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Empowering patients with diabetes: a qualitative primary care study focusing on South Asians in Leicester, UK

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Objectives. We aimed to explore the experience and attitudes of primary care patients with diabetes living in a UK community with a high proportion of South Asian patients of Indian origin, with particular reference to patient empowerment.

Methods. Semi-structured interviews were conducted with patients with diabetes attending two general practices in Leicester, UK. Patients were interviewed in English, Gujarati or Punjabi and interviews were transcribed with translation into English where necessary. Broad themes were identified and Framework charting was used to organise data for analysis.

Results. Interviews were conducted with 15 South Asian and 5 white patients. We identified both similar and culturally specific elements within the experience, attitudes and barriers in the two ethnic groups. High regard for education, particularly in South Asians, was associated with a positive attitude to empowerment through knowledge, but also sometimes led to low motivation to become partners in diabetes management. High prevalence of diabetes and strong family networks meant that families were an important source of knowledge for South Asians and that these patients generally had good emotional support. Practical considerations such as the need for a convenient venue for educational initiatives were common to both ethnic groups, but some cultural preferences were also identified, for example for appropriate language provision and separate gender sessions.

Conclusions. Educational initiatives aimed at promoting self-management in chronic diseases such as diabetes need to be designed with an awareness of the complexity of social and cultural experiences and attitudes in target communities.

Keywords. Diabetes mellitus, education, ethnicity.

Introduction

Involving patients as partners in their care may lead to more effective chronic disease management[1] and there has been a call to empower patients with chronic conditions such as diabetes through education to encourage self-management.[2] An example of such an initiative is the Expert Patient Programme.[3] A systematic review of patient self-management educational initiatives identified small to moderate positive effects for selected chronic diseases including diabetes.[4] Although no controlled studies relating to South Asian populations were included in a review of diabetes self-management interventions in disadvantaged populations,[5] a pilot randomised controlled trial published since this review found that an educational programme for a predominantly Pakistani Moslem population in the UK was ineffective.[6] An uncontrolled study reported in 1987 found that merely providing advice in an Asian language was ineffective as an educational intervention to encourage dietary modification in South Asian patients with diabetes in Leicester.[7] It is clear that meeting the educational needs of South Asian patients with diabetes is a challenging task; there is, however, some limited

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evidence that education and support initiatives aimed at meeting the needs of this group can be effective.[8,9]

The need to reduce health inequalities has been emphasised.[10] In addition, it is particularly important to address the needs of patients who may have a raised risk of developing diseases such as diabetes. The prevalence of Type 2 diabetes in the UK is known to be much higher in South Asians compared to Caucasians,[11–15] with an associated increase in coronary heart disease.[15]

Ethnicity is not just a question of language; cultural differences including experiences and health beliefs need to be identified and acknowledged. A study in patients attending outpatient clinics found for example that individuals from ethnic minority backgrounds were less likely than Caucasians to agree that their diabetes was a chronic condition.[16] A study in a Bangladeshi community in East London[17] identified some particular health beliefs and attitudes in this group, but the authors also found that factors associated with social deprivation were at least as important as cultural barriers to behaviour change.

For any educational initiative to be successful in meeting the needs of the target community, providers need to be informed by an understanding of patients' lifestyles, attitudes and beliefs, including the patient experience of their condition. It is therefore important to add to this understanding in relation to different communities, since ineffective patient education is likely to be wasteful in terms of resources and missed opportunities to improve patient wellbeing. In this qualitative study we aimed to begin to explore these areas of interest in patients with diabetes, particularly those of South Asian ethnic origin, registered with GPs in the city of Leicester, UK. In particular we aimed to consider attitudes to patient involvement in diabetes management and cultural barriers and preferences related to possible educational interventions aimed at encouraging self-management.

Methods

A topic guide containing suggestions for open-ended questions and prompts was developed by the research team for use in a series of semi-structured interviews. Suggested topics for discussion included the patient experience of diabetes, sources of knowledge about this condition, views on patient involvement in diabetes management and attitudes to possible educational initiatives to encourage self-management. The Expert Patient Programme was not specifically mentioned; possible initiatives were described in general terms as structured or informal group sessions or one-to-one sessions. A quota of 20 interviews was set, reflecting our estimate of an achievable target which would enable us to reach saturation in terms of the identification and exploration of key themes. A sampling frame was drawn up to ensure a varied sample of patients; the quota set included recruitment of 15 South Asian patients, reflecting our primary interest in this ethnic group, with 5 interviews with patients of Caucasian origin from the same community to be recruited for comparison.

Two volunteer general practices in Eastern Leicester Primary Care Trust (PCT) were recruited to assist with the study. This PCT serves a community with a high prevalence of South Asians, predominantly Gujararati speaking and of Indian origin. Patients attending for review of their diabetes at the two participating practices were initially approached by their doctor or practice nurse. The research assistant with relevant language skills working on the study was generally available at the surgery to assist with giving a more detailed explanation of the research project to any patients who expressed an interest. A written information sheet in English was supplemented by audio-taped versions in Gujarati, Hindi and Punjabi. Interviews were conducted in English, Gujarati or Punjabi by one of two interviewers either in the patient's home or at their general practice, according to the interviewee's expressed preference. All interviews were transcribed; where the interview had been conducted in a South Asian language, transcription with simultaneous translation into English was carried out by the person who conducted the interview. Transcripts were regularly reviewed and discussed during the conduct of the study, in order to identify emerging themes and inform subsequent interviews.

All transcripts were reviewed in detail by two members of the research team who agreed broad themes for the analysis. Framework charting[18] was subsequently used to organise and summarise the data for more detailed thematic analysis.

Results

Patient sample

Interviews were conducted with 15 South Asians of Indian origin and 5 Caucasian patients (Table 1), in accordance with our sampling frame. Seven interviews (including 2 with patients of South Asian origin) were conducted in English, 12 in Gujarati and one in Punjabi. After completing our pre-set quota, it was considered that themes had been well explored and that saturation had been reached in terms of the emergence of relevant new themes.

The patient experience: attitudes to diagnosis

Two broad typologies were identified when looking at what patients said about their reactions to being diagnosed with diabetes. For some the diagnosis had been a shock and they had therefore found it difficult to accept; others, however, demonstrated an attitude of resignation or sense of inevitability. There was no

TABLE 1 *Characteristics of patients interviewed*

	All patients $n = 20$	South Asians $n = 15$	Caucasians $n = 5$
Male, female	9, 11	6, 9	3, 2
Age in years: mean (range)	57 (33–80)	58 (37–80)	53 (33–72)
Diabetes: Type 1, Type 2	1, 19	0, 15	1, 4
Years diagnosed: mean (range)	9.4 (<1–35)	8.7 (<1–35)	11.4 (<1–25)
Current treatment:			
Lifestyle modification	1	1	–
Oral medication	13	1	12
Insulin	6	4	2

clear-cut categorisation by ethnic origin, but South Asians most commonly fell into the second category of patients who had accepted their diagnosis with resignation, due to the frequency of a family history of diabetes in this high risk group and in some cases an expressed view that their condition had been sent by God.

> ''My dad was diabetic, but he's passed away now; my mum's diabetic—so I knew that along the line I'd end up with it.'' (South Asian male, interview no. 15)
> ''It's all to do with God whether you get it [diabetes] or don't get it.'' (South Asian male, interview no. 3)

The patient experience: difficulties faced

Modifying diet was the most frequently cited difficulty faced by interviewees. South Asians sometimes felt that their traditional diet presented particular problems, for example relating to high usage of fat in South Asian cooking and the high sugar content and popularity of Asian sweets. Specific concern about coping with diet when visiting relatives in India was also mentioned. Problems with diet modification were not, however, exclusive to South Asians.

> ''You know how Indian sweets are, and I used to have a lot of them.'' (South Asian male, interview no. 1)
> ''Sometimes we go to India for a month—we need advice on … what light foods to eat so we don't have problems.'' (South Asian male, interview no. 10)
> ''You know, it's hard, because you think one thing's good for you and you find out it's not, it's full of sugar and—you know what I mean?'' (White female, interview no. 19)

Interviewees also often mentioned anxiety and frustration associated with their experience of diabetes. South Asian women in particular appeared to find coping with impaired health difficult.

> ''I eat less of the fried food, I don't eat sugar, I drink tea without sugar, and then when I do get this dizziness I feel really upset that I do all this dieting and controlling—then why do I still get this?'' (South Asian female, interview no. 9)
> ''I was first told by the doctors not to take medicine and to try and control it myself, but I know I couldn't control it myself because of my depression. Depression makes me angry and then you can't control it.'' (South Asian female, interview no. 5)

Anxiety was often related to concern about possible future complications of diabetes.

> ''I am able to walk properly, see properly, so I don't have any problems … but I don't know what is going to happen in time ahead.'' (South Asian male, interview no. 2)

Types of support: emotional support

In seeking to understand the ways in which patients in this community found help in coping with their diabetes, we identified two main types of help, that is emotional support and empowerment through knowledge. We found that shared experience was an important source of emotional support. White British interviewees sometimes benefited from this type of support; however, South Asians in particular frequently appeared to be well supported in this way.

> ''Mm, he asks me sometimes, I ask him, I say 'what level, you know, when you test yours?' When we see each other, so he asks me, I ask him, 'how much is yours?' and like that, you know.'' (South Asian male, talking about his brother, also with diabetes, interview no. 1)
> ''sometimes I feel dizzy and sometimes I feel weak, so we all talk to each other [friends with diabetes] and they tell me what they do and eat and I tell them.'' (South Asian female, interview no. 18)
> ''I've got my husband to talk to. We confer about things. If he's not feeling well he'll say 'oh, I don't feel right, do you think it could be this or that?' and I'll say 'try this or try that.' So we talk to each other about it.'' (White female, interview no. 19)

One interviewee, however, raised the issue of possible negative effects of sharing experiences with peers in the absence of good understanding of diabetes, in terms of the potential for increasing tension and anxiety.

> ''I have got diabetes, why do I need to keep talking about it? … It's like my friend who came over and said 'I have got diabetes and I am taking these tablets and it is all normal for me' and then I said

> 'I take the same tablets—so why is it not working for me?' I just got worried on top.'' (South Asian male, interview no. 3)

For South Asians, emotional support in accepting and living with their condition was sometimes complemented by spiritual support provided by their religion.

> ''The saying is those who have no one have God, so see God has given me my son, he looks after me.'' (South Asian female, interview no. 4)

Types of support: empowerment through knowledge

Relatives were mentioned as an important source of knowledge about diabetes, particularly for South Asian interviewees.

> ''Well my dad, grandma and aunt had this so I got to learn from them.'' (South Asian female, interview no. 13)

Other sources of knowledge were health professionals, including leaflets offered by the general practice in an appropriate South Asian language. Some interviewees had been given access to videos and some had gained additional information from libraries, the internet, newspapers or television.

Attitudes to self-management

Interviewees felt that it was possible to play a part in controlling their diabetes through lifestyle modification and adherence to treatment, but both white and South Asian interviewees varied in the extent to which they felt they would wish to be involved in decision making. South Asians in particular appeared to value education and generally expressed high regard for knowledge acquired from an 'educated person'.

> ''if someone is willing to explain to me then I am willing to learn ... what it is, you can learn more from an educated person.'' (South Asian male, interview no. 2)
>
> ''if it was someone who is educated then they can teach me something whereas if it was someone just like me, someone with diabetes, what will I learn from them?'' (South Asian female, interview no. 4)

However, it was apparent that this expressed interest in increasing their ability to be involved in their own management through education might not necessarily be matched by action. Most interviewees demonstrated only a fairly basic understanding of their condition, often restricted to the concept that they needed to control their 'sugar' levels and that diabetes can cause complications. South Asians in particular often said that they did not know the names of their medication. When possible educational initiatives were discussed, interviewees generally said that these sounded very useful, but they did not necessarily give the impression that they would be likely to attend a group or individual session themselves.

Those interviewed were not routinely asked about self-monitoring, since our study related to patient involvement in wider terms, but it was noted with interest that only five of the 20 interviewees mentioned blood or urine home monitoring during discussion about patient involvement in diabetes care. One of these complained that they had not been offered any means of testing at home, whilst another seemed unsure of how home monitoring could assist with modifying diet.

> ''... controlling your diet, how to keep it in control. We take tablets, but how are we supposed to know if it's in control or not? I've got this stick thing to measure it with and I have also got this machine and with that you know what it is, whether it is 7.5 or 8.5 or whatever.'' (South Asian male, interview no. 11)

Barriers to knowledge acquisition

We identified various barriers to acquiring knowledge, some of which were common to interviewees from both ethnic groups and some of which were more culturally specific. Those interviewed often had multiple health problems, which were sometimes seen as restricting their knowledge seeking behaviour. Practicalities such as getting to the venue for educational sessions were sometimes seen as barriers and most interviewees emphasised that group sessions would need to be held somewhere very convenient such as their general practice. The issue of cultural preferences in relation to education was also raised, with South Asian women in particular sometimes expressing a preference for gender specific sessions.

> ''I don't feel very comfortable talking to a man.'' (South Asian female, interview no. 7)

In some interviews, limited understanding was suggested as a barrier to acquiring knowledge and this was sometimes related to English language difficulties.

> ''I don't know English very well, so what he [the doctor] tells me and what I understand are two very different things and what I say he might not understand, so we end up in trouble.'' (South Asian male, interview no. 3)

However, language was not necessarily seen as a barrier to acquiring knowledge by South Asians with limited English, since they often had access to a health professional with Asian language skills and/or written materials in their native language. Most of those whose English was limited had a relative who could interpret and translate for them. It was apparent from the interviews that language is not the only consideration in terms of understanding. Many of those interviewed

appeared to find the idea of a structured group education initiative difficult to grasp and difficulties with conflicting advice had also caused problems for some. White British patients as well as South Asians suggested that information offered about their condition could be difficult to understand.

> ''Do you know how it happens? I go to the dietician and she gives me different advice, the nurse gives me different advice, everybody says different things to me.'' (South Asian female, interview no. 5)
> Interviewer: ''Would you have liked to have been offered someone to talk to?''
> White male, interview no. 20: ''If they talked in layman's I would, knowing what they say what these tablets are for. It's when they start using the technical terms . . .''

Although high regard for education, as noted above, could have a positive influence on motivation to acquire additional knowledge, it was also apparent that in some cases this could also be a barrier to self-help for both South Asians and White patients, by creating a feeling that management should be left to qualified health professionals.

> ''I'd rather leave it up to those with more information.'' (South Asian male, interview no. 11)
> ''I'm sort of following doctor's orders. As far as I know the stuff he's giving me is holding me nice and steady.'' (White male, interview no. 20)

Discussion

Health professionals working in primary care play an important role in the management of patients with diabetes, particularly those with Type 2 diabetes. Those working in multi-cultural populations need to be aware of the cultural experiences and needs of their patients, but research, particularly recent work, in this field has been limited. In our multi-ethnic study population in Leicester we identified both shared and culturally specific factors affecting patients' experience of and attitudes to their health. We found that the high prevalence of diabetes in the South Asian population and strong family ties play a key role in shaping the attitudes and experience of patients from this ethnic group. Although diet was a concern for both groups, South Asians felt that they faced particular problems in this respect. Patients from this ethnic group expressed high regard for education, but demonstrated poor levels of knowledge about their disease and limited motivation to attend educational sessions. Communication problems were not restricted to language and were sometimes also experienced by white British patients. Health related anxiety and sometimes depression were commonly suggested in those interviewed, particularly South Asian women.

This study was based on a limited sample of qualitative interviews with South Asian patients of Indian origin from a particular community in Leicester. Our findings may not therefore be generalisable to the South Asian population throughout the UK and need reinforcing through further work. Nevertheless, we have identified a number of key themes which may be useful in raising awareness of the experience and attitudes of South Asian patients with diabetes and which may need consideration when designing and publicising educational initiatives aimed at promoting patient self-management.

The high fat and sugar content of the traditional South Asian diet has been previously noted, including high use of ghee and cooking oils and frequent consumption of fried snacks by Gujarati Hindus.[19–21] The importance of offering and accepting food in the strong hospitality culture of South Asians has also been recognised.[7] Our study underlined the fact that some South Asians see their traditional diet as a specific barrier which makes diabetes control more difficult for them than for their white British counterparts.

It is unclear how many interviewees had experience or knowledge of home urine or blood monitoring, but the small number who mentioned this would suggest that in our sample it was not seen as playing an important role in empowering patients with diabetes. Patients demonstrated low overall levels of knowledge about their condition, confirming previous findings. In the Coventry Diabetes Study,[21] knowledge of diabetes was found to be low in both Asians and European with diabetes, but particularly in South Asians.

Some attitudes, such as high regard for education, were noted to have potential for both a positive and negative influence on motivation to be involved in self-management in diabetes. Similarly, some features of the South Asian experience, for example strong family networks and frequent family history of diabetes, could be positive in terms of providing emotional support, but might also reduce patients' motivation to seek additional support such as that offered by educational initiatives. Our study provides no evidence for the likely rate of uptake if patients in the study community were actually offered self-management education, but limited interest in the types of initiative discussed shown by most interviewees accords with previously reported difficulty in recruiting South Asian patients to attend an educational programme.[9]

The link between anxiety and depression and diabetes needs further clarification, but a meta-analysis[22] showed that the risk of depression in controlled studies of patients with Type 1 and Type 2 diabetes was twice that of the non-diabetic comparison group. Lower rates of consulting[23] and prescribing[24,25] for mental disorders have been reported for Asians registered with GPs

compared to their white British counterparts, but the actual prevalence of treated or untreated anxiety and depression in the South Asian community is unknown both overall and in patients with diabetes. Although findings from our small qualitative sample cannot provide evidence in terms of prevalence, there was some suggestion that South Asian women with diabetes may be at particular risk in terms of anxiety and depression.

Further work is needed in order to identify in more detail the needs of patients with diabetes in this type of multi-ethnic inner city community, including practical and organisational needs, and to consider the best ways of addressing these needs. Educational initiatives which aim to promote self-management in diabetes need to be designed with an awareness of the complexity of these issues.

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