

Knowledge gaps and other barriers in type 2 diabetes management: Findings from interviews with South Asian women

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Article points

1. South Asian women with type 2 diabetes, in general, face more obstacles during diagnosis and treatment of type 2 diabetes than South Asian men.
2. Changes to diet, physical activity and language and cultural barriers are the main hurdles that were found to be faced by South Asian women when a small cohort was interviewed as part of this study.
3. Bilingual services and literature would help to reduce the knowledge gap that some women have in terms of diabetes development and control.

Key words

- Knowledge gap
- South Asian
- Women

Author

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The prevalence of type 2 diabetes in the South Asian population is alarmingly high compared to European counterparts. This article reports the results from interviews carried out with South Asian women with type 2 diabetes in the UK. South Asian women with type 2 diabetes are an understudied population and may face different obstacles to South Asian men in diabetes management. The knowledge of interviewees of diet and physical activity recommendations for the prevention and management of diabetes were investigated, as were the potential language and cultural barriers that may influence the knowledge gap among South Asian women when receiving care and advice from healthcare professionals.

The term “South Asian” in this article is used to refer to people of Pakistani, Indian, Bangladeshi and Sri Lankan origin (King, 2009). Alarmingly, people of South Asian descent living in the UK have a four to six times greater risk of developing type 2 diabetes, and its onset is a decade earlier compared to their European counterparts (Bellary et al, 2008). The prevalence of type 2 diabetes in the UK as a whole is set to increase to around 4 million by 2025, which is equivalent to “400 people every day, [or] almost 17 people every hour” being diagnosed with the condition (Lawton et al, 2006; Diabetes UK, 2010). The incidence of type 2 diabetes is also rising considerably amongst the South Asian community, particularly in children, who are 13 times more likely to develop type 2 diabetes when compared to their European counterparts (Diabetes UK, 2010).

Studies focusing on the South Asian population living in the UK have shown that there are certain critical factors which increase their susceptibility to diabetes (e.g. diet, levels of physical activity, socio-economic status and cultural barriers [Khunti et al, 2009]). To

my knowledge, previous qualitative studies involving South Asian people with type 2 diabetes have not been limited to a specific gender. Here I investigate whether there is a diabetes management and control knowledge gap among South Asian women and whether there are particular factors that affect South Asian women’s susceptibility to type 2 diabetes.

Important factors affecting the prevention and management of type 2 diabetes

Diet

South Asians’ diets consist of mainly carbohydrate and fat with very little protein (Khunti et al, 2009). Some Indians, specifically Gujaratis and Punjabis, consume a lot of fat in their diet due to the high quantities of oil or clarified butter (ghee) that is used in traditional dishes. Research has shown that after type 2 diabetes diagnosis, some people continue to eat traditional cuisine as they do not want to isolate themselves from their community (Khunti et al, 2009). However, the dietary preferences of South Asian ethnic groups are diverse (McKeigue et al, 1985) and can not be generalised across regional groups; for

example, *gudh* (a natural sweetener) is commonly used by people with Gujarati origin (a north-west state of India along the coast) but rarely used in northern India.

Physical activity

Physical inactivity is a major risk factor for diabetes development in South Asian people. This may be due to cultural reasons, social expectations, time constraints and already present health problems (Khunti et al, 2009). Findings from a previous study showed that South Asian women with diabetes emphasised the cultural importance of being active on a daily basis, rather than attending organised exercise (Khunti et al, 2009). However, lower levels of physical activity were found in South Asian women with diabetes due to household responsibilities, not being able to make childcare arrangements, and cultural and social reasons (such as not being able to go swimming in the appropriate clothing; not being able to find friends to exercise with; and not being able to find single-sex exercise classes [Rhodes et al, 2003]).

Language barriers

Many South Asian first-generation immigrants have a limited knowledge of the English language, which Khunti et al (2009) have reported as a major issue during diagnosis because “interpreters are still not widely available in healthcare except by prior arrangement.” Rhodes et al (2003) found that consultations with South Asians who have low levels of English were longer than consultations with English-speaking patients, despite having an interpreter. This has led to a style of working for healthcare professionals where “speed is valued as a measure of efficiency” (Rhodes et al, 2003). Away from the consultation room, some South Asians could face difficulty in correctly managing their blood glucose levels (Khunti et al, 2009).

Cultural barriers

The diagnosis of diabetes occurs in four stages:

“patients, or others around them, having sufficient concern about their symptoms to seek medical help; the opportunity to seek help and

the type of help sought; obtaining a suitable appointment; and health professionals making a correct diagnosis” (Rhodes et al, 2003).

Research has shown that at each stage of the process, South Asians have encountered difficulties (Rhodes et al, 2003). One of the reported reasons for this difficulty in diagnosis is that they often cancel or miss appointments due to not being able to make childcare or transport arrangements, or not being able to take time off work (Rhodes et al, 2003). Further, Bangladeshi people experience poorer healthcare when compared to other South Asian groups (Rhodes et al, 2003; Osman and Curzio, 2012). Also, cultural and religious beliefs may make it difficult for individuals to attend clinics at certain times or on certain days, to speak openly to members of the opposite sex, or for women to travel alone to clinic appointments (Khunti et al, 2009).

Aim of this study

The aim of the qualitative study reported here was to investigate whether there was a knowledge gap among South Asian women with type 2 diabetes about diabetes development and management. The understanding of dietary and exercise recommendations was investigated, and other aims included assessing whether there were any language or cultural barriers present that affected the management of diabetes within this ethnic minority, with the hope of recommending possible culturally appropriate educational materials in bilingual languages to overcome any potential knowledge gap.

Methods

The criteria for the targeted study group were South Asian women with type 2 diabetes. Potential participants were recruited either in Warwickshire or in Birmingham through the local community by word-of-mouth over a 2-week period. Volunteers were not incentivised and were blinded to the aim of the study. Participants who volunteered were interviewed on a one-to-one basis in their own homes by myself, and interviews were conducted in English, Hindi, Gujarati or Punjabi depending on which language the interviewee preferred.

Page points

1. Cultural and religious beliefs make it difficult for individuals to attend clinics at certain times or on certain days, to speak openly to members of the opposite sex, or for women to travel alone to clinic appointments.
2. The aim of the qualitative study reported here was to investigate whether there was a knowledge gap among South Asian women with type 2 diabetes about diabetes development and management.

Table 1. Participant profiles of the interviewed South Asian women with type 2 diabetes.

#	Age (years)	Years since type 2 diabetes diagnosis	BMI (kg/m ²)	Level of education reached	Religion	First language	Generation of immigrant in the UK*
1	73	13	25.9	Secondary	Hindu	Gujarati	First
2	47	5	28.9	Secondary	Muslim	Gujarati	Second
3	61	3	30.2	Primary	Hindu	Punjabi	Second
4	66	9	38.2	Graduate	Hindu	Hindi	First
5	61	26	24.8	Primary	Sikh	Punjabi	First
6	52	8	27.8	Secondary	Muslim	Bangladeshi	Second

#=participant number.
*First=a foreign-born citizen who has immigrated to the UK; Second=a citizen born in the UK to at least one first-generation immigrant parent.

The interviews were semi-structured and followed an outline planned by myself and a senior researcher working in the field. This allowed the interviewee to talk about things not directly asked by the interviewer. Each interview included questions analysing the interviewees’ knowledge of the causes and prevention of diabetes. For example: What is diabetes? Why might an individual develop diabetes? How might one manage diabetes? Why do you think South Asians have an earlier onset of diabetes? What are the long-term effects of diabetes?

The interview also included questions from the EQ-5D™ (EuroQol Group) questionnaire to investigate how diabetes impacted on their quality of life (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). The participants were also asked how diabetes affected other aspects of life (e.g. their sleep), and data of a typical day for the participants in terms of diet and physical activity were recorded.

The interviewees were also asked about the care they received from healthcare professionals, whether they faced any difficulties in understanding instructions from healthcare professionals and whether they had any thoughts on how care for South Asian people could be improved.

The participants’ current height, weight, BMI, last dated HbA_{1c} result, other medical conditions and family history of diabetes were recorded.

Results Participants

Six South Asian women with type 2 diabetes responded to the invitation to participate and

all were interviewed as part of this study. They ranged in age from 47 years to 73 years, and had been diagnosed with type 2 diabetes for an average of 10 years (see *Table 1* for participant profiles). Interviews lasted between 1.5 and 2 hours.

Diabetes knowledge

Among the participants, knowledge of diabetes development was very low, particularly in first-generation female immigrants whose highest level of education was primary education. Only one participant (Participant 2) knew the medical reasons for the onset of diabetes (i.e. either not enough insulin is produced by the body or the insulin produced is not effective). Participant 3 described diabetes as:

“a bad thing preventing individuals from enjoying themselves.”

Participant 1 described diabetes as:

“a disease in which you cannot consume sugar and potatoes.”

Two participants (Participants 1 and 3) perceived that diabetes was a result of stress and heredity.

However, most of the participants (all except Participant 3) were able to identify that South Asians have an earlier onset of diabetes than other populations due to personal lifestyle choices including diet (consumption of fatty foods) and physical inactivity. But all participants were able

Page points

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to report on ways to control and manage their diabetes and its long-term effects.

Diet

From the answers given, participants appeared to have limited understanding of healthy eating concepts and appropriate dietary habits for someone with diabetes. Participant 4 was the only participant to reduce the amount of sugars and saturated fats, particularly ghee, used in their cooking after diagnosis. Participants noted that traditional Indian food would not taste the same without ghee or high-fat oil.

In our NHS trust, we recommend that individuals with diabetes consume 45–60 g of carbohydrates every meal and drink at least 8–10 glasses (2 L) of water every day. However, the participating women did not even consume half of the recommended quantity of water and had an excess intake of carbohydrate even after diabetes diagnosis. All of the participants ate traditional Indian food at least once a day, which usually consisted of dal (lentils), two to three chapattis, sabji (spiced vegetables) and rice. Participant 2 reported eating three chapattis twice a day, which exceeds the recommended amount of carbohydrates as, on average, one chapatti has 25 g of carbohydrate. Also, the results showed that 50% of participants had two large meals a day rather than the recommended three smaller-sized meals.

At present, all six participants associated bananas, potatoes and apples with a worsening of blood glucose levels. This perception led them to consume fewer fruits and vegetables than the recommended “5 a day”.

Many of the participants also reported their enjoyment in having takeaway meals at least once a week, which are notoriously high in saturated fat and sugar, and for which it is hard to determine the nutritional information. Participant 1 expressed that “it is highly important to switch between different cuisines,” and this can be simply achieved by having takeaway meals.

Physical inactivity and a healthy lifestyle

Among the women interviewed, the reported levels of physical activity were lower than

30 minutes 5 days a week, which we recommend at our trust. There was variation in the number of hours participants spent engaging in physical activity. Four participants did not engage in any vigorous exercise; their only reported exercise was walking around the house. Of these four, they stated that the main barriers preventing them from engaging in the recommended time spent exercising was lack of time, social reasons, other household responsibilities and not being able to find single-sex exercise classes.

Maintaining weight control is essential during the treatment of type 2 diabetes. Results showed that three participants perceived themselves to be lighter than they actually were. For a South Asian person with diabetes, a BMI greater than 23 kg/m² is considered to be overweight and a BMI of 25 kg/m² is considered obese and to put the person at risk of cardiovascular disease (WHO Expert Consultation, 2004). According to these values, all of the participants were either overweight or obese. Three participants exceeded a BMI of 30 kg/m², the value used to define obesity in the general population.

English fluency and language barriers

Five participants reported that they had had language problems at some point during their type 2 diabetes diagnosis or treatment. However, all the participants stated that they encountered fewer problems if they were registered with a GP of South Asian origin who could speak to them in their own language or if they were provided with an interpreter at every appointment. Language barriers were noted to be more prominent among the participants that were first-generation immigrants.

Potential improvements to the NHS

Participants reported that the NHS could improve services by providing more information in bilingual formats or using simpler language (i.e. less medical terminology) on English information leaflets, and training staff on giving culturally appropriate advice to South Asian people with diabetes. Many said they would like to be seen by a South Asian dietitian who may understand their diet and culture. They also reported wanting to be referred to a dietitian

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2. Among the women interviewed, lower levels of physical activity were reported.
3. Five participants reported that they had had language problems at some point during their type 2 diabetes diagnosis or treatment.
4. Participants reported that the NHS could improve services by providing more information in bilingual formats and training staff on giving culturally appropriate advice to South Asian people with diabetes.

Page points

1. In response to interviewer questions asking how diabetes affected participants' quality of life, the participants reported that their diabetes affected all five dimensions of quality of life (mobility, self-care, usual activities, pain/discomfort and anxiety/depression).
2. Healthcare professionals have an important role in the management of individuals with diabetes, and this may be particularly important for people from high-risk ethnic backgrounds.

annually to monitor their progress. Also, they suggested that more awareness on prevention and management of diabetes should be raised within the South Asian community.

Other findings

When asked about the care they received from healthcare professionals and whether they faced any difficulties in understanding instructions from healthcare professionals, the participants did not report any barriers to treatment.

In response to questions asking how diabetes affected their quality of life, the participants reported that their diabetes was affecting their overall health status and all the five dimensions of quality of life (mobility, self-care, usual activities, pain/discomfort and anxiety/depression). Interestingly, four out of six participants reported that their sleep was disturbed, which could be an early symptom for cardiovascular disease; but this needs to be addressed by further research.

Discussion

This study highlights the difficulties South Asians in the UK face as a result of being diagnosed with type 2 diabetes. Whether they are first-generation or second-generation immigrants, women may have to overcome more obstacles compared to their male counterparts after diabetes diagnosis.

This gap in knowledge surrounding diabetes development and management may have prevented the participants from accessing relevant information from the NHS about treatment, and may also have formed a major barrier during diagnosis (Choudhury et al, 2009; Alam et al, 2012).

The high intake of saturated fats reported by the participants may be a result of them not wanting to be isolated from the community. Many South Asians believe in preparing the best food, often with ingredients rich in fat, on special occasions (Grace et al, 2008; Johnson et al, 2011). These meals are usually prepared by women of the household, so even after a diagnosis of diabetes, they may not change the way they eat so that they continue to please family and friends and not feel isolated from the

community. Therefore, they continue to prepare and eat high-fat meals on a daily basis even after a diagnosis of diabetes (Grace et al, 2008; Johnson et al, 2011).

South Asian ethnic minorities, on the whole, tend to not consume enough fruit and vegetables to adhere to the recommended "5 a day", which was supported from findings of this study.

Among the women interviewed, levels of physical activity were lower than recommended in national guidelines. The reasons given for low levels of physical activity were similar to those already published in the literature: lack of time (Netto et al, 2007; Grace et al, 2008; Johnson et al, 2011), social reasons, other household responsibilities, not being able to make childcare arrangements, and not being able to find single-sex exercise classes (Stone et al, 2005; Grace et al, 2008; Johnson et al, 2011).

Healthcare professionals have an important role in the management of individuals with diabetes, and this may be particularly important for people from high-risk ethnic backgrounds. The potential improvements to NHS diabetes services that were suggested by the participants are supported by Rhodes et al (2003), who stated that the NHS should use a comparable approach when dealing with South Asian people with diabetes in order to avoid unsuccessful diagnosis and treatment. In addition, Osman and Curzio (2012) believe that healthcare staff should be more understanding when treating South Asian people with diabetes, especially women, because of factors that may prevent them from modifying their diet and doing physical activity.

Findings from this study are comparable to other studies investigating the language barriers faced by South Asian people with type 2 diabetes. For example, Alam et al (2012) argued that the majority of the South Asian population, particularly women, in the UK face language difficulties when attending appointments with healthcare professionals, and often bring children or other English-speaking members of the family as interpreters to appointments. In the published literature, people of Bangladeshi origin were found to be most affected in this way compared to other

ethnicities (Choudhury et al, 2009; Alam et al, 2012; Osman and Curzio, 2012). However, they do adhere to regular medication (and often take complementary herbal medicines due to their cultural beliefs [Gilani, 2013]).

This piece of research could be used to inform a large, robust, qualitative study of the knowledge of South Asian women with type 2 diabetes.

Summary

In summary, this research has further illustrated that there is a considerable knowledge gap of the causes and effective management of type 2 diabetes among South Asians in the UK, particularly women. Despite living with this chronic condition for an average of 10 years, the women interviewed as part of this study had limited understanding of carbohydrate and fat control with regard to a balanced diet and of the appropriate level of physical activity required for a healthy lifestyle. Their diabetes was affecting their overall health status and all the five dimensions of quality of life (mobility, self-care, usual activities, pain/discomfort and anxiety/depression). Finally, they reported social and language barriers as potential reasons for their limited understanding, which highlights the importance of effective communication with healthcare professionals to provide South Asian people with the best possible care. ■

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