Health beliefs and folk models of diabetes in British Bangladeshis: a qualitative study

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Abstract

Objective: To explore the experience of diabetes in British Bangladeshis, since successful management of diabetes requires attention not just to observable behaviour but to the underlying attitudes and belief systems which drive that behaviour.

Design: Qualitative study of subjects' experience of diabetes using narratives, semi-structured interviews, focus groups, and pile sorting exercises. A new qualitative method, the structured vignette, was developed for validating researchers' understanding of primary level culture.

Subjects: 40 British Bangladeshi patients with diabetes, and 10 non-Bangladeshi controls, recruited from primary care.

Result: Several constructs were detected in relation to body image, cause and nature of diabetes, food classification, and knowledge of complications. In some areas, the similarities between Bangladeshi and non-Bangladeshi subjects were as striking as their differences. There was little evidence of a fatalistic or deterministic attitude to prognosis, and most informants seemed highly motivated to alter their diet and comply with treatment. Structural and material barriers to behaviour change were at least as important as "cultural" ones.

Conclusion: Bangladeshi culture is neither seamless nor static, but some widely held beliefs and behaviours have been identified. Some of these have a potentially beneficial effect on health and should be used as the starting point for culturally sensitive diabetes education.

Bangladeshi population of East London

The frontiers of present day Bangladesh were drawn after the second world war, when British India was partitioned. The Muslim majority of Bengal, along with Sylhet district in the far north east, came to form East Pakistan. In 1971 Bengal seceded from Pakistan and became the separate state of Bangladesh. The country is flat, with a monsoon climate, prone to flooding, and served mainly by inland waterways. The economy is pre-industrial, and most people live in scattered homesteads with an atomistic social organisation (that is, the family is the dominant unit with no effective social organisation or hierarchy beyond the family). The staple crop is rice, and the diet is largely fish, rice, and vegetables. Although about 95% of the population is Muslim, the society contains vestiges of its Buddhist and Hindu cultural roots. In the 1960s and '70s, large numbers of economic migrants came to Britain, particularly from certain villages in rural Sylhet. Men tended to emigrate several years before their wives followed.

Data from the 1991 census suggest that British Bangladeshis account for about 0.3% of the population of England and Wales,[7] and about a quarter of the population of Tower Hamlets (East London and City Health Authority; unpublished estimates for 1997 based on projections from 1991 census data).

Introduction

Successful management of diabetes requires that we understand the lifestyle, beliefs, attitudes, and family and social networks of the patients being treated.[1] Qualitative methods are particularly useful when the subject of research is relatively unexplored and the research question is loosely defined or open ended.[2] With two recently published exceptions[3 4] and a small British study based entirely on individual interviews,[5] such methods have rarely been used in the study of diabetes.

Anthropological analysis accepts that there are three levels of cultural behaviour: what people say they do (for example, during an interview), what they are actually observed to do, and the underlying belief system which drives that behaviour (Hall's "primary level culture"[6]). In addition, consideration must be given to the wider context in which the behaviour takes place. In particular, the British Bangladeshi informants in this study must be viewed as members of an atomistic rural society living as recent immigrants in a socioeconomically deprived urban environment (see box).

Subjects and methods

Subjects

After gaining approval from local research ethics committees, we recruited patients from three general practices in east London known to have a high proportion of Bangladeshi patients. Using computerised diabetes registers where available, and otherwise by manual search of case notes, we identified patients with diabetes and approached them to request a tape recorded interview. Recruitment was usually by letter

A longer version of this paper is available on our website

Table 1 Characteristics of subjects interviewed in qualitative study

	Bangladeshi (n=40)	Non-Bangladeshi (n=10)
Age (years):		
21–40	6	0
41–60	23	5
61–80	11	5
Education:		
None	13	0
<3 years school	15	0
>3 years school	10	10
Higher	2	0
Employment:		
Employed	1	2
Unemployed	16	3
Housewife	15	1
Pensioner	8	4
Housing:		
Owner occupied	2	1
Council rented	38	9
Language:		
Sylheti only	24	0
Sylheti plus standard Bengali	8	0
Sylheti plus standard Bengali plus English	8	0
English only	0	10
Type of diabetes (method of control):		
Diet alone	6	1
Diet plus tablets	32	6
Diet plus insulin	2	3
Generation of immigrant:		
Indigenous	0	9
First	39	1
Second	1	0
Extended family in United Kingdom:		
Yes	33	8
No	7	2
Known diabetes complications:		
Yes	21	4
No	19	5
Missing data	0	1
Type of care:		
General practitioner only	15	3
Shared (general practitioner plus hospital)	25	7
Hospital only	0	0

followed up by telephone call, but in one practice we recruited opportunistically through practice receptionists when patients came to book appointments or collect prescriptions. In all, 40 of the 44 Bangladeshi subjects we approached agreed to be interviewed.

We interviewed these 40 Bangladeshis and a control group of eight white British and two Afro-Caribbean subjects who lived in east London and had similar socioeconomic background. We used purposive sampling methods (that is, we intentionally sought to interview subjects with certain characteristics) to ensure a range of demographic variables and experiences (see table 1).

Methods

The research methods used are summarised in the box. We allowed the subjects to tell their story in their own words and in no particular order, but we used a checklist of semistructured prompting questions to make sure that the domains listed in the box were covered at some stage by all subjects.

Translation

Interviews with Bangladeshi subjects were conducted in Sylheti, a dialect of Bengali spoken as a first language by all our Bangladeshi subjects. Since Sylheti has no written form, the interviews were simultaneously translated and transcribed by an independent translator and were all checked by AMC (a Sylheti anthropologist), who listened to the original recording while reading the draft translation.

Analysis

Transcripts were analysed with NUDIST software. The entire text of the interview was entered onto a computer database and text blocks were coded into 11 broad categories of statement such as body image, information sources, professional roles, and so on.

The objective of the analysis was to identify constructs—that is, provisional inferences about primary level culture drawn from statements and observations.[9] Using the powerful cross referencing facility of the software, we considered together all statements relevant to each construct and modified the construct accordingly.

Qualitative methods used in study

Audiotaped narrative in which subject "tells the story" of his or her diabetes (all subjects)
Semistructured interview in which defined domains are covered (all subjects), including
- Personal medical history
- Psychological reaction to diagnosis of diabetes
- Knowledge about causes, complications and treatment objectives in diabetes
- Body image and beliefs about physiological and pathological processes
- Attitude to dietary restriction
- Attitude to physical exercise
- Perceived social constraints resulting from diabetes
- Satisfaction with current diabetes service
- Experience of, and attitude to, health professionals

Focus group discussion of 6-9 participants grouped by sex, in which similar topics are covered and areas of controversy and dissent within the group specifically explored (total of 24 subjects)[8]
Construction of genogram ("family tree") (all subjects)
Pile sorting exercises (all subjects), comprising
- Disease ranking—Diabetes is ranked against 10 other medical conditions (heart attack, gastric ulcer, flu, asthma, gall stones, back pain, tuberculosis, cancer, stroke, and malaria)
- Foods—Raw foodstuffs are grouped into "permitted" and "not permitted" and the classification then discussed
- Meal menus—Above exercise is repeated with complete meals
- "Preferred" and "healthy" body size—A selection of eight photographs of Bangladeshis (all of similar age and same sex as informant but of varying body mass index) is sorted into "most [aesthetically] preferred" through to "least preferred" and again into "most healthy" through to "least healthy"

Structured vignette method (see text for details) (18 subjects)
Feedback of preliminary constructs to focus groups, in which responses were videotaped (eight subjects)
Study of patients' general practice case notes (the "Lloyd George" record), which also contain correspondence about hospital admissions and outpatient visits (all subjects)

Validation

An important technique for demonstrating the validity of qualitative findings is triangulation—comparing data obtained by one method with similar data obtained by another method.[10] After developing the constructs, we presented them to a smaller sample of the subjects to determine whether our interpretation of the initial interviews had been correct. For this, we used two methods, the first being a further set of sex specific focus groups in which we presented our initial constructs and recorded the group's responses on videotape. In the second, we developed the new qualitative technique of structured vignette.

Structured vignette—We presented our constructs in the form of a story recorded on tape about Mr (or Mrs) Ali, a person with diabetes. The story was first played in full and then played back slowly, sentence by sentence. After each sentence, the tape was stopped and the subject asked: "Do you agree that this person would have [acted in this way/thought this/etc]?" (A sample paragraph of the vignette is reproduced in the appendix.) The vignette included some deliberately incorrect statements to check that subjects were not simply agreeing with all the statements. This method was developed to avoid the problems, which have been well documented in non-European cultures,[11] of asking informants to respond to closed questions about their own beliefs or behaviour, which would require them to challenge directly statements made by the interviewer. We performed the structured vignette study on a sample of 18 subjects, and repeated it on 10 of these same subjects after an interval of two months. The internal reliability of the technique was high (overall, 89% of questions received identical answers on repeat interview).

Results

Sources of explanatory models

The desire of the informants to understand and explain the onset and experience of illness was often strong. However, it tended not to lead to a systematic search for professional or scientific explanations but rather to a reflection on personal experience and the experiences of friends and relatives. Lay sources of information were frequently cited as a major influence on behaviour. In the structured vignette study, 17 of the 18 informants agreed that the best way to find out about diabetes was to ask friends and relatives.

While strong religious (Muslim) views were held by all the Bangladeshi informants and explanations often given in terms of "God's will," such views were usually held in parallel with acceptance of individual responsibility and potential for change. Indeed, both stoicism and adherence to particular dietary choices were perceived as the duty of the ill person.

Constructs

Body concepts

Youth and health were usually viewed as virtually synonymous, and physical degeneration and weakness as an inevitable consequence of aging—"Once you are 40 eyes tend to give trouble. I am almost 55. So I am expected to have bad eyesight" (Bangladeshi man).

In contrast, Crawford's study of white women in the United States indicated that "health" for them was not merely the absence of illness but had to be earned by taking positive action in terms of diet and exercise in leisure time.[12]

Both men and women chose photographs of large individuals when asked to "pick out the healthiest person." Large body size was generally viewed as an indicator of "more health" and thinness with "less health," but many also perceived that "too much health" (that is, too large a body size) was undesirable, especially if the body is weakened by diabetes. Airhihenbuwa has discussed the phenomenon of immigrants holding simultaneously both "traditional" constructs (deeply rooted values and perceptions drawn from the culture of origin) and "recent" ones (drawn from the host culture and less likely to be enduring in the long term).[13]

Origin and nature of diabetes

Illness was generally attributed to events or agents outside the body rather than to primary failure of an organ within it. This model may reflect the predominance of acute infectious illness in the recent cultural history of this group. All informants believed that the primary cause of diabetes, and that of poor diabetic control, was too much sugar and, to a lesser extent, other features of a Western diet, both of which feature strongly in folk models of other cultural groups.[2 4 14 15]

Other aetiological factors mentioned by the Bangladeshi informants included heredity (the notion of an agent transmitted through "shared blood" rather than an inherited predisposition) and germs. Many informants mentioned physical or psychological stress, either as a perceived cause of diabetes or simply when reporting the experience of daily life—especially in relation to economic difficulties, poor housing, and fear of crime.

Impact of diabetes

The diagnosis of diabetes was generally seen as devastating, and the expression "I was spoiled" was used by several informants. Virtually all felt that diabetes was a chronic, incurable condition and a potential threat to life. They feared acute complications (collapse and "dropping dead"), and a minority volunteered specific long term sequelae in the heart, eyes, and kidneys. Control of diabetes (and therefore reduction in disability and prolongation of life) was felt to lie in restoring the body's internal balance via taking particular foods and fighting the "germ" with medicine.

Many informants expressed difficulty obtaining food that was both acceptable and palatable. Other practical difficulties included confusion over sickness benefits; language barriers when speaking to professionals, especially the use of children as interpreters; and the inability to understand leaflets, either because of the concepts presented or because the leaflets were printed in standard Bengali (some informants said they were better able to understand the English alphabet, such as in road signs or notices, than standard Bengali).

Diet and nutrition

In the pile sorting exercise, foods were not grouped according to Western notions of nutritional content

but in terms of their perceived strength (nourishing power) and digestibility. "Strong" foods, perceived as energy giving, included white sugar, lamb, beef, ghee (derived from butter), solid fat, and spices. Such foods were considered health giving and powerful for the healthy body and suitable for festive occasions, but liable to produce worsening of illness in the old or debilitated. "Weak" foods, preferred in the everyday menu and for the old or infirm, included boiled (pre-fluffed) rice and cereals.

Raw foods, and those that had been baked or grilled, were considered indigestible, as were any vegetables that grew under the ground. Foods of low digestibility were considered unsuitable for elderly, debilitated, or young people. Thus, the recommendation for diabetic patients to bake or grill foods rather than fry them may not accord with cultural perceptions of digestibility.

The structured vignette study showed almost universal agreement that strong foods, solid fat, and ghee should be avoided in diabetes. All 18 agreed that Mr Ali should not eat spicy foods because of his diabetes and that a person with diabetes should eat a different diet from the rest of the family.

Some informants indicated that body components may be linked to certain foods because of physical similarity. For example, sugar, butter, ghee, body fat, bone marrow, semen, and white vaginal discharge were perceived by some to be the same fundamental entity, because their colour is the same and they all solidify when cool and liquefy when heated. Eight of 18 informants in the structured vignette study thought that molasses (a dark form of raw sugar, liquid at room temperature) was an acceptable substitute for sugar in the diet.

"Sugar is the white substance that is stored in the bone marrow, is it not? From this semen is produced. Since I have diabetes, I have come to think that [it is] because of using the semen more. When the 'calcium' inside the bone is exhausted at that time our diabetes starts" (Bangladeshi man in focus group). This statement brought general agreement in the focus group. These findings are consistent with Lambert's work on the traditional South Asian "humoral" concepts of health, which centre on the ecological flow of substances and qualities between the environment, food, and the human body.[16]

Many informants believed that the same amount of rice could be taken as frequent small meals since it was imbalance, rather than total quantity, that mattered. In the structured vignette study, 16 of 18 informants agreed that Mr Ali's doctor had underestimated the amount of rice he needed when advising him to reduce his food intake, and all 18 agreed he should take biscuits or other snacks between meals to sustain his strength. Only five thought that such snacks could cause any harm.

In Bangladeshi society, feasts, festivals, and social occasions are common, culturally important, and centre on eating sweet and rich food. A calculated compromise between dietary compliance and social duty was usually made.

Smoking

Of our Bangladeshi informants, nine of the 23 men and none of the 17 women smoked; only a few took paan (chewing tobacco) regularly, and those who did acknowledged that it was harmful and expressed a desire to quit. In the structured vignette study, only four of 18 informants disagreed that tobacco was harmful.

Concepts of balance

Many cultures equate balance with health and imbalance with illness.[17] There was a strong and almost universal belief among the Bangladeshi informants that both the onset and the control of diabetes depended on the balance of food entering the body and on balanced emission of body fluids such as sweat, semen, urine, menstrual blood, etc. Excess emission was perceived to deplete the internal stock, low quantity of emissions to indicate inner build up and putrefaction, and thin quality a weakening of the internal stock. Weakness (as in diabetes) was perceived to occur as a result of such depletion or weakening.

Absence of sweating (due to the cold British climate and lack of physical labour) on immigration to Britain was commonly cited as a cause of diabetes and a reason why the condition improved or disappeared on return to hot countries. In the structured vignette study, 14 of 18 informants agreed that if Mr Ali returned to Bangladesh his diabetes might be cured.

Exercise

Exercise in the context of health and fitness seemed to have little cultural meaning for the Bangladeshi informants, even though they often recalled specific advice on this topic from their doctor. Exercise was viewed as potentially exacerbating illness or physical weakness. The association between sweating (see above) and exercise in leisure time was not made by any informant, but ritual Muslim prayers (namaz) were often cited as a worthy and health giving form of exercise.

The Sylheti language has no expression for physical activity that has the same connotations of vitality, improvement in body condition, social desirability, and inherent "moral" value as the word "exercise." Sports and games are not generally pursued by adults in Bangladesh[18] or by Bangladeshis in Britain.[19] The closest translation for the word "exercise" is "beyam," a word of obscure etymology. Interestingly, the prefix "bey" in Sylheti often has negative connotations—for example, "beyaram" (meaning illness, literally "no comfort") or "beytamiz" (poor etiquette, literally "no manners")—and we were struck by the lack of positive connotations accorded to the concept by our Bangladeshi informants compared with the white British and Afro-Caribbeans.

Some informants gave physical or material constraints to taking exercise. In particular, many of the women rarely left their house, apparently through fear of physical attack. Some informants lived in high rise flats with no working lift, and some commented on the absence of parks, dirty pavements, and street crime.

Professional roles

The doctor was viewed as a busy, authoritative and knowledgeable person who rarely makes mistakes and has full understanding of the conditions he or she treats. Several informants felt that the doctor's instructions should always be obeyed, and 12 of 18 in the structured vignette study agreed that "Mr Ali's doctor

[general practitioner] knows everything about diabetes." Twelve also agreed that it would be impertinent for Mr Ali to ask the doctor any questions. In contrast, both white British and Afro-Caribbean informants were openly assertive and critical of health professionals. Nurses were sometimes viewed in a traditional caring and technical role but were sometimes recognised as providers of information and advice.

Diabetic monitoring

Informants generally tested their urine regularly, and all who did so seemed to understand the importance of a change in the colour of the test strip. Most informants seemed to believe that, in the absence of symptoms, diabetes was well controlled. The need for regular surveillance when asymptomatic was rarely acknowledged, and only one of 18 informants in the structured vignette study thought that Mr Ali should ever visit the doctor if he did not feel ill. Preventive care was not well understood—"He [the doctor] explained to me and said before complications start, start wearing glasses. This is because your eyes are all right. The diabetes may affect either your eyes or your feet. So if you take the glasses, your eyes may be spared" (Bangladeshi man).

Discussion

Strengths and limitations of the study

This study addressed an important and previously underexplored subject in health research.[20] We used a wide range of qualitative techniques on a sample that is likely to have included the least acculturated members of British Bangladeshi society, since we recruited from practices with Bangladeshi general practitioners, nurses, or advocates, we required neither literacy (in any language) nor spoken English or Bengali for participation in the study (indeed, 24 of the 40 informants spoke only the Sylheti dialect), and the response rate for the individual interviews was high (91%). Furthermore, our main field worker was an experienced anthropologist who has worked with this community for 25 years and speaks Sylheti as his first language.

The sample does, however, have limitations. In recruiting subjects from general practices, we failed to access those who do not seek or receive Western medicine in any form. We recruited only one second generation Bangladeshi, probably for demographic reasons. We did not assess any measure of diabetic control in our informants (such as glycated haemoglobin, which was inconsistently recorded in case notes) so we were unable to relate individual perceptions or experiences to level of control.

Implications for policy and practice

Although the differences in body image and illness maps shown here are of considerable anthropological interest, we believe that our findings support the notion that the similarities in health beliefs and health related behaviours (for example, failed attempts to lose weight or give up smoking) between minority groups and the host culture are often understated and may be of more practical importance than their differences.[21]

A recurring theme in this research was that of structural and material barriers to improving health. Poor housing, unsafe streets, and financial hardship were at least as important in preventing certain outcomes (such as taking regular exercise) as religious restrictions or ethnic customs, a finding noted by other researchers in this area.[21 22] It is not within the remit of this paper to expand on the profound socioeconomic disadvantage of many British Bangladeshis, nor on the literature linking poverty with health inequalities in general,[23] but the importance of this factor as a barrier to health gain should not be ignored.

Health education that concords with people's "lay epidemiology" and folk models is more likely to lead to changes in behaviour than that which seems to contradict such models. Airhihenbuwa and colleagues, in the context of AIDS prevention, have exposed the fallacy of the assumption that health education is merely a matter of determining "deficiencies" in knowledge and meeting those deficiencies with educational material such as leaflets, teaching seminars, or mass media programmes. Instead, educators must centralise the cultural experiences of those who have hitherto been marginalised.[13 24] Given that the Bangladeshis in this study indicated a high regard for oral explanations from informal sources (friends, relatives, and other patients with diabetes), we think that the potential for learning via oral sources within Bangladeshi culture is high.

Hence, rather than designing an education programme to be delivered externally to rectify "deficiencies" in knowledge or "incorrect" behaviour,[25] we suggest that health promotion programmes attempt to build on those beliefs, attitudes, and behaviours already existing in Bangladeshi culture that promote good diabetes control, prevent complications, and improve quality of life, and address practical barriers to positive health behaviours such as non-availability of particular foodstuffs. The box lists examples of constructs which, though not universally held, are sufficiently prevalent in Bangladeshi culture to form the starting point for successful culturally sensitive health education and promotion.

Table 2 draws on a framework developed by Danial and Green to identify perceptual, structural, and reinforcing factors that influence specific behavioural outcomes in health promotion.[26] We have used the recommendation for regular, low intensity, physical

Constructs which might be used as starting points for culturally sensitive diabetes education in British Bangladeshis

- Diabetes is caused by sweet things, a Western diet, and stress
- Diabetes is chronic and incurable, but its effects can be lessened by changes in lifestyle
- Dietary modification is essential for diabetes control, and effort must be made to prepare special food for the family member with diabetes
- A person with diabetes should aim to lose weight if overweight
- Physical labour which produces sweat is beneficial to health
- Sugar, fatty food, and solid fat (including ghee derived from butter) are harmful
- Complications may occur if diabetes is poorly controlled
- Poor diabetic control can be detected by change in the colour of the urine testing strip

Table 2 Examples of Bangladeshi patients' perceptions, structural and material barriers, and reinforcing factors affecting acceptance of a behavioural priority in diabetes education—"People with diabetes should take regular sustained low-intensity physical exercise"

	Implications for health education and health policy
Perceptions	
Loss of body sweat, such as occurs during physical labour, is good for health	Recommendations for physical exercise should focus on the potential for producing sweat in ways other than physical labour
Prayers (namaz) are a form of physical exercise	Educators should be aware of the perceived association of prayer with exercise
Sport and organised physical exercise have no cultural meaning and are inappropriate for women and older men. Sports clothing and footwear are "not appropriate for our community"	Non-sporting activities that do not require special clothing or footwear may be more acceptable than pressure to become involved in sport
Walking is an acceptable form of exercise, but fast walking is inappropriate, especially for women and those of high social status	Promotion of walking and other indigenous activities may allow activity level to be increased in a culturally acceptable way, at least for males
Women should generally remain within the home, dress modestly, and remain demure. Young children should remain with their mother or grandmother at all times	Activities that can be done discretely and in private (such as home exercise videos) may be more acceptable to women
Structural and material factors	
Walking in the street is considered unsafe, particularly for women and elderly people, because of fear of crime and harassment	Effective local and national policies on crime and racial harassment, and community policing in particular, are required on health as well as social grounds
Opportunities for exercise in daily living often go unrecognised	Health promotion campaigns should encourage walking to school and shops rather than using motor transport
Reinforcing factors	
Advice from educators and health professionals is held in high regard	Even though physical exercise is not part of the culture, it should be encouraged in individual doctor-patient encounters
Approval or disapproval by family seems to strongly influence lifestyle choices	Involvement of key family members in education for exercise is likely to improve its success

exercise as an example of a desired behavioural priority for people with diabetes. As table 2 shows, many of the constructs identified in our fieldwork have direct implications for educators working on an individual or public health level. In addition, however, this framework highlights both the broader social and political context within which behaviour change in minority ethnic groups must be placed, and the danger of assuming that "non-compliance" with such advice about lifestyle is always attributable to "cultural factors."

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Appendix: Sample section from structured vignette

Statement	Agree	Disagree	Not sure	Comment
Mr Ali thought that living in Britain had caused his diabetes				
He thought that if he went back to Bangladesh the diabetes might be cured				
He thought that the lack of sweating in Britain was unhealthy and that it predisposed people to get diabetes				
He also thought that diabetes was caused by something that got into his body, like a germ or some other bad thing from outside				