

Research paper

Cultural negotiations in health and illness: the experience of type 2 diabetes among Gujarati-speaking South Asians in England

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What is known on this subject

- We know that South Asian communities in the UK have a higher risk of type 2 diabetes than white British people.
- Current health policy and research indicate that there are deficits in education and knowledge about the best ways to manage diet, exercise and medication within South Asian communities.
- There is much potential for exploring in depth understandings of the lived experience of diabetes within South Asian communities, to complement the existing knowledge base.

What this paper adds

- This study indicates that, as health science discourse often uses a combination of genetic, cultural and lifestyle factors to explain high rates of diabetes, there is a parallel and related construction of a South Asian diabetes risk.
- Using qualitative in-depth methods to explore the study participants' experiences, it is possible to identify how health and illness are situated within complex social, cultural and biographical frameworks.
- It is possible to look beyond constructions of diabetes risk towards the way participants with diabetes utilise their life experience, their history and their social and cultural community to manage their condition. In doing so they demonstrate a form of resistance to the constructions of diabetes risk that can be imposed by health science discourse. This paper shows how their ethnic and cultural identities are often invoked in dynamic and flexible ways to help them to deal with their condition.

ABSTRACT

Diabetes has become a global health problem, with both physical and psychosocial effects on people's lives. The South Asian communities in the UK have been identified as high-risk groups, with high rates of type 2, non-insulin-dependent diabetes (NIDDM). This paper reports on an exploration, based on qualitative methods, of South Asian Hindu Gujarati-speaking people's experiences of type 2 diabetes. Participants were recruited through purposive and snowball sampling, and a grounded theory framework was utilised to generate and analyse data. The emergent themes suggest that while health science discourse in a variety of forms has constructed a type of South Asian diabetic risk, alluding to a particular relationship between health and ethnicity, the participants in the present study expressed active resistance to this construction, through their accounts of diabetes management. By exploring the biographical,

historical and socially embedded contexts of diabetes, the participants constituted culture and ethnicity as dynamic entities, contingent on social and personal contexts. There were four major themes in the study, namely notions of familiarity with the illness through family and social connections, the management of physical exercise and activity, the personal and social moderation of food and nutrition, and the use of complementary remedies. This paper argues that it is these active and dynamic constructions of cultural and ethnic identity which health science discourse needs to acknowledge in order to understand how people manage their diabetes, and where help and support might best be channelled.

Keywords: constructions of risk, culture, South Asian, type 2 diabetes

Introduction

The 2001 UK Census (Office for National Statistics, 2005) indicated that Asian and Asian British groups represent 3.96% of the total population of the UK, and 50.29% of the total non-white groups. Specific research into black and minority ethnic (BME) health has shown an over-representation of illness in these communities (Nazroo, 1997). Hindu Gujarati-speaking people are a subgroup of the South Asian population in England. This paper focuses on the experiences of 18 members of this subgroup, consisting of 17 individuals with type 2 diabetes and one with type 1 diabetes.

Diabetes is a global health issue, and the total number of people with diabetes is projected to rise from 171 million in 2000 to 366 million in 2030 (Wild *et al*, 2004). Currently there are 2.5 million people in the UK diagnosed with diabetes mellitus (Khunti *et al*, 2009). People of South Asian origin have a higher incidence of diabetes, especially of type 2, non-insulin-dependent diabetes (NIDDM), 2.5 to 5 times higher than in the white population (D'Costa *et al*, 2000; Davies, 2001; Department of Health, 2004), and they present with the condition at a younger age (Khunti *et al*, 2009).

Gujarati people and migration to the UK

Gujarat is a state that lies north of Mumbai on the west coast of India. Historically, its location made it an ideal place for trade routes to a variety of locations, including other Indian states, Africa and the Middle East. Trade meant that Gujarat developed a thriving culture of trade, commerce, hard work, frugal living and entrepreneurial skills that continued as the 19th century progressed. Gujarati migration was initially the result of trading activities, and later a response to the British colonial expansion into East Africa (Warrier, 1994). Later still there developed a pattern of migration to the UK (Hill, 1969; Hiro, 1992; Ballard, 1994; Visram, 2002). There are estimated to be 750 000 Gujarati-speaking people resident in the UK, of whom 80% are Hindu, thus representing a significant culturally specific diaspora (Ballard, 2002).

Research on the experience of diabetes

Approaches to research on living with diabetes have focused mainly on the overall coping, control and

management systems that people employ in their everyday lives. Studies have, for example, examined issues that affect physiological, psychosocial and practical arenas (Kelleher, 1988), and the application of a variety of chronic illness frameworks, such as biographical disruption (Bury, 1982; Rajaram, 1997), post-structuralist theories (Drummond and Mason, 1990) and lay theories of causation (Mercado-Martinez and Ramos-Herrera, 2002).

Much of the in-depth work on the diabetes experience of BME communities in the UK has been conducted with Bangladeshi and Pakistani groups (see, for example, Kelleher and Islam, 1994, 1996; Greenhalgh *et al*, 1998, 2005; Lawton *et al*, 2006), mainly due to the higher illness rates. A qualitative study by Greenhalgh *et al* (1998) demonstrated the role of narratives and sharing stories, specifically in the context of group forums and action research. In a more theoretical vein, Kelleher and Islam (1994, 1996) examined coping strategies and management of diabetes among a group of Bangladeshi people in London, and highlighted problems of structure and agency in health issues.

The experiences of South Asian Hindu Gujarati-speaking communities with regard to diabetes are relatively under-addressed, although there is a growing body of research in this area (see, for example, Simmons *et al*, 1992; Stone *et al*, 2005, 2008; Khunti *et al*, 2009). Research has tended to use distinctions between groups based on national and intra-national boundaries (hence Indian, Pakistani and Bangladeshi groupings). However, this is an oversimplification of a complex issue. The homogenising of groups, as Ballard (2002) emphasises, which are clearly distinctive in terms of culture, language, religion, social and community networks and migration histories, does little justice to people's diverse experiences.

Theoretical approaches to culture and ethnicity

The simplistic use of the terms 'culture' and 'ethnicity' as static and unchanging ideas has been vigorously critiqued (Ahmad, 1993; Smaje, 1995; Bhopal, 1997; Ahmad and Bradby, 2007). As reified markers of difference they can lead to what Ahmad (1993) has suggested is a loss of fluidity and dynamism. There is also the resultant loss of explanatory power in research, caused by rigid notions of what it means to belong to a specific cultural and/or ethnic grouping and the assumed related behavioural mechanisms involved (Kelleher, 1996). There is a need to credit individuals and groups of people in society with agency, with the specific need in health and illness to elaborate how people demonstrate their agency and its relationship with other

social forces. For example, Ferreira and Lang (2006), in their anthropological study of diabetes experiences, gained access to cultural worlds in the context of group history and culture in symbolic and practical terms, by locating health ideas, solutions and avenues for better lives within social and cultural lived contexts. The qualitative study by Greenhalgh *et al* (1998) emphasised how cultural beliefs in their Bangladeshi sample could be used effectively in culturally sensitive diabetes education.

Constructing and deconstructing the South Asian diabetes risk

Health science discourse, including policy and academic research, has attempted to explain the high incidence and prevalence of diabetes in South Asian communities. Studies vary in their emphases, and include genetic predispositions to insulin resistance (McKeigue *et al*, 1991), primary metabolic effects (Abate and Chandalia, 2003), 'lifestyle' factors such as lack of exercise (Gupta *et al*, 1995; British Heart Foundation, 2001), and diet and nutrition (Gupta *et al*, 1995; Naeem, 2003). The often vaguely conceptualised role of culture (see, for example, Hill, 2006) can again propose problems for South Asian groups by making generalised claims that South Asian diets are lacking in fruit and vegetables, and that their lifestyles are lacking in physical exercise. While alerting us to the need for sensitive and specific diabetes healthcare, this seems to invoke the cultural pathology notions of the past which appear to persist even though health promotion has been under the watchful critique of sociology (Bunton *et al*, 1995), as has health promotion for ethnic minorities (Bhopal and White, 1993).

The epidemiology of diabetes is not in question, but placing the burden of responsibility on 'aspects of South Asian culture' (Hill, 2006, p. 64) needs to be done with caution. Policy-led initiatives have in the past been limited in their efficacy in treating the concepts of ethnicity and culture. In a research review, the Department of Health and the Medical Research Council Research Advisory Committee on Diabetes (2002) attempted to address the increase in diabetes cases among minority communities. The recommended method was implementation of 'innovative lifestyle educational methods' which 'involve working with Indian restaurants to provide low-fat alternatives on their menus' (Department of Health and the Medical Research Council Research Advisory Committee on Diabetes, 2002, p. 129). Reducing the amount of unhealthy fats consumed by people may well have a biological and public health logic behind it, but it is

unclear how such menus might affect the experience of diabetes management and health maintenance among South Asian people with diabetes. The theoretical and practical purpose of this idea about menus needs to be questioned. Embedded within this line of reasoning is the assumption that there is something 'faulty' within South Asian diets which needs to be 'fixed' in some way, thus reverting health analysis to the older models of cultural pathology. It also, of course, suggests that the primary market for these restaurants consists of South Asian people, which any glance at the diners will show to be fallacious. The national dish of Britain is still 'curry' rather than either fish and chips or roast beef!

The explanatory utility of these various approaches is questionable. For example, the study by Gupta *et al* (1995) implied that South Asians could be seen as a genetically distinct group (i.e. a race) who used too much *ghee* (clarified butter) for cooking, and consistently did not take enough exercise. All of these notions have been refuted by other research (Abate and Chandalia, 2003). Other studies have shown that diet alone does not contribute to insulin resistance (Sevak *et al*, 1994).

In this paper I shall argue that health sciences discourse has constructed what can be termed a *South Asian diabetes risk*, a discursive and practical mechanism through which a particular risk identity is shaped, using ethnicity and culture as fixed and static entities. The participants' narratives in this study suggest that there is what can be articulated as a *resistance* to these constructions in people's everyday lives, and that this is activated through the negotiation of socio-cultural landscapes.

Method

The findings in this paper were generated by conducting in-depth interviews with South Asian Hindu Gujarati-speaking participants. Qualitative approaches facilitate the elaboration of the different dimensions in which the social world operates, by emphasising the 'understandings, experiences and imaginings of our research participants ... and the significance of the meanings they generate' (Mason, 2002, p. 1). This emphasis on in-depth exploration of the subjects' lived world formed the basis of the study. Sociological investigation needs to provide what Smaje (2000, p. 114) has termed 'a critique of ideology' in relation to health, illness and ethnicity. This means locating the concepts of race and ethnicity in a wider socio-historical context, thereby rendering them as 'ideological categories ... and not analytical concepts.' Part of this project of re-examining these concepts is to look to qualitative research in health and ethnicity, which articulates people's experiences in terms of their

own voices, rather than the formulations imposed by ideologically imposed frameworks.

Data collection and analysis

A topic list was used to guide the process of questioning and interacting with the participants, and focused on the experience and management of diabetes within the context of migration histories and the use of different medical systems. As the study progressed, more items and lines of inquiry were added so that experiences which emerged as important to the participants could be explored fully. In accordance with the generally accepted model of theoretical sampling in qualitative research (Mason, 2002), the recruitment of participants and the search for data ended when the rate of emergence of new codes and categories began to decrease.

Most of the interviews took place in participants' homes, and in most cases there was a third person present, usually an immediate relative. Contrary to the suggestion by Boeije (2004) that the presence of a third person decreases validity, here it was seen as a resource for the study, which could be utilised to obtain a rich account of the socially and culturally embedded experience of diabetes. This seemed to be an appropriate strategy, since the management of type 2 diabetes is rarely a lone biographical project, but rather a personal and social activity that is carried out in the context of relationships (Peyrot *et al*, 1987). People were aided by significant others in complex webs of knowledge, beliefs and products, so it seemed appropriate that a qualitative and situated sociology should engage in these relationships rather than negate or ignore their value.

The interviews were conducted in English and or Gujarati, lasted for between 40 and 100 minutes, and were audio taped. The interviews were translated, and were then transcribed and analysed using a grounded theory style of framework so that the process of theory building was rooted in the data (Charmaz, 2006). The process was similar to the exploratory, ethnographic approach adopted by Hodkinson (2008), which allows a continual process of data generation and analysis to occur in a flexible and dynamic way. Many of the procedural guidelines of grounded theory were used, such as memo taking, making detailed field notes, and comparison of categories. However, the emergent themes arose through an interaction of the data and field notes with existing knowledge and literature, as well as aspects of my own Gujarati identity and cultural knowledge. The interactions between myself and the participants were the connections of identities, linked by language, dialect, accent, history, biography and forms of ethnic belonging. I suggest here that this series of linkages constituted *cultural validations*,

harnessing and channelling the interaction of identities whereby the researcher is clearly and openly positioned in the research process (Keval, 2009, in press). This has a particular resonance for the study of health and ethnicity, where the roles and ethnicities of researchers have been the subject of detailed scrutiny (Song and Parker, 1995; Gunaratnam, 2003). In this study, these intersections or connections are regarded as fluid and contingent rather than as essential and fixed, and they characterise the research and findings.

Ethical approval and informed consent

Ethical approval was obtained from the University Ethics Committee. Each participant was given an informed consent form to read and sign. Anyone who was not able to read the form in English was given the opportunity to keep the form, and have it read and translated for them by someone they knew. Although Lloyd *et al* (2008) have recently discussed the option of audio-recording consent, in this study written consent forms were provided. I also read out the form to the participants, translating where necessary. This gave the participants an opportunity to discuss the consent form with someone whom they trusted and with whom they felt able to share their thoughts. Those participants whom I felt were not entirely sure about agreeing to take part were reassured that they could speak to someone in their family or social circle before they made a decision.

Although the study fully conformed to the ethical guidelines set out by the University of Surrey and the British Sociological Association's ethical framework for research in relation to informed consent, it raised an interesting set of issues. Most of the participants were not aware of, familiar with or interested in the subject or concept of informed consent. On the whole, when the forms were explained to them, they told me that they would sign anything they needed to, so long as it was helpful to me. In many cases they would also question why I had asked their permission, stating that there was no need to ask, as there was an inherent trust by virtue of my presence in their house, and the fact that they were talking to me about this important health topics. This raised issues of conceptual conflict between what I term here the *cultural versus professional* validations conundrum, issues of vulnerability and the inherent trust that is built up in this type of research, which can be a problem if personal ethical principles are not rigorous enough. I was very aware that it was possible to forego the 'paperwork' involved and get straight to the interview or discussion, but I made a conscious decision not to do this. Consequently, informed consent guidelines were fully adhered to and all of the participants gave their

signed permission. For the purposes of anonymity and data protection, all names used here are pseudonyms.

Sampling and recruitment

This study used theoretical/purposive (Strauss and Corbin, 1990) and snowball sampling (Hughes *et al*, 1995) to recruit South Asian Hindu Gujarati-speaking participants and to generate data. The age range of the participants was 40–88 years, and a total of eight women and ten men took part (see Table 1). The interviews took place in three areas of the UK, namely the Midlands, one city in the North West and one location in the South East.

As a person of South Asian Gujarati origin, I was already familiar with the culture and language of the community under study. This enabled me to gain access to individuals and groups using both personal contacts and gatekeepers who facilitated my presence at a number of gatherings in local temples and

community centres, and who could make the appropriate contacts and inform people about my study, passing on my contact details (Fielding, 2008). This meant that access was mediated by and partially validated by someone who was known to the participant. This approach is quite common in ethnographic work (see, for example, Emerson *et al*, 1995; Berg, 2009). Contact details were collected from potential participants, who were then telephoned to discuss the possibility of an interview. However, this process was not without problems, and in some cases participants were hesitant about taking part in the research, or perhaps felt unsure of their role in relation to the research. In these circumstances I engaged with the individual and other trusted representatives in the community and ensured that the potential participants understood both their own and my role in the process. The cooperation of the participants was facilitated by adhering to ethical guidelines to ensure minimal risk, as well as using my own linguistic, cultural and origin-based identity.

Table 1 Study participants

	Name (pseudonyms)	Location	Age (years)	Gender	Type 1/tType 2 diabetes	Length of time with diabetes (years)
1.	Dhansuk	Midlands	54	M	T2	6
2.	Jagan	Midlands	58	M	T2	5
3.	Sunita	Midlands	70	F	T2	8
4.	Deena	Midlands	70	F	T2	6
5.	Sushila	Midlands	45	F	T2	3
6.	Rina	Midlands	40	F	T1	3
7.	Naresh	Midlands	72	M	T2	6
8.	Harish	Midlands	74	M	T2	20
9.	Kanti	Midlands	88	F	T2	18
10.	Bikhu	South East	58	M	T2	5
11.	Basanti	South East	65	F	T2	6
12.	Pramod	Northwest	59	M	T2	15
13.	Bharti	Northwest	54	F	T2	8
14.	Preeti	Midlands	56	F	T2	1.5
15.	Hasmukh	Midlands	53	M	T2	N/a
16.	Nilesh	Midlands	51	M	T2	28
17.	Rajesh	Midlands	51	M	T2	6
18.	Kishore	Midlands	59	M	T2	25

Findings

Four key themes were identified, namely familiarity with diabetes, exercise and physical activity, diet and social obligations, and the use of complementary remedies. The findings with regard to each theme are presented below.

Familiarity with diabetes

All of the respondents were aware of diabetes through families and social connections, and referred to it as a 'sugar problem.' This included awareness of the general nature of the illness, the medication regimes, the necessary changes in lifestyle, and the physical effects. Familiarity also functioned as a buffer to reduce the emotional impact of the diagnosis. For example, Kanti, an 88-year-old widow who was living on her own in the West Midlands, explained:

'I didn't think anything because my mother had diabetes, at the age of 30, well I got it very late, and the doctor said it's not an inherited thing, it's because your pancreas is not working.'

Apra ma bho che ('there is a lot of it in our community') was a phrase which was used repeatedly during the interviews, where 'it' refers to *sugar* or *sugar diabetes*.

When I asked the participants about their first thoughts on finding out that they had the condition, there were a variety of responses. Previous experience and familiarity with diabetes served as a protective factor against anxiety:

'It wasn't a matter of fear. I used to be a teacher – I know – I read the literature ...'

(Kanti)

Others recognised their own symptoms from watching other people:

'Because my elder brother had it, and I saw his symptoms, as soon as I started having those symptoms within a month I went to see the doctor ... when it came to my turn I thought that's not right, so I went to the doctor.'

(Kishore)

Familiarity with diabetes is important here because it illustrates that, within groups of people, loosely defined as faith communities, there is a level of knowledge about diabetes which might provide the basis for further work. This expertise can be conceptualised as *lay health beliefs* which have their own logic and consistency (Gerhardt, 1987), but they may also be thought of as *access points*, which can be used to start the process of diabetes management. In this study, familiarity often reduced the anxiety associated with the illness, but also represented a kind of membership

of a group or club. Although such membership was not always welcomed, respondents gained some comfort and support from the fact that there was a shared space, associated with the condition, that facilitated support and the active management of the illness. Thus participants could be seen as *social actors* taking on board health discourse information about South Asian diabetes trends and actively using this to manage their condition.

Exercise and physical activity

All of the participants seemed to be aware of a link between physical activity and diabetes, and of the fact that they, as a high-risk group, had a responsibility to take regular exercise. However, some admitted that they did not exercise as much as they knew or felt that they should, and thought that this had contributed in some way to the onset of their diabetes. The following three extracts are examples of people talking about the reasons for lack of exercise among South Asian communities, as well as the reasons for being able to participate in physical activity:

'They tend to lead sedentary lives, sit in front of the telly, we (use) vacuum (cleaners); (whereas) we used to sit on the floor, we never had a washing machine for 20 years, people don't walk anywhere, they get in a car. Most families have got two cars. I'm the same. Exercise and lifestyle.'

(Rina)

'Taking plenty of exercise, whatever you can ... rather than living a very sedentary life, eating too much, just sleeping, not doing anything, being lethargic, that's a sure sign that you are suffering.'

(Dhansuk)

'I'm very careful with my food, no sugar in tea, etc., but in rice and carbohydrates you do get some sugar, so ... I exercise as well, cycling, "up-downs", but walking is difficult because of the climate, and I've some problems with balance.'

(Kanti)

McKeigue *et al* (1992) showed that it is not lack of activity in general or of work activity, but lack of leisure-time activity which had decreased among South Asians in the UK. Participants in this study consistently talked about walking, exercising in the privacy of their own home, and attending classes held at temples or community centres. Accessing daily yoga sessions, broadcast from India via satellite TV, was also mentioned. Thus there were opportunities for exercise that were culturally and socially sanctioned, but which differed from western ideas about fitness centres and classes (Lawton *et al*, 2006).

Diet and social obligations

The conceptualisation, preparation and consumption of food are of course cultural and social entities mediated by both tradition and modernity (Bradby, 2002). How people think of and consume food, especially when there are added elements of the effects on their body and the social impact on their interactions, will be facilitated by ideas of social eating and notions of moderation. Decisions about food and nutrition are rarely made in a cultural vacuum, and the participants in this study were no exception. They took on board the requirements of their bodies, and located these within a social and cultural framework, acknowledging that doing so would have an impact on their social and community relationships:

'I just tell them I won't eat that, forget it. Because the temptation is always going to be there, but you have to think about yourself, and if I do eat this, then I'm the one who will suffer.'

(Naresh)

Special occasions, such as offerings in the temple or Divali, the Hindu festival of lights, meant that the participants had to strike a balance between managing their condition and not causing offence:

'When it's sweet stuff, especially if it's the blessing at the temple, then I'll have a bit, but a little. I won't lie [to you], It's not going to hurt you, but if you're eating this all the time, then that's different.'

(Sunita)

Management could include the avoidance of disclosure about diabetes to those who did not need to know:

'At Divali, if you've gone somewhere and someone hands you sweet offerings, I won't have a whole bit, I'll have a little bit, and then no one feels like I didn't. I don't tell people because there's no reason that people need to know really.'

(Rina)

These examples point towards an understanding and demonstration of moderate eating. Participants played an active part in the management of their diabetes. They assessed, monitored and evaluated the social significance of eating and weighed this against the effect it would have on their diabetes.

Use of complementary remedies

The use of complementary and alternative medicine has been widely discussed in health and illness research (Cant and Sharma, 2003), and there are a number of studies that report on how South Asian people use many herbal remedies in the management of their diabetes as a complement to medical interventions and advice (Bailey *et al.*, 1986). One common example identified by the participants in this study was the use

of *karela* (*Momordica charantia*), also known as bitter melon or bitter gourd, a vegetable which has long been used for health and medicinal purposes in many Asian, Chinese, African and Caribbean cultures. Karela is used either as a vegetable or in a derivative form known as *bitter powder*. Studies have reported some clinical significance in the way that this compound interacts with and sometimes replaces the medicines used in the treatment of diabetes (Leatherdale *et al.*, 1981; Shetty *et al.*, 2005).

Many participants drew on cultural knowledge about *karela* and other remedies, using these alongside western medicines. The ways in which these remedies were used, and the ways in which both the physical products and the intellectual knowledge were acquired, involves a variety of mechanisms:

'I always check my levels, and then take my tablets, and if I need to I'll have some chocolate or something. I'll also take some 'kurvat ni phaki' [bitter powder] ... this makes quite a difference to me. This is from Dubai ... whatever happens I always take my medication ... I use karela as well.'

(Deena)

'At the moment I'm eating 'Methi' [fenugreek] because I believe in Ayurvedic medicine. But I'm also very pro western medicine as well – it's a question of trial and error.'

(Dhansuk)

Although the use of traditional medicines to treat a variety of illnesses is not a new phenomenon in the South Asian community, and their use in ancient times has been documented (Subbulakshmi and Naik, 2001), the sociological implications of using combined remedies have an important place in this research area. Reed (2003, p. 2) pays detailed attention to the phenomenon through what she calls the 'transcultural flow of goods.' I argue that it is not only the physical flow of goods (i.e. the remedies themselves) which is of importance, but also the intellectual knowledge and skill that accompanied them. Modern-day connections to India, through family and the media in the UK and overseas, were exploited to provide information and products as well as past experiences and knowledge based on living in the country concerned:

'Well, we're from India, so my mother and others used them. My brother was always using these medicines ... he used to write to me with advice and send them to me.'

(Deena)

'There was an article ... in a newspaper which we get from India, and my niece sent the Jambu (rose apple) powder from India ... but you can get this information from Gujarati newspapers here as well. Karela we also use, both as a curry and tablets.'

(Naresh)

'It's fine, there's no side-effects, it's all herbal ... there should be more information about these things. We also use Neem powder, which we used to use for malaria in India, we got this from here. We alternate these remedies, to balance the different things.'

(Naresh)

This imported knowledge and skill was woven into the everyday management of the condition. Two systems of medicine were expertly combined (Reed, 2003) to facilitate optimum health and well-being:

'First I take a quarter spoon of turmeric in warm water, then I use Methi [fenugreek], and then I take ajmo [ajwain], which reduces the amount of gas we get ... turmeric is an antibiotic, oftentimes diabetics get this and that, and I still don't have any infections from where I have been hurt.'

(Kanti)

Discussion

This research provided an in-depth exploration of the experience of South Asian Hindu Gujarati-speaking participants, most of whom had type 2 diabetes. They talked about their sense of familiarity with diabetes, their ideas about exercise and physical activity and its importance in managing diabetes, the association between diet and social obligations, and their knowledge and use of complementary remedies. All of these aspects of their experience were embedded within a social and cultural framework which, they argued, enabled them to manage their condition more effectively. The participants were therefore active in their resistance to the construction (through discourse) of particular forms of South Asian diabetes risk. Their personal and family management activities, routines and conceptions of remedies revealed that there was an active process of conceptualisation and help seeking, embedded within matrices of social action. These findings raise a number of issues.

First, a large part of the general discourse surrounding type 2 diabetes focuses on adherence to medicine, advice related to diet, nutrition, exercise and glucose monitoring, as well as the role of culture. Much of this discourse provides an invaluable source of information for creating biomedical and other support systems, such as those provided by the South Asian Health Foundation and Diabetes UK, for at-risk populations. However, there is a place in diabetes research for more in-depth work to be undertaken on those aspects of the experience which involve reconstructive social processes, through life narratives and biographical qualitative methods. Situating experiences within life course continuums and supporting this analysis with a socio-cultural analytical framework can enhance both

the description of diabetes experiences and their significance to all parties. The process of re-negotiating identity needs to be placed in the context of categories of difference. For example, consider how an elderly South Asian woman, who has been diagnosed with type 2 diabetes, and is suffering from symptoms of fatigue and pain, and experiencing isolation and language barriers, deals with her diabetes and negotiates her social landscape. This may be interpreted within the context of her socio-cultural factors, including her migration history, her networks of friends and family in India and the UK, and her contacts with complementary medicine and religious beliefs. The outcome will be a more rounded and richer picture which can help to reveal the various intersections between identity, health, and social and economic experiences (Smaje, 1996).

Secondly, people's strategies for coping with the condition were varied, numerous, and consistent with their own ideas of their identity in the context of their past and the present. This was a constantly negotiated order, utilised effectively to actively assess their health and illness states, particularly in relation to their diabetes. Sometimes they would use traditional medicines combined with allopathic medicine; sometimes they would reject the traditional methods because there was no objective evidence of their efficacy. Eade (1997) has argued that the use of combinations of remedies is reflective of the process of cultural constructions as both local and global in nature and as a way to make sense of identity and manage diabetes. The participants appeared to be constructing fluid and dynamic notions of their ethnic identities that resisted the risk-laden South Asian identities generated by health science discourse. Thus they were making their culture as much as responding to given notions of it (Lambert and Sevak, 1996).

Thirdly, the findings of this study show that people's experiences of health and illness are underpinned by both personal and biographical issues, as well as by wider social and cultural complexities. Participants employ individual agency to configure their perceptions of their identity within society, and actively engage in decisions about their health and illness state. The insights gained from exploring biographically and culturally embedded diabetes management contribute to the wider discussion of how best to incorporate these understandings into help and support. The participants in this study utilised many resources around them, including their membership of different groups, their involvement in local and global dialectics (as manifested in remedies and nutritional ideas), and their conceptualisations of 'ethnic' and cultural identity framed by their migration histories. As Plummer (1995) has emphasised, stories bond together people's histories, identities and politics. This allows for the complex interplay between agency

and structure, providing a framework that observes power and structural inequalities, as well as individual and group choices, and the active summoning of cultural resources to manage a variety of experiences, including type 2 diabetes.

Limitations of the study

Although the merits of qualitative methodology in health research are now firmly established, this study has a number of limitations. The small sample size makes generalisation of experiences difficult, although this is mitigated by the richness of the data, which yielded interesting insights. More follow-up interviews could have generated important data about continuity in experiences and practice.

Recommendations for practice

The use of situated qualitative and ethnographic methods which explore people's everyday experiences can provide important insights into how a condition such as diabetes is conceptualised and managed. Therefore one recommendation is that the design of community-based programmes should include an in-depth understanding and inclusion of people's pre-existing knowledge, histories, and concepts of diabetes. Where appropriate, these can be incorporated into the intervention so that empowerment is furnished with a sense of belonging through cultural heritage, and successful management of diabetes is situated in both individual biography and group or community processes. Furthermore, it is recommended that practitioners should be encouraged to maintain a view of culture and ethnicity as dynamic entities. This supports the changing nature of the health and diversity landscape, so that service providers can more fully engage with the needs of service users through a critical social and cultural understanding of people's needs in diabetes management.

Conclusion

The aim of this research was to obtain an in-depth understanding of the experience of diabetes among a sample of Hindu Gujarati-speaking people in the UK. Using qualitative interviews and ethnographic field work, the study demonstrated that the participants' management of diabetes was embedded within personal biographical, social and cultural frameworks. The main themes within the data were familiarity with diabetes, the moderation and consideration of dietary intake, and the use of herbal and traditional remedies as a complement to allopathic medicine. These were

biographically, socially and culturally contextualised. The study indicates that we need to apply ideas of culture and ethnicity to health and illness and specifically to diabetes research with great care, so that as indicators of identity they retain their dynamic nature. By doing so we can obtain a richer picture of how health and identity are bound together and may be used in conjunction in order to achieve better outcomes. There is also a need to assess constructions of forms of South Asian diabetes risk which rely too heavily on static and fixed ideas of cultural and ethnic identity. The data obtained from this study demonstrate that using individual and group resources, the participants often showed resistance to these constructions within their everyday lives. The role of a critical assessment of health discourse in relation to South Asian diabetes risk, and the in-depth understanding of experiences that are culturally embedded, is therefore crucial to developing this area of research and practice.

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CONFLICTS OF INTEREST

None.

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