

Research paper

Disclosure of type 1 diabetes status: a qualitative study in a mixed South Asian population in central England

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What is known on this subject

- The incidence of type 1 diabetes in the South Asian population in the UK is increasing.
- There is a paucity of research on the attitudes and beliefs that influence and affect self-management of this condition in the South Asian population.

What this paper adds

- For pragmatic reasons, people with type 1 diabetes are generally willing to disclose their need for insulin. However, in some people of South Asian origin, there may be an exception regarding disclosure where marriage prospects are an issue.
- Those involved in diabetes management need to be aware of the social and cultural context of patients. For South Asian patients, this may include awareness of issues such as marriage prospects which may have an impact on physiological and psychological well-being.

ABSTRACT

The findings presented in this paper are drawn from a qualitative study which used in-depth interviews, facilitated by a flexible topic guide, to explore the attitudes and experiences of insulin initiation and management in a multi-ethnic population with type 1 diabetes. The 15 South Asian adults who participated were recruited, using purposive sampling, through specialist care clinics in Leicester, UK. Progressive focusing was used to identify key themes for further exploration and interpretation of the

data. This paper focuses on a major theme regarding disclosure of diabetes status. Some of those interviewed described experiencing and observing negative perceptions and views about diabetes and the use of insulin. These perceptions did not deter participants from revealing their diabetes in certain situations. Disclosure of diabetes was seen as beneficial in terms of work and social occasions at which they would need to inject, and in terms of ensuring that they would receive insulin during hypoglycaemic

episodes. However, disclosing diabetes was sometimes problematic in the context of marriage prospects. This paper suggests that the disclosure of diabetes is influenced by the cultural and social contexts in which people live and work. The participants in this study generally adopted a pragmatic approach to disclosure, because this facilitated self-care activities in their social and working lives. They

were less inclined towards disclosure in relation to marriage prospects. This factor may have implications for both the management of diabetes and psychological well-being.

Keywords: disclosure, qualitative methods, South Asian, type 1 diabetes mellitus

Introduction

There is limited knowledge of the experiences, attitudes and beliefs that influence the management of type 1 diabetes among people of South Asian origin living in the UK. This may be due, in part, to a perception that type 1 diabetes is an uncommon condition in South Asian people. Some previous studies support this view in reporting a lower incidence of the condition, compared with the UK, in both South India (Ramachandran *et al*, 1992) and Pakistan (Staines *et al*, 1997), but there has been very little research on this issue. However, the incidence of diabetes in people of South Asian origin living in the UK appears to be increasing, so that it is now similar to that of the white British population (Bodansky *et al*, 1992; Raymond *et al*, 2001; Feltbower *et al*, 2002). The incidence of type 2 diabetes is also increasing in this population, and recent evidence suggests that social, culturally based attitudes and beliefs shape and influence experiences of managing this condition (Stone *et al*, 2005; Lawton *et al*, 2006). In this context, insulin therapy is particularly important. Studies of other minority groups (Latinos and African-Americans) indicate that the management of insulin therapy is influenced by the social context. Feelings of anxiety, shame or embarrassment may lead people with diabetes to avoid injecting at work or in social environments (Tak-Ying Shiu *et al*, 2003). This may adversely affect their glycaemic control and contribute to the development of complications such as neuropathy and retinopathy (Liburd *et al*, 2004; Gee *et al*, 2007; Weiler and Crist, 2009). The complications of diabetes have a permanent and deleterious effect on health, and on quality and length of life. It is therefore important to understand the contexts in which people live, so that education about their condition can be tailored to help them to cope with the challenges ahead.

Aims of this study

The findings reported here are drawn from a larger study on insulin therapy among South Asian adults with type 1 diabetes living in Leicester, UK, which will be the subject of another publication. Tables 1 and 2 provide information about the ethnic composition of Leicester. This paper focuses on one of the main themes from this study, namely the perceptions of South Asian people with type 1 diabetes with regard to other people's attitudes to insulin therapy, and the impact of these attitudes on their willingness to disclose their status as individuals who require insulin.

Methods

The study was informed by the principles of grounded theory, which ensures that themes emerge from the data, but we also recognised that some of the areas explored during the interviews were predetermined by the research aims (Strauss and Corbin, 1990).

Leicestershire, Northamptonshire and Rutland Research Ethics Committee provided a favourable ethical opinion.

Sampling

Purposive sampling was used to capture the views of a range of South Asian people with diabetes in terms of age, gender and number of years since diagnosis. The eligibility criteria were a diagnosis of type 1 diabetes, age 18 years or over, and ability to speak English or Gujarati. Individuals who were unable to give informed consent and/or who were considered by healthcare professionals involved in their care to be unsuitable for the study were excluded.

Consent

Eligible participants were approached at two specialist care diabetes outpatient clinics between October 2008

Table 1 Ethnic composition of the population of Leicester, UK

Ethnic group	Percentage in Leicester*	Percentage in England and Wales*
White		
British	60.54%	87.49%
Irish	1.29%	1.23%
Other white	2.03%	2.59%
Mixed		
White and black Caribbean	1.01%	0.46%
White and black African	0.19%	0.15%
White and Asian	0.68%	0.36%
Other mixed	0.44%	0.30%
Asian or Asian British		
Indian	25.73%	1.99%
Pakistani	1.53%	1.37%
Bangladeshi	0.69%	0.54%
Other Asian	1.97%	0.46%
Black or black British		
Caribbean	1.65%	1.08%
African	1.23%	0.92%
Other black	0.20%	0.18%
Chinese	0.51%	0.44%
Other ethnic groups	0.32%	0.42%

* Data from 2001 Census. In 1991, the population of Indian origin represented the largest single ethnic community group in the city, at 22.3% (60 300) of the total population. By 2001, this figure had increased to 25.7% (72 000). If this trend continues, Leicester is likely to become one of the first cities in England, outside of specific areas of London, to have a majority of people with an ethnic minority background. This is due to a range of factors, including higher birth rates among ethnic minority groups, increases in existing communities due to consolidation of families, increases in the number of new arrivals, and increases in white migration out of the city. Source: www.leicester.gov.uk/your-council-services/council-and-democracy/city-statistics/demographic-and-cultural

Table 2 Estimates of ethnic minority languages spoken in Leicester, 2001

First language	Hindu	Muslim	Sikh	Total
Gujarati	37 453	12 848	354	50 655
Punjabi	990	1791	10 451	13 233
Kutchi	0	7289	0	7289
Bengali	41	1977	0	2018
Hindi	907	124	59	1090
Urdu	0	2872	0	2872
English and others	1856	6856	932	9645

Source: www.leicester.gov.uk/your-council-services/council-and-democracy/city-statistics/languagestatistics

and May 2009. Initially a member of the clinic staff provided information about the study to patients. If individuals expressed an interest in participating, they

were then introduced to the researcher (NP), who is fluent in both English and Gujarati. She discussed the study with them, gave them written information

about it (in English or Gujarati), and obtained their initial written consent and permission to record their contact details in order to arrange the interview. A minimum period of 24 hours was allowed to elapse before the researcher contacted them by telephone to arrange a mutually convenient time for an interview. Full written consent was obtained at the start of the interview.

Data collection and analysis

In-depth interviews took place in participants' homes and were informed by a topic guide (see Box 1). This was used flexibly to enable participants to tell their stories as they wished. The interviews were audio-recorded and transcribed verbatim. Those conducted in Gujarati were translated into English by the researcher (NP). A random sample of these translated transcripts, together with anonymised audio recordings, was assessed by an independent professional translator, who confirmed the linguistic accuracy and conceptual equivalence of the translations. The interview transcripts were reviewed (by NP and MAS) throughout data collection as part of an ongoing process of topic guide development. For example, emerging themes relating to negative perceptions, disclosure of diabetes status and marriage prospects were more specifically explored in later interviews. Regular review of transcripts also helped to identify when saturation had occurred.

All of the transcripts were open coded by one member of the team (NP), and a random selection was independently coded by two other members of the team (MAS and HE). Discussions (by NP, MAS and HE) led to the development of an initial coding frame incorporating both descriptive and conceptual (interpretative) categories. Further discussions (by NP, MAS and HE) took place to adapt and refine the coding

Box 1 Topic guide: areas for discussion relevant to this paper

- Impact on family, social and working life
- Support from family, friends and work colleagues
- Views and perceptions of friends and work colleagues about their condition
- Where and how they obtain knowledge and information about their condition
- How they manage the condition on a day-to-day basis in their work and social life

Note: Additional areas for discussion included in the overall study were reactions to the diagnosis, impact on confidence, role of healthcare professionals, and diabetes education.

frame on an ongoing basis during the subsequent process of progressive focusing and systematic coding (Charmaz, 2006). This led to the development of a final thematic framework that was mutually agreed by the researchers (NP, MAS and HE). This included agreement about the positioning of higher-order themes and sub-themes within the coding frame. Framework charting (Ritchie and Spencer, 1994) was subsequently used to organise the data in accordance with these themes, to facilitate further exploration and interpretation. This included exploring relationships within the charted data in terms of both cases (interviewees) and themes. Throughout the process of analysis, care was taken to ensure that findings were grounded in the data collected (Strauss and Corbin, 1990). Qualitative software (QSR N6) was used for data management during the coding phases of the analysis.

Findings

Interview data were obtained from 15 people of South Asian origin (see Table 3). The majority of these interviews were conducted in English ($n = 9$), and the rest

Table 3 Characteristics of the participants who were interviewed*

Characteristics of patients interviewed ($n = 15$)	n
Age group (years)	
18–25	2
26–40	7
40–59	3
60–75	3
Gender	
Male	7
Female	8
Duration of diabetes	
< 10 years	3
10–20 years	6
> 20 years	6
South Asian subgroups	
Gujarati Hindu	10
Gujarati Muslim	1
Pakistani Muslim	2
Punjabi Sikh	1
Other South Asian	1

* Religion has been omitted, as this could identify some of the participants.

were conducted partly or entirely in Gujarati ($n = 6$). The findings presented here are concerned with perceptions of social stigma and disclosure of diabetes.

Influence of other people's perceptions on disclosure

The participants reported the negative reactions of other people on finding out about their diabetes and their need for insulin therapy. A common factor in these accounts related to responses about the lifelong need for daily injections. Examples included the following:

'Yah, they say "Oh my God! How can you take injections for that long?"'

(Interview 6, in Gujarati, female, aged 60–75 years)

'When you tell them, they say "Oh, insulin, diabetes, you have to have injections every day. Oh, no, no, no good, no good having them, to take them every day."'

(Interview 4, in Gujarati, male, aged 40–59 years)

These reactions were sometimes associated with an element of blame, and were attributed to a lack of understanding about type 1 diabetes:

'Everyone just assumes it's to do with your diet it was this assumption, you know, that I'd done something wrong.'

(Interview 19, in English, female, aged 26–40 years)

However, most of the participants appeared to be willing to disclose their need to take insulin, and did not mind being asked about their condition or making it apparent.

'Because if I take insulin injection I've had a few people asking what, what I am doing because they don't see it as normal. Apart from that, um, I personally don't think it's a problem, um, because it's been in my family. ... So I don't see a problem with any, any stigma with that.'

(Interview 12, in English, male, aged 18–25 years)

Reasons for willingness to disclose diabetes status

Participants' responses suggested that they made conscious decisions to disclose their diabetes and that this was motivated by pragmatism. They described a number of ways in which disclosure helped. These included enabling them to eat on time when attending social events, to inject in public or at work, and to make others aware of the possibility of hypoglycaemia and what to do if it occurred. For instance:

'I have to take it at six o'clock in the afternoon, the latest I take it is 1.30 pm. I inject, even if I wear a sari or Punjabi suit [indicates use of plate to hide it] if I go to a wedding I keep my insulin with me and when it's time I take it.'

(Interview 27, in Gujarati, female, aged 40–59 years)

'You have to let work know, friends circle there, let the supervisor know, sometime, people say if your blood sugar goes really low and you fall down, if nobody knows, then they are going to get confused, what's happened to him, is it a heart attack or low sugar, nobody will know. If the ambulance people come they won't know either.'

(Interview 4, in Gujarati, male, aged 40–59 years)

One participant viewed disclosure as a way of educating other people about this condition:

'It can help other people if we talk like this. So it's better to talk.'

(Interview 10, in Gujarati, male, aged 40–59 years)

Two male participants described a more strategic approach to disclosure, on a need-to-know basis. This appeared to be linked to attitudes to privacy rather than concern about being stigmatised:

'It's quite common these days, it seems you always tend to know someone that has diabetes, so it's not really a major issue about sort of not wanting people to know, but rather simply the fact that I don't, don't feel the need to tell everyone.'

(Interview 25, in English, male, aged 26–40 years)

'Well I share with people I need to share with. I don't, if I go to the temple I wouldn't necessarily say I'm diabetic, I can't do this, do that. I just say I don't want it and that's fine.'

(Interview 15, in English, male, aged 40–59 years)

Disclosure in the context of marriage prospects

An issue relating to marriage prospects emerged during the interviews. In this context, some unmarried participants described a more inhibited approach to disclosure:

'When I'm introduced to people, or to guys especially, I wouldn't normally tell them the first time I meet them, but eventually I will. And it's always that thing, when do you tell someone or when you don't because that's probably the only situation where, um, it has been used against me. That yeah, you're a lovely person, we like you, but because you're diabetic, no.'

(Interview 19, in English, female, aged 26–40 years)

'I haven't actually got to that stage yet, but it is one of the things that does worry me because initially when I meet a person I wouldn't tell them "OK I'm type 1 diabetic", because you don't even know that, if you're gonna go any further, with that person or not.'

(Interview 20, in English, female, aged 26–40 years)

One of the women went on to describe pressure from other people, including her parents, not to disclose diabetes until a marriage has taken place:

‘my parents included, will say “Don’t tell them, they will find out after the marriage once you’re married it doesn’t matter then. They’re gonna have to put up with it.”’

(Interview 19, in English, female, aged 26–40 years)

An older participant confirmed that even if young people themselves feel uninhibited about disclosure, their parents might still have concerns about compromising their marriage prospects:

‘These days the children themselves they mingle with each other and they do know about these things, but their parents if it is for the sake of arranged marriages they won’t discuss any illness.’

(Interview 26, in English, male, aged 40–59 years)

However, another older woman took a different view. She described how she disclosed her own son’s type 1 diabetes:

‘I telling “I sorry my dear, don’t put sugar in my tea, I’m diabetic.” My son is the same. My son married, telling in the first month: “My son, he’s diabetic. You look after [him], he look after you”.’

(Interview 13, in English, female, aged 40–59 years)

The main concern that emerged about the effects of disclosure on one’s marriage prospects was associated with perceptions about the hereditary nature of diabetes:

‘Some people say if one person does have diabetes then it follows everybody, that’s what people say, everybody can get [it] if one person in the family has it.’

(Interview 4, in Gujarati, male, aged 40–59 years)

‘the Asian community generally, then it’s issues like how’s she going to get married, who’s going to marry her, is she going to be able to have kids?’

(Interview 19, in English, female, aged 26–40 years)

Discussion

Despite the negative attitudes reported here, the majority of participants were undeterred about disclosing their condition. Disclosure conferred benefits at social events and at work. It facilitated self-care activities, alerted people to possible emergencies arising from hypoglycaemia, and elicited supportive behaviours from others. Marriage prospects were the only exception to this, and appeared to be linked to beliefs about the hereditary nature of the condition. This finding is

consistent with media reports from India about difficulties that people with type 1 diabetes experience in securing and maintaining marriage partners (The Tribune, 2006). In particular, the perception that people with type 1 diabetes are unable to have healthy children is thought to prevail in India, and families in India are reported to experience difficulty in securing marriages for girls with this condition (The Tribune, 2006). A study of people with type 2 diabetes in a Bangladeshi community in the UK revealed that refusal to commence insulin therapy was partly due to beliefs about the potentially negative impact on marriage prospects (Khan *et al*, 2008). Consequently, some people choose not to disclose their condition before marriage (Kalra *et al*, 2009).

In a metasynthesis of qualitative studies involving South Asian people with diabetes, culture was argued to be one of many factors that a person with the condition interprets and acts upon (Fleming and Gillibrand, 2009). The present study supports this argument. Although the practical demands of managing the condition exerted a strong influence in favour of disclosure, the cultural context retained a powerful role in deciding when the risks associated with disclosure outweighed the benefits (Kalra *et al*, 2009).

Limitations of the study

This study contributes to the literature about the social and cultural context in which South Asian adults with type 1 diabetes in the UK live with their condition. Although the number of interviews was small, sampling was based on rigorous methods involving purposive selection of participants and regular review of transcripts to consider the question of saturation. However, we acknowledge that people who are comfortable discussing their diabetes are more likely to take part in such a study. Our sample may have been biased in terms of positive attitudes to disclosing diabetes status. This was apparent during the recruitment phase of the study, when a young married woman discussed with the researcher how social stigma, among other factors, had a detrimental effect on the support that she received from family and friends. The process of describing these experiences became too emotionally disturbing for her, and she felt unable to continue with providing initial consent.

We also acknowledge that our findings about a specific group of people in one city cannot be assumed to be generalisable to other South Asian groups in the UK or elsewhere. The term ‘South Asian’ is used in the UK to refer to people who originate from several countries, who have different migration histories, languages and religions. Those living in western countries are also distinguished by the geographical settings

in which they live and, like our sample, have developed their own unique characteristics. In our view, further research is needed to confirm our findings in other settings.

Conclusion

It is important to view all patients, including those from South Asian backgrounds, in their social context, and to be aware that they may be affected by other people's perceptions. For South Asian people, the impact of a diagnosis of diabetes on marriage prospects may be a particular concern, and may compromise social and family support (Polonsky *et al*, 1995). Our findings have implications for patient education and the specific needs of South Asian people with type 1 diabetes.

ACKNOWLEDGEMENTS

We would like to thank Ninaben Patel for checking the translated transcripts, the hospital staff for their assistance with patient recruitment, and the participating patients for their contributions to this study. This study was funded by the Insulin Dependent Diabetes Trust.

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CONFLICTS OF INTEREST

None.

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