, I didn't even think about it. (participant 8)

Culturally tailored resources were created to overcome the cultural barrier South Asian immigrants face in diabetes management education. However, women with GDM, a growing subgroup who could benefit from this culturally tailored education, are not aware that these resources exist. Therefore, better dissemination strategies are needed so that these resources reach women with GDM and their health-care teams.

Overabundance of GDM information

Second, although technology has increased the availability and accessibility of GDM management information, the overabundance of informational sources makes it difficult for women to decide which advice to follow.

For example, participant 8 described her experience with accessing GDM management education:

[I use] websites like the Diabetes Association, like those kind of places. So, places that actually give you actual, nutritional information, from like scientists, or doctors or nutritionists. I'll actually follow those guidelines. But I'll actually get the suggestions from other places, I guess from people who are actually

have the same experience, and then I'll cross-reference... So, say for example, this person is eating, or somebody says, "okay, I eat bitter melon, right? To help manage my blood sugar." So, I'm going to go check online, is that really something that will help? And then you see, oh no, no, you can't eat that when you're pregnant, you'll get miscarriage right? So, I'm like no. It's like everything is cross-referenced for me, because, like, you can never really trust any one person.

Technology enabled our participants to get support from family and friends all over the world. For example, participant 1 got her information from "the dietitian and the YouTube. And also friends and relatives talking." However, some of the advice that women were getting from relatives in South Asia, the United Kingdom and the United States did not meet Canadian guidelines:

My sister had GDM, and she did tell me some things, but, like, she's in US, so like type of devices we use, the type of ranges we use they are different ... things are different. (participant 6)

There are some things like cultural, like bitter gourd, like karela, it's considered good for reducing the sugar. I was having it and my dietitian told me, no that's not something you should have, it increases the risk of miscarriage. (participant 3)

Technology further allowed women to access both national and international forums to seek out support and advice from other mothers with GDM all over the world. However, the participants in this study did not blindly trust any one source of information, whether it be family and friends or web-based resources and forums. As demonstrated, participant 8 discussed joining GDM groups on Facebook and participating in forums on babycenter.ca; however, she made it clear that she cross-referenced information, so that she could follow the best advice.

Similarly, participant 13 cross-referenced information by perusing multiple websites and checking in with family members:

I use my judgment. So I'd go through 4 or 5 website sites, and from there I'd see which information pops up more often. And, which ones don't sound right, you know, and then I'll speak to my elders, my mother-in-law, my mother, and from there I try to make a judgement myself to find out, okay these things are coming up more often and maybe these are the right information.

Conversely, other participants chose not to look for further resources online due to the vast amount of information:

Everybody does go online, and I did too. But I'm mostly following the advice I'm getting here [at the Diabetes in Pregnancy clinic]. Because there's too much on the internet ... I don't want to stress myself out. I already have a lot to do. (participant 9)

Although the abundance of informational sources may seem like a barrier to GDM management as patients may not be able to discern medically correct information from myths, most of our participants were Internet savvy and knew how ascertain which advice to follow. Ultimately, in response to our second objective, there was variability in how our participants ranked accuracy of information. Participant 13, for example, prioritized advice from her elders over the Internet, whereas participant 9 mostly followed the advice of her health-care team.

Gendered role reversal

Third, there was a gendered role reversal present. In cultures across the world, women carry the burden of emotional labour and mental load (37). This emotion work refers to the routine tasks associated with caring for adults and children, such as meal planning, making doctors' appointments, etc (38). However, we found that husbands, parents and even children pick up the mental load to help the mom-to-be during her GDM pregnancy. Patients reported the entire family coming together and providing them with care and support.

For example, participant 7 spoke about how she does not have to worry about her meals because her mother-in-law "...takes care of [her] food, and what [she] eats, and what time [she] eats." Similarly, participant 1 indicated not having to worry about forgetting to take her medication, because "My kids and my husband remind me to take my pills, check my blood sugar level every time."

Families also do additional research to help the patient manage her GDM:

[Husband] will make sure ... I'm not taking too much of sugar. He'll go and check online that what I'm having has the proper content of carbs in it, proper content of nutrition into it. So all these things that would have taken a lot of time for me, energy from me, and probably I would not have done. (participant 6)

The physical and emotional support from family members enabled participants to make healthy behaviour changes to manage their GDM. As participant 6 stated, GDM management takes time and energy, and participants' support networks along with gendered role reversal may have enhanced participants' ability to make the necessary behaviour changes to best manage their GDM.

Discussion

In this qualitative study, we have assessed the awareness of culturally tailored diabetes management resources among South Asian immigrant women with GDM, their trust of various sources of diabetes management recommendations and any other barriers and facilitators they experience for GDM management. First, we found that both our participants and the health-care team had low awareness about culturally tailored resources. South Asian women with GDM already face cultural barriers with regard to food. For example, restricting diets during a GDM pregnancy conflicts with cultural myths about "eating for two" (21). Therefore, having to spend additional time and energy explaining cultural foods to health-care providers and finding cultural replacements for Canadian foods could further impede the ability of South Asian women to make healthier dietary choices. Increasing awareness of culturally tailored resources would enable women to make and maintain the necessary diet changes by including dishes which are already a part of their cultural palate. Moreover, communication of these educational resources by health-care providers may increase the trust and rapport between the health-care team and patients.

Improved dissemination of culturally tailored resources could also positively affect cultural groups other than South Asians, as having to spend time explaining cultural food to health-care providers is not limited to South Asian immigrant women, but also occurs among other immigrant groups (39). Diabetes Canada has translated and culturally tailored resources for Latin American and Chinese groups as well (40). It is not practical to assume that health-care providers will have cultural competence in all the diverse cultures that live in large Canadian urban centres. However, it is feasible for health-care providers to be able to direct patients to

culturally tailored educational and informational materials created by reputable sources.

Second, we found that some participants valued the advice of their health-care team over other sources of GDM information. However, we found that, even though the participants we interviewed followed the advice of health-care providers, they were still seeking out information from other more culturally aligned sources. Awareness of their other sources of health information would allow health-care providers to endorse or dispel these sources, and thus enhance the alignment and trust between patients and their providers.

Our finding that some of the participants trust advice of their health-care team over other sources contrasts with studies from the UK which showed that South Asian women with T2DM and GDM were likely to comply with medical advice offered by peers and elders (15,21). These contradictory findings may reflect the differing methodologies between studies. For example, our study conducted the interviews in English, whereas the GDM study in the United Kingdom conducted focus groups in Urdu, Tamil and Guj-rathi. South Asians who rarely speak English are highly likely to obtain health advice from family members (27), which may explain the discrepancy in findings. Furthermore, our study population is well educated and is knowledgeable about how to obtain accurate information on the Internet. This may further explain why a priority was not given to advice from family and friends. In addition, we found that our participants respected the advice of allied health professionals (i.e. nurses and dietitians) just as much as the advice from physicians. Another study conducted in Ontario showed that dietitians felt that South Asians with T2DM viewed physicians as the only credible source of information (19). This difference may indicate a generational difference as women with GDM would, on average, be younger than those with T2DM (41,42), or may be due to South Asians viewing GDM and T2DM differently (9,10,21).

Finally, we found that there was a gendered role reversal, where women with GDM were being taken care by their family rather than being the care providers. Because family support during the GDM pregnancy was high, culturally tailored resources should include advice to family members as well. In addition, because family members are very involved in caring for the mom-to-be, clinics should strongly encourage family members to attend GDM classes to understand nutritional recommendations and Canadian guidelines for medication and blood sugar levels. Further research can assess whether this gendered role reversal is indicative of changing gender roles and ideas surrounding motherhood and fatherhood, or if it solely exists during pregnancy. A study with a sample of mostly post-GDM South Asian women found that women felt they had very little family support for healthy behaviour changes (21). This finding may indicate that family support is very common during the GDM pregnancy, but decreases once the baby is born. Including the family during the GDM pregnancy offers an opportunity to solidify the significance of family support in maintaining healthy behaviour changes postpartum.

Strengths of this study include its utilization of an interpretivist approach to conduct semistructured interviews. This approach allowed for a deeper understanding of patient experiences that may not have been possible through more structured or quantitative methods. In addition, by using a semistructured approach we could cover the predetermined set of questions, but we also had the flexibility to probe for additional avenues of inquiry. Finally, the interviewer may have been considered an “insider” by participants as she was also a South Asian immigrant woman (43). This may have increased the rapport between the interviewer and participants, encouraging deeper discussions. However, the interviewer being an insider also creates opportunities for bias. For example, cultural subtleties are not stable over time, which may have caused some cultural nuances to be missed

during analysis (43). This study has other limitations as well. First, participants were sampled from a single clinic in Toronto. South Asian immigrant women with GDM visiting other clinics may have different experiences. Second, due to the multiple languages spoken in South Asia, our team only interviewed women who could speak conversational English. Therefore, the results may not generalize to immigrant women who experience a language barrier within the health-care system.

Conclusions

In this qualitative study, we found that awareness of culturally tailored resources was low among patients. In addition, findings suggest that there may be a gap in health-care providers' awareness as well. Furthermore, the overabundance of GDM management information was a barrier to knowing which source to trust. We also found that there was a gendered role reversal, where families were taking care of the women with GDM, instead of the women being the providers of care. Better dissemination of culturally tailored resources, having health-care providers inquire from which sources their patients are obtaining information and engaging family members in GDM management could potentially improve the care experience and outcomes for South Asian immigrant women with GDM and their families.

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Author Disclosures

Conflict of interest: None.

Author Contributions

S.D. contributed to research design, conducted interviews, coded and analyzed data and wrote the manuscript. I.H. and L.L.L. contributed to research design and reviewed and edited the manuscript.

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