Research paper

Cultural barriers impeding ethnic minority groups from accessing effective diabetes care services: a systematic review of observational studies

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What is known on this subject

- Many authors have reported the existence of inequalities in health and access to diabetes healthcare provision among ethnic minority groups.
- There is much emphasis on the need to provide patient-centred care, but little is known about specific cultural barriers that prevent or discourage members of ethnic minority groups from accessing effective diabetes care.

What this paper adds

- Eight key cultural barrier themes are identified that hinder members of ethnic minority groups from accessing effective diabetes care services.
- It is proposed that these eight themes could inform professional education as to how to develop and deliver culturally competent diabetes services for members of ethnic minority groups.
- Gaps in current diabetes service delivery are identified.
- Based on the findings, suggestions are offered to improve the commissioning and diabetes service delivery tailored to the needs of ethnic minority groups with diabetes.

ABSTRACT

A number of reports indicate that cultural barriers may prevent members of ethnic minority groups from accessing diabetes services, but little is known about the specific nature of these barriers. This systematic review of observational studies aimed to identify and explore cultural barriers as a basis for improvements in care. Articles published from inception to September 2011 were retrieved from four databases (Medline, CINAHL, Cochrane and DARE), two National Health Service specialist libraries (Diabetes, and Ethnicity and Health), Warwick Medical School publications and reference lists. Inclusion criteria were qualitative or quantitative studies involving ethnic minority groups with diabetes. Two reviewers independently conducted paper selection and appraisal. A total of 316 studies

were retrieved, 22 of which were included in the review. Due to the heterogeneity of the studies, a narrative analysis was undertaken. Eight key cultural issues emerged, namely participants' strong adherence to cultural norms, religious beliefs, linguistic diversity, low health literacy levels, different beliefs about health and illness, belief in expert and professional support, low accessibility of culturally appropriate services/information, and low concordance with western professional advice. These issues compromised the level of diabetes care services received by members of ethnic minority groups. It is recommended that further attention is given to the development of culturally competent interventions for improving access to healthcare and diabetes outcomes for members of specific ethnic minority groups.

Keywords: cultural barriers, diabetes, effective diabetes care delivery, ethnic minority groups, health workers

Introduction

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Diabetes is a long-term, serious and challenging metabolic condition and a major health issue worldwide. Although diabetes affects every society, some populations are particularly susceptible but also lack understanding of the condition (Baradaran and Knill Jones, 2004; International Diabetes Federation, 2009; Alam et al, 2012). Evidence suggests that, where members of susceptible populations are in the minority, they may not receive equitable diabetes care. This is attributed to a mixture of cultural factors and some service providers' lack of cultural competence (Hawthorne et al, 1993; Narayan and Rea, 1997; Cone et al, 2003; Brown et al, 2002; Zeh, 2010; Zeh et al, 2012; Mainous et al, 2007). The National Service Framework for Diabetes stipulates the minimum standards of diabetes care to be offered to all patients, irrespective of ethnicity, language, culture, religion, gender, disability, age and location (Department of Health, 2001). Healthcare practices should be designed to ensure that health workers take into account the individual patient's background and deliver tailored services (Cone et al, 2003; NHS Health Scotland, 2004). However, few studies have explored the effects of cultural and linguistic barriers which may compromise the quality of care delivered to members of ethnic minority groups with diabetes (Davies, 2006; Hill, 2006; Fleming and Gillibrand, 2009). Very little is known about how these barriers may operate in particular societies, and some service providers do not appear to appreciate the nature of these barriers or how they may prevent members of ethnic minority groups from receiving patient-centred diabetes care (Department of Health, 2001; Roberts, 2007; Wilson et al, 2012). A better understanding of these cultural issues may guide healthcare commissioners and clinical commissioning groups (CCGs) to reconfigure diabetes services in primary care, which may improve both care service engagement and outcomes in minority populations (NHS Health Scotland, 2004).

Culture is a shared and dynamic phenomenon displayed by the behaviours and attitudes of a social group, which remains difficult to interpret, but requires a good understanding by health workers (Naeem, 2003). In this review, culture is defined broadly as a shared system of values, beliefs, identities, traditions, behaviours, and verbal and non-verbal patterns of communication that bind a group of people together and differentiate them from other groups (Salimbene, 1999). It encompasses beliefs, language, social norms and values, including practices which can create a sense of social support and belonging for individuals who share the same core beliefs. These can both facilitate and impede health coping styles, access to and utilisation of healthcare services, and implementation of professional advice. This study focused on the cultural barriers to accessing and use of diabetes services. In this review, the term *ethnic minority group* refers to a population group with an ethnic origin different from that of the majority population of the host country (Bulmer, 1996; Modood and Berthoud, 1997).

Scoping searches identified 10 reviews that reported cultural barriers among members of ethnic minority groups with diabetes. Two were systematically conducted reviews (Brown *et al*, 2002; Fleming and Gillibrand, 2009) and eight were literature reviews with some methodological flaws, for example, reviews with no inclusion criteria (Hawthorne *et al*, 1993; Davies, 2006; Hill, 2006; Gohdes, 1988; Brown, 1997; Oldroyd *et al*, 2005; Greenhalgh, 1997, 2008) and single-authored reviews (Davies, 2006; Gohdes, 1988; Brown, 1997; Greenhalgh, 1997, 2008; Hill, 2006). Although these reviews provided some insight into cultural barriers, the following two questions seemed to have received less attention. The present systematic review aimed to address these.

1 What specific cultural barriers impede members of ethnic minority groups from receiving effective diabetes care services, and how do they do so?

2 What can be done to minimise these cultural barriers?

Methods

Design, search strategy, data sources and eligibility

This is a systematic review, which included qualitative, quantitative and mixed methods study designs. CINAHL and MEDLINE databases were searched from inception to September 2011 using the search terms listed in Table 1. In addition, searches were conducted using Cochrane and DARE databases, two NHS Evidence specialist libraries based at Warwick University for diabetes (www.library.nhs.uk/diabetes) and for ethnicity and health (www.library.nhs.uk/ethnicity), and Warwick Medical School Research Publications from 2004 to 2011 (http://www2.warwick.ac.uk/fac/med/ staffintranet/staffresources/researchpublications/n = 1) and diabetes and behavioural change research (n = 1)were contacted for advice and to identify additional studies. The journal Diabetes Primary Care was hand searched as these articles were relevant to our topic but not accessible via PubMed or other major databases.

The inclusion criteria were as follows:

- Participants: children or adults with any type of diabetes, provided that they were an ethnic minority population in the country of study.
- Design: observational studies using qualitative or quantitative methods. Randomised controlled trials and quasi-experimental studies are deliberately excluded from consideration in this paper, as they are included in another published review using the same search strategy (Zeh *et al*, 2012).
- Setting: participants were recruited from any setting.
- Reporting: studies were included if they reported on cultural differences and data extracted from themes that explored any cultural barriers.
- Only primary published studies with no language restriction were included.

The screening and mapping exercise for the papers identified as a result of the search strategy (see Table 1) identified two issues, namely *cultural barriers preventing members of ethnic minority groups from accessing effective diabetes care services*, which is the focus of this review, and *culturally competent healthcare interventions in ethnic minority groups with diabetes*, which has been published elsewhere (Zeh *et al*, 2012). We found that 'any structured intervention, tailored to ethnic minority groups by

Table 1 Search strategy

Search terms

Unless otherwise specified, search terms are free text terms: MeSH for Medical Subject Headings (CINAHL and MEDLINE medical index terms); exp = exploded MeSH; adj = adjacent; ti,ab = title, abstract; * = truncation.

'Diabetes' search terms:

exp DIABETES MELLITUS/ OR exp DIABETES MELLITUS, EXPERIMENTAL/ OR exp DIABETES MELLITUS, TYPE 2/; (diabet*2 adj2).ti,ab; NIDDM.ti,ab; T2DM.ti,ab; (gestational AND diabetes*).ti,ab; (Juvenile AND diabetes*).ti,ab; Diabet*1adj1.ti,ab; (Type AND 1 AND diabetes*).ti,ab; T1DM*.ti,ab; IDDM*.ti,ab; exp DIABETES MELLITUS/ OR exp DIABETES MELLITUS, TYPE 2/

'Cultural barriers' search terms:

culture*.ti,ab; (cultural AND competent*).ti,ab; (language AND barrier*).ti,ab; exp COMMUNICATION BARRIERS/ OR exp INTERDISCIPLINARY COMMUNICATION/ OR exp NONVERBAL COMMUNICATION/ OR exp COMMUNICATION/ ; (NHS AND healthcare AND systems).ti,ab; (NHS AND health AND care AND systems).ti,ab; (delivery AND healthcare).ti,ab; exp HEALTH SERVICES ACCESSIBILITY/; exp CULTURAL DIVERSITY/ OR exp CULTURAL COMPETENCY/ OR exp HEALTH SERVICES ACCESSIBILITY/ OR exp NURSING STAFF/ ; (religious AND beliefs*).ti,ab; (cultural AND awareness*).ti,ab; (cultural AND characteristics*).ti,ab; multicultural*.ti,ab; transcultural*.ti,ab; crosscultural*.ti,ab

'Population' search terms:

gujerat*.ti,ab; bengal*.ti,ab; exp ASIA, WESTERN/; exp INDIA/; bangladesh*.ti,ab; gujarat*.ti,ab; pakistan*.ti,ab; (south*adj2 AND asian*).ti,ab; ((south*adj2 indian*)).ti,ab; Punjab*.ti,ab; Urdu*.ti,ab; Hindi*.ti,ab; Hindu*.ti,ab; (African ADJ Caribbean).ti,ab; (ethnic AND minorities).ti,ab; (ethnic AND minority AND groups).ti,ab; human*.ti,ab

integrating elements of culture, language, religion, and health literacy skills, produced a positive impact on a range of patient important outcomes' (Zeh *et al*, 2012, p. 1237). This strengthens the case for further exploring and understanding specific cultural barriers to diabetes healthcare provision.

Selection criteria

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All citations were downloaded into Endnote Web and duplicates removed. All types of cultural and linguistic themes from any study involving any ethnic minority group with any type of diabetes in any setting globally were included. The titles/abstracts were independently scrutinised for eligibility by two reviewers (PZ for 100% of all papers, and JS or HS for 50% of the papers) using the inclusion criteria, and disagreements were resolved through discussion and a third opinion (JS or HS or AMC). Cohen's kappa was used to test the screening process inter-coder reliability and to calculate agreement levels. Cohen (1960) sets a threshold of 0.85 as representing a very high level of agreement, whereas Landis and Koch (1977) stipulate limits of greater than 0.61 as a substantial agreement and greater than 0.81 as a perfect agreement. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram details the results of the screening and selection processes (see Figure 1) (Moher *et al*, 2009).

Data extraction and quality assessment of studies

One reviewer (PZ) read and re-read each of the full included publications to understand how cultural barriers hindered the studied populations from accessing effective diabetes care services within the research settings. He extracted data using a revised data extraction form (Zeh et al, 2012; see Box 1). This form was piloted by three reviewers on three random included papers by cross-checking independent notes for consistency. The methodological quality of the qualitative studies was assessed using Popay et al (1998) and Jadad et al (1996) for quantitative and Creswell and Plano Clark (2007) for the mixed method research studies (see online Tables S1S3). Individual quality assessment checklists, in contrast to a universal tool (Pluye et al, 2009), were deemed more appropriate to facilitate specific study design assessments due to the heterogeneity of the included studies.

Data analysis

A narrative synthesis of the evidence was used because of the heterogeneity of the included studies. Following coding, thematic analysis was performed for each study and then tabulated across studies. Themes were discussed among all the researchers until agreement was reached. The results were triangulated without sep-



Figure 1 Flow chart (adapted from Moher et al, 2009) for screening and including studies.

Box 1 Data extraction form

Study number Title First author Year of publication Country of publication Aim of the study Number of participants Ethnicity of participants Cultural theme Methodological details Content of the cultural issues Summary of findings Notes and follow-up questions for the authors

arating the study designs (qualitative, quantitative or mixed-methods) to reduce duplication of themes and to improve validity and generalisability.

Results

Available evidence

The searches identified 316 studies (310 studies from databases and 6 studies from other sources) (see Figure 1) and of 55 potentially relevant studies (all in English), a total of 22 were included (see Table 2). The inter-coder reliability of the screening process was high (kappa score = 0.92).

Characteristics of the included studies

Of the 22 included studies (see Table 2), 18 used qualitative methods (one used mixed-qualitative methods (Greenhalgh et al, 1998), 13 used in-depth interviews (Kelleher and Islam, 1994; Duthie-Nurse, 1998; Rhodes and Nocon, 2003; Rhodes et al, 2003; Fagerli et al, 2005; Hjelm et al, 2005; Lawton et al, 2005, 2006a, 2006b, 2007, 2008), two used focus groups (Greenhalgh et al, 2011; Brown et al, 2006), and two used case study methods (Narayan and Rea, 1997; Fleming et al, 2008). Two studies used mixed methods (Greenhalgh et al, 2006; Lloyd et al, 2008) and three used quantitative methods (Naeem, 2003; Sedgwick et al, 2003; Povlsen et al, 2005). Studies were conducted in six different countries, namely the UK (n = 16), the USA (n = 2), Denmark (n = 1), Sweden (n = 1)1), Norway (n = 1) and the Netherlands (n = 1). A total of 1897 participants with varied ethnicities, of which 15 were stated and two were unspecified (see Table 3), were recruited from three settings (community, primary care and acute sectors). Nine studies included adults with type 2 diabetes (Greenhalgh et al, 2006, 2011; Fleming et al, 2008; Lawton et al, 2005, 2007; Lloyd et al, 2008; Kohinor et al, 2011; Duthie-Nurse, 1998; Kelleher and Islam, 1994), two studies involved women with gestational diabetes (Narayan and Rea, 1997; Hjelm et al, 2005), one study included children with type 1 diabetes (Povlsen et al, 2005), four studies included participants with both type 1 and type 2 diabetes (Fagerli et al, 2005; Stone et al, 2005; Rhodes and Nocon, 2003; Rhodes et al, 2003), and five studies did not specify the diabetes type (Brown et al, 2006; Greenhalgh et al, 1998; Naeem, 2003; Sedgwick et al, 2003; Gonzalez, 2008). The characteristics and cultural and linguistic needs of these populations were varied. Participants' ages in all 22 studies ranged from 0 to 80 years. Although 21 of the studies included between 5 and 1100 ethnic minority participants each, one study (Narayan and Rea, 1997) included only one participant with gestational diabetes.

Quality assessment of the included studies and risk of bias

Of the 22 included studies (see online Tables S1S3), 14 studies were of good quality and met 80100% of the quality criteria (scored A) (Lloyd et al, 2008; Greenhalgh et al, 1998, 2006, 2011; Kohinor et al, 2011; Gonzalez, 2008; Lawton et al, 2005, 2007; Stone et al, 2005; Hjelm et al, 2005; Fagerli et al, 2005; Rhodes and Nocon, 2003; Rhodes et al, 2003; Chowdhury et al, 2000). A further 8 studies were of moderate quality and met 5079% of the quality criteria (scored B) (Fleming et al, 2008; Brown et al, 2006; Duthie-Nurse, 1998; Narayan and Rea, 1997; Kelleher and Islam, 1994; Povlsen et al, 2005; Naeem, 2003; Sedgwick et al, 2003). No study scored below 50%. Ten studies included a range of different ethnic minority groups; the largest was black Caribbean (n = 522) in a UK study (Sedgwick et al, 2003), and the smallest number of minority participants involved in the studies were Lebanese (n = 1) in a Swedish study which included 27 participants from four ethnicities (Hjelm et al, 2005). Of all the included studies, 73% (n = 16) were published in the UK, and smaller numbers were published in the USA (n = 2), Denmark (n = 1), Sweden (n = 1), Norway (n = 1) and the Netherlands (n = 1).

Cultural barriers to diabetes care and management

Analysis revealed eight themes related to cultural barriers to diabetes care and management:

- cultural adherence in diet, exercise, and social interactions
- commitment to religious beliefs

Reference (first author and year)	Country of publication	Ethnic minority group and numbers studied	Comparison and numbers studied	Design	Key cultural findings reported
Greenhalgh <i>et al</i> (2011)	UK	82 adult participants: African Caribbean (<i>n</i> = 7), Bangladeshi (<i>n</i> = 23), Tamil (<i>n</i> = 11), Punjabi/ Urdu (<i>n</i> = 34), Somali (<i>n</i> = 7)	Nil	Qualitative study based on narrative story-sharing in groups	Strong attachment of social meaning and moral worth of real-life accounts of diabetes self- management Disapproval of shared facilities such as swimming pools (due to social/cultural beliefs about modesty), especially the Bangladeshi participants Strong adherence to religious beliefs (Muslim, Hindu, Sikh or Christian), with the perception that diabetes self-management is secondary Language barriers and unfamiliarity with the healthcare system (e.g. participants not aware of the availability of interpretation or advocacy services) Low levels of health literacy among participants (e.g. some participants lacked knowledge and skills in diabetes complications and prevention) Illness storylines affecting all life choices and decision making (e.g. great stigma attached to diagnosis of diabetes, and further increased by going on to insulin, which caused participants to feel awful, frightened, isolated and worthless to family or society) Strong adherence to fatalism (feeling of powerlessness against fate) at initial diagnosis of diabetes Reliance of older participants (especially women) on relatives for overseeing medication and operating technological devices, or on health workers for those who did not have relatives to rely on

Kohinor <i>et al</i> (2011)	Netherlands	32 Surinamese adults: African Surinamese (<i>n</i> = 16), Hindustani Surinamese (<i>n</i> = 16)	Nil	Qualitative study using in-depth interviews	Strong adherence to Surinamese traditional food even though participants were aware of the need to change their dietary behaviour in line with healthy dietary guidelines Strong adherence to cultural maintenance identity of traditional Surinamese cooking and eating practices Perception by many participants that dietary guidelines were based on Dutch eating habits, which are not in line with Surinamese cooking/ eating practices Participants' food choices based on Surinamese beliefs with regard to 'good' (e.g. bitter vegetables) or 'bad' (e.g. spicy dishes) foods for diabetes, rather than being based on their nutritional qualities Participants' perception of healthy recommendations (e.g. eating at fixed times) as interfering with their traditional values, such as hospitality
Gonzalez (2008)	USA	12 adult Puerto Ricans (Latinos) with diabetes recruited from six sites in a South Florida city	Nil	Narrative inquiry approach using semi-structured interviews in their preferred language: English $(n = 3)$, Spanish $(n = 8)$, both Spanish and English $(n = 1)$	Participants' preference for ethnically and culturally concordant healthcare providers (e.g. one participant who received care from an ethnically discordant provider described feeling rushed, and not being given time to express their feelings and issues of concern) Participants' preference for linguistically competent healthcare providers (e.g. some participants expressed disappointment with the inability of service providers to meet their cultural needs due to language differences)

Table 2 Continueds						
Reference (first author and year)	Country of publication	Ethnic minority group and numbers studied	Comparison and numbers studied	Design	Key cultural findings reported	
					Greater trust in the culturally concordant Puerto Rican physicians for their diabetes care service delivery Strong reliance of participants (11 out of 12) on family for support and guidance, such as accompanying them to the physician's office to act as translators and/or providing emotional and physical support Religiosity and spirituality helped the participants to cope with their diabetes, but these two aspects did not influence their decision making Preference for western medicines to treat their diabetes, even though they were aware of culturally based ethno-medicine.	
Lawton <i>et al</i> (2005, 2006a, 2006b, 2008)	UK	32 adult South Asian patients with type 2 diabetes: Pakistanis (<i>n</i> = 23), Indians (<i>n</i> = 9)	Nil	Qualitative study using in-depth interviews in participants' first language (English or Punjabi) by a bilingual researcher	Strong adherence to traditional diets/food (due to attachment of social and symbolic meanings) despite an awareness of their detrimental effects Strong adherence to religious beliefs about food and fasting during Ramadan, and attribution of beliefs to Allah's will Perceived cultural beliefs included the notion that health, illness and death are pre-ordained by Allah, and that diabetes 'weakened and aged' the body (barrier to physical exercise and stigma associated with diabetes) Strong adherence to cultural norms (e.g. family engagements, business and childcare come first, before their own interests)	

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Perception that western medicines have detrimental effects if taken in excess or without traditional foodstuffs, leading to self-adjusting without medical advice Perception that oral hypoglycaemic agents (oral

hypoglycaemic agents)give them the identity of a sick person, reflecting their uncertain attitudes towards western drugs

Strong attachment to commensal acts, and their need to eat 'strength-giving' South Asian foods; managing diet by cutting down on rather than replacing perceived unhealthy South Asian foodstuffs Inappropriate and/or conflicting information from health workers leading to non-concordance with dietary, medication and other healthcare advice Lack of culturally sensitive single-sex facilities (e.g. at swimming pools) or same-sex instructors in gyms, as well as lack of culturally sensitive advice from white health workers with traditional dietary needs Prefer receiving hospital rather than primary care reviews, as perceived services for prompt detection and treatment of complications, rather than provision of advice on management Language barriers leading to lack of diabetes knowledge reinforcing women's vulnerability with regard to the cultural norms of staying indoors Low levels of health literacy among participants Gratitude for the availability of free diabetes services in the UK

Low perception of professional competency in India; health workers are financially motivated when prescribing, giving preferential treatment to their relatives

Table 2 Continue	Table 2 Continueds						
Reference (first author and year)	Country of publication	Ethnic minority group and numbers studied	Comparison and numbers studied	Design	Key cultural findings reported		
Lawton <i>et al</i> (2007)	UK	32 adult South Asian patients with type 2 diabetes (Pakistani and Indian)	32 adult white patients	Qualitative in- depth interviews	South Asian participants consider the British weather, unfamiliar lifestyles, UK values or past offences as responsible for their diabetes onset in particular, whereas white British participants perceive their own lifestyle (e.g. eating the wrong food, sedentary lifestyle) as responsible for their diabetes South Asian participants consider life circumstances such as poverty, limited access to healthcare services and family-related stress to be responsible for their diabetes onset generally, whereas white participants associate their own lifestyle choices and personal lifestyle failings (e.g. non-adherence to healthy lifestyle, and lack of self-discipline in diet and physical exercise) with their diabetes onset, portraying themselves, rather than their circumstances, as being to blame Some South Asian participants attribute their diabetes onset to the will of Allah, who is responsible for dictating their health and destiny		
Greenhalgh <i>et al</i> (2006)	UK	98 British Bangladeshi adults	Nil	Multi-phase study involving narrative interview, vignette construction, questionnaire development, and questionnaire validation in relation to two scales (well-being and cultural adherence	Strict adherence to Bangladeshi culture (e.g. conserving their traditional dishes) Low literacy level among participants Participants with language barriers need assistance to complete questionnaires		

Cultural barriers to accessing effective diabetes care services

Table 2 Continued

UK	12 Bangladeshi adults	Nil	Qualitative in- depth interviews in English $(n = 1)$ and Bengali $(n = 11)$	Very limited interpretation services resulting in communication difficulties between health workers and patients Use of informal interpreters is a necessity due to limited availability of professional interpreters, resulting in both positive and negative effects Preference for same-sex consultations, especially by females, irrespective of language barrier Poor professional attitudes and methods of working, especially doctors, whose manner was described as 'abrupt and peremptory', resulting in unsatisfactory consultations
UK	40 first-generation immigrant Bangladeshi adults	Nil	Diverse qualitative methods involving interviews and focus group discussions conducted in their language (Sylheti)	Diverse range of individual food choices partly based on affordability and availability as well as cultural influences Strong adherence to religious restrictions on particular food items (e.g. Islamic prohibition of pork, wine or spirits) Food choices determined by two interrelated and intersecting binary classification systems: 'strong'/ 'weak' and 'digestible'/'indigestible' Conservation of cultural identity by adhering strictly to traditional diets/food (with social and symbolic meanings) despite an awareness of their detrimental effects
UK	20 first-generation adult Hindu women of South Asian origin	Nil	Qualitative face-to- face questionnaire- based interview by researcher in the presence of a Gujarati speaker	Strong adherence to traditional diets/food (with social and symbolic meanings) despite an awareness of their detrimental effects Strong adherence to their cultural identity (e.g. social, religious and familial)
	UK	UK12 Bangladeshi adultsUK40 first-generation immigrant Bangladeshi adultsUK20 first-generation adult Hindu women of South Asian origin	UK12 Bangladeshi adultsNilUK40 first-generation immigrant Bangladeshi adultsNilUK20 first-generation adult Hindu women of South Asian originNil	UK 12 Bangladeshi adults Nil Qualitative in- depth interviews in English (n = 1) and Bengali (n = 1) UK 40 first-generation immigrant Bangladeshi adults Nil Diverse qualitative methods involving interviews and focus group discussions conducted in their language (Sylheti) UK 20 first-generation adult Hindu women of South Asian origin Nil Qualitative face-to- face questionnaire- based interview by researcher in the presence of a Gujarati speaker

Table 2 Continu	Table 2 Continueds						
Reference (first author and year)	Country of publication	Ethnic minority group and numbers studied	Comparison and numbers studied	Design	Key cultural findings reported		
					Language barriers reinforced women's vulnerability to the cultural norms of staying indoors, coupled with fear of racial harassment Perceived belief of being 'cured' when they go to India resulting in the association of illness with living in the UK, rather than with their diet and physical inactivity		
Narayan and Rea (1997)	USA	1 Indian woman	Nil	Case study of an Indian woman at 34 weeks' gestation, diagnosed with gestational diabetes	An experienced nurse failed to meet client's needs due to lack of knowledge of South Asian cultural beliefs and practices Nurse advice and dietary prescriptions contrary to Indian Hindu tradition of not eating beef perceived as unacceptable and taboo Participant's family not aware of nurse culture; feeling of humiliation and embarrassment as not involved in the patient's care planning		
Greenhalgh <i>et al</i> (1998)	UK	40 first-generation immigrant Bangladeshi adults with diabetes: male (n = 23), female $(n = 17)$	10 non-South Asian: white (n = 8), African Caribbean $(n = 2)$	Qualitative study using narratives, semi-structured interviews, focus groups, structured vignette and pile- sorting exercises conducted in Syheti and English	Lay sources of information within Bangladeshi culture cited as key influence on behaviours; oral sources of information highly valued Strong adherence to religious views (Muslims); explanation given in terms of 'God's will', with the perception that it is the duty of the ill person to adhere to dietary choices Adherence to health beliefs (e.g. perception that diabetes is caused by western lifestyle, as it may be cured if they return to Bangladesh) Language barriers and low levels of literacy even in their own Bengali language, resulting in the use of informal assistance		

				Food classifications not based on western notions of nutritional content, but rather on perceived strength of their nourishing properties Bangladeshi participants displayed more negative attitudes towards physical exercise, and linked exercise to worsening of their illness; women were afraid to leave their homes due to fear of physical harassment Perception by Bangladeshi participants that doctors know all about diabetes, but the other participants were openly assertive about and critical of health workers
Kelleher and Islam UK (1994)	20 Bangladeshi adults: male (<i>n</i> = 12), female (<i>n</i> = 8)	Nil	Qualitative study using in-depth interview, conducted in Sylheti dialect (n = 18) or English (n = 2)	Despite receiving dietary advice, still strong adherence to religion and traditional foods; fasting during Ramadan and perception that western diets have a weakening effect Religion seen as a major influence for understanding illness and managing the treatment; explanation of the condition given in terms of 'God's will' (God is in front, the doctor is behind) Perception that even with diabetes, God's orders must be adhered to, and that disobeying them could lead to something worse
Fleming <i>et al</i> (2008) UK	5 English-speaking Gujarati Muslim men	Nil	Case-study approach using interviews and participant observation methods in English	Strong adherence to the use of traditional foods, which involves consuming very high-fat, fried foods (an integral part of Gujarati culture), with awareness of the detrimental effects of this Personal choice influenced by contextual factors such as the choice of allopathic or homeopathic medicines.

Table 2 Continueds						
Reference (first author and year)	Country of publication	Ethnic minority group and numbers studied	Comparison and numbers studied	Design	Key cultural findings reported	
Lloyd <i>et al</i> (2008)	UK	31 participants from two ethnic minority groups, both male and female, whose main spoken language is Sylheti ($n =$ 16) and Mirpuri ($n =$ 15), conducted by two researchers fluent in English and either Sylheti or Mirpuri	Nil	Five focus groups of 5 sessions to consider the content and method of delivery; two questionnaires measuring diabetes knowledge and confidence in diabetes self-care	Culturally competent content successful for both questionnaires Particular terminology, such as HbA1c (glycosylated haemoglobin) and carbohydrate, not universally understood, or has a single meaning/ interpretation Mirpuri participants' groups (Pakistanis) preferred assisted or partially assisted completion in their spoken language, whereas Sylheti (Bangladeshi)) groups preferred independent audio delivery in their spoken language Low literacy level, with more than half of Sylheti men and women illiterate (59% of men and 62% of women)	
Brown <i>et al</i> (2006)	UK	39 adults with diabetes from multicultural ethnic minority groups	Nil	Qualitative study using a participatory approach with consumer groups (6 focus groups)	Lack of culturally appropriate diabetes information for African Caribbeans and South Asians, especially in their own language Lack of information on culturally specific foods, especially in restaurants and cafes African Caribbeans and South Asians valued one- to-one support from their health workers Ethnic minority groups valued culturally and linguistically appropriate services; there was a need for bilingual health workers for direct communication Mixed perceptions about cultural beliefs, with some participants feeling that they should take more responsibility for their condition, and others in denial about the associated consequences of diabetes	

Table 2 Continued						
Stone <i>et al</i> (2005)	UK	15 South Asian adults	5 white adults	Qualitative study using semi- structured in-depth interviews in their preferred language: English $(n = 7)$, Gujarati $(n = 12)$ or Punjabi $(n = 1)$	Most South Asian patients expressed an attitude of resignation at diagnosis (family history or an expressed view that their diabetes is God's will), whereas the white participants were very shocked and in some cases in denial Strong adherence to traditional diets by South Asians, coupled with a lack of specific dietary information compared with their white counterparts South Asian patients expressed more health- related anxiety than white patients, and were supported more by families and religious leaders Cultural barriers (e.g. preference for gender- specific education sessions); location and health problems are restrictive factors Communication problems, including conflicting messages expressed by both groups as health workers use technical terminology not understood by patients, with South Asians experiencing more language barriers	
Povlsen <i>et al</i> (2005)	Denmark	58 child participants from ethnic minority groups	919 Danish young participants	Survey question- naire (about gender, age, diabetes mellitus duration, HbA1c, incidents of severe hypoglycaemia and ketoacidosis) from a national register to all 20 Danish paediatric diabetes centres and to 38 ethnic minority group families, completed by professional interpreters	HbA1C significantly higher in ethnic minority groups (mean value 9.05 +/- 1.4%) than in the Danish patients (mean 8.62 +/- 1.3%; $P = 0.018$) No significant difference in HbA1C among the different ethnic minority groups, or in the prevalence of severe hypoglycaemia or ketoacidosis Low literacy rate with limited educational backgrounds Language barriers among the ethnic minority groups, and need for interpretation support	

Reference (first author and year)	Country of publication	Ethnic minority group and numbers studied	Comparison and numbers studied	Design	Key cultural findings reported		
Hjelm <i>et al</i> (2005)	Sweden	14 Middle Eastern women: Iraqi (<i>n</i> = 10), Iranian (<i>n</i> = 3) and Lebanese (<i>n</i> = 1)	13 Swedish-born women	Qualitative study using in-depth semi-structured interviews conducted at weeks 34–38 of gestation in their first language using Arabic-speaking interpreters when required	Lack of knowledge about gestational diabetes by Middle East women; healthcare professional dependent, not concerned to discuss their own role in their healthcare Swedish women had a good knowledge of gestational diabetes; searched for help and advice from health workers; expressed beliefs about health and illness in medical terms, whereas others were reluctant to seek medical advice as influences are based on perceived social and supernatural factors Swedish women reacted more with negative feelings and worries when informed of gestational diabetes diagnosis, unlike the other who had a family history of diabetes and attributed it mostly to God's will Strict adherence to traditional and religious celebrations and feastings by Middle Eastern women, and eating of traditional foods Low educational and literacy levels of Middle Eastern women, who were all housewives, unlike the others with high-level education/jobs.		
Fagerli <i>et al</i> (2005)	Norway	15 Pakistani adults	Nil	Qualitative in- depth interviews	Communication problems due to language barrier and use of concepts and terminology not understood by participants Lack of interpreters in consultations Non-availability of preferred traditional foods Professional advice generally perceived by participants as inadequate, leaving them to do the translation between different levels of knowledge		

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Table 2 Continue	Fable 2 Continued						
Sedgwick <i>et al</i> (2003)	UK	1100 participants: black Caribbean ($n = 522$), black African ($n = 163$) and other ethnic minority groups ($n = 415$)	799 white participants	Questionnaire survey	No evidence that black African or black Caribbean people received less access to diabetes healthcare than their white counterparts in relation to their need; perhaps low quality due to language and cultural differences Need for interpretation support		
Rhodes <i>et al</i> (2003)	UK	23 participants from ethnic minority groups: Bangladeshi $(n = 12)$, Pakistani $(n = 14)$, Indian (n = 4), Eastern European (n = 2) and West Indian (n = 1)	22 white British participants	Qualitative in- depth interviews	Participants' experiences were varied, and their problems were not solely attributed to cultural insensitivity caused by their providers' 'like it or lump it' approach Bangladeshi participants were dissatisfied with primary care due to lack of confidence in the doctors' competence, inadequate appointment systems, inappropriate information, lost files, failure of health workers to follow up missed appointments, and difficulty in seeing doctor of choice Bangladeshi participants perceived negative attitudes of doctors in primary care Lack of professional language support, resulting in limited choice which led to the use of informal support, not fully favoured Low literacy level even in their own Bengali language		
Naeem (2003)	UK	106 Muslim Kashmiri men	Nil	Survey using face- to-face question- naire completed by the researcher of ethnic background who understood their culture and spoke the language as well	Strong adherence to religious beliefs and practices, resulting in failure of participants to control and manage their condition; overall perceived attitude that one should enjoy life and 'leave the rest to Allah' Strong adherence to cultural practices; influence of cultural values dominated their behaviour (e.g. eating traditional food) Participants were in denial about being overweight; belief influenced by cultural norms in which overweight figures tend to convey prosperity and well-being in the community Cultural practice of first-cousin marriages; such cultural practices may lead to future hereditary complications		

Table 3	Ethnicity of ethnic minority
groups	

Bangladeshi	222
Black African	163
Black Caribbean	522
Eastern European	2
Gujarati Muslim	5
Hindu	20
Indian	38
Iranian	3
Iraqi	10
Lebanese	1
Multicultural ethnic minority group	543
Muslim Kashmiri	106
Pakistani	121
Puerto Rican	12
South Asian	15
Surinamese	32
Mixed ethnicity participant	82
Total	1897

- linguistic differences between patients and health workers
- low health literacy levels
- different beliefs about health and illness
- belief in expert and professional support
- low accessibility of culturally appropriate services/ information
- low concordance with western professional advice.

Cultural adherence with regard to diet, exercise and social interactions

A total of 13 studies reported strict adherence to cultural norms (Kelleher and Islam, 1994; Narayan and Rea, 1997; Greenhalgh *et al*, 1998, 2006, 2011; Chowdhury *et al*, 2000; Naeem, 2003; Hjelm *et al*, 2005; Lawton *et al*, 2005, 2006b, 2008; Stone *et al*, 2005; Fleming *et al*, 2008; Gonzalez, 2008; Kohinor *et al*, 2011). Participants in ten of these studies were of South Asian origin (Narayan and Rea, 1997; Kelleher and Islam, 1994; Lawton *et al*, 2005, 2006b, 2008; Stone *et al*, 2005; Stone *et al*, 2005; Chowdhury *et al*, 2000; Greenhalgh *et al*, 1998, 2006, 2011; Fleming *et al*, 2008; Naeem,

2003). They had strong traditions with regard to food, and their traditional dishes generally had a very high content of fat or deep-fried food despite awareness of the detrimental effects of these on health and wellbeing. Food classifications were based on their perceptions of the strength of the food's nourishing powers, rather than on western notions of nutritional content. Participants reported managing their diet by 'cutting down on' rather than replacing perceived unhealthy foodstuffs (Lawton et al, 2008). Food choices were determined by two interrelated and intersecting binary classifications, 'strong'/'weak' and 'digestible'/ 'indigestible', which have social and symbolic meanings (Chowdhury et al, 2000). Some participants perceived western medicines as having detrimental effects if taken in excess or without eating traditional foodstuffs; this could lead to inappropriate self-adjustment of medication without medical consultation (Lawton et al, 2005). Surinamese participants also reported strong traditions related to food despite an awareness of the need to change their behaviour and adapt to healthy dietary guidelines (Kohinor et al, 2011).

Some participants of South Asian origin displayed more negative attitudes towards exercising, which they perceived as worsening their condition (Greenhalgh et al, 1998; Lawton et al, 2006b). Women reported more barriers to physical exercise, including fear of physical harassment, gender norms, social rules and cultural expectations that women should be indoors. It was stated that diabetes 'weakened and aged' the body, and this was reported as an additional barrier to undertaking physical exercise. Social interactions, and consumption of traditional dishes at social and cultural events such as weddings and religious festivals were regarded as very important (Chowdhury et al, 2000; Duthie-Nurse, 1998; Hjelm et al, 2005; Lawton et al, 2008). There was a strong attachment to social meanings and moral worth in real-life accounts of diabetes self-management (Greenhalgh et al, 2011).

Commitment to religious beliefs

Religious beliefs (Muslim, Christian, Hindu and Sikh) and practices were reported in 12 studies (Greenhalgh *et al*, 1998, 2011; Kelleher and Islam, 1994; Duthie-Nurse, 1998; Hjelm *et al*, 2005; Lawton *et al*, 2005, 2006a, 2007, 2008; Naeem, 2003; Kohinor *et al*, 2011; Stone *et al*, 2005; Gonzalez, 2008; Chowdhury *et al*, 2000). Eleven of these studies reported that participants, especially Muslims, demonstrated a strict commitment to religious beliefs about food and fasting during Ramadan, and diabetes self-management was a secondary consideration. All but one study (Lawton *et al*, 2007) identified religion and spirituality as major influences on coping with, managing and/or understanding diabetes. Religion was seen to be a source of

support in coping with anxiety in one study (Stone *et al*, 2005).

Many studies found that most Muslim and some Hindus and Sikh participants reported an external health locus of control. For example, Muslim participants reported that having diabetes was the will of Allah, and thus beyond their control, and therefore they accepted their fate. They generally attributed their beliefs and other behaviours to Allah's will, and held the view that adhering to dietary choices was the duty of an ill person. Although most of the participants were generally concerned about the impact of poor diabetes control, some Muslim participants held an attitude of 'enjoying life and leaving the rest to Allah', which resulted in poor diabetes control, especially during fasting periods (Naeem, 2003). In studies involving both ethnic minority and white European adults (Lawton et al, 2007; Hjelm et al, 2005; Stone et al, 2005), the ethnic minority participants, most of whom were Muslims, showed resignation at the diagnosis of diabetes, citing family history or a view that it was Allah's will, whereas their white counterparts reacted with shock, denial, and concern about the perceived consequences of diabetes complications.

Linguistic differences between patients and health workers

In total, 14 studies attributed ineffective diabetes management to communication difficulties and lack of linguistically appropriate healthcare services (Greenhalgh et al, 1998, 2006, 2011; Duthie-Nurse, 1998; Rhodes and Nocon, 2003; Rhodes et al, 2003; Sedgwick et al, 2003; Fagerli et al, 2005; Hjelm et al, 2005; Stone et al, 2005; Lawton et al, 2005, 2006a, 2006b; Brown et al, 2006; Povlsen et al, 2005; Gonzalez, 2008). Five of these studies identified lack of knowledge about diabetes in ethnic minority groups arising from their inability to communicate in English (Greenhalgh et al, 1998, 2011; Hjelm et al, 2005; Lawton et al, 2005; Gonzalez, 2008). In three studies, participants preferred linguistically competent healthcare providers to interpreters because they wanted communication to be direct, and interpreters were perceived as a source of anxiety and frustration (Gonzalez, 2008; Brown et al, 2006; Lawton et al, 2006a). Two UK studies (Duthie-Nurse, 1998; Lawton et al, 2006b) reported that linguistic barriers between participants and the public limited participants' knowledge of their neighbourhood and reinforced their vulnerability and social isolation, which led to some participants, especially women, staying indoors.

Seven studies identified a need for interpreter support (Greenhalgh *et al*, 1998, 2011; Rhodes and Nocon, 2003; Rhodes *et al*, 2003; Sedgwick *et al*, 2003; Fagerli *et al*, 2005; Povlsen *et al*, 2005), with four reporting a preference for professional interpreters rather than friends, relatives or receptionists (Rhodes and Nocon, 2003; Rhodes et al, 2003; Sedgwick et al, 2003; Fagerli et al, 2005). Reliance on family members or friends to interpret was inconvenient, as it disrupted people's routines and responsibilities. These participants also reported being uncomfortable discussing some aspects of their illness in front of their relatives or friends, and preferred to 'die in silence' (Rhodes and Nocon, 2003; Fagerli et al, 2005). Some participants were unaware of the availability of local interpretation or advocacy services (Greenhalgh et al, 2011). Participants cited the use of medical jargon or technical terminology by health workers as a communication barrier (Fagerli et al, 2005; Stone et al, 2005; Lloyd et al, 2008).

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Low health literacy levels

Eight studies reported low health literacy levels (low reading and numerical ability, resulting in reduced access to health information), which were perceived by the specific populations as hindering them from receiving effective diabetes care services (Narayan and Rea, 1997; Greenhalgh et al, 1998, 2011; Rhodes et al, 2003; Hjelm et al, 2005; Lawton et al, 2005, 2008; Povlsen et al, 2005; Gonzalez, 2008; Llovd et al, 2008). Some participants' lack of knowledge about diabetes was seen as a barrier to effective glycaemic control and/or diabetes self-management. For example, some participants only took their prescribed oral hypoglycaemic agents (OHAs) when their blood glucose levels were very high, over 18 mmol/l, or skipped meals in order to avoid taking them (Lawton et al, 2005).

In studies involving majority and minority populations, lower levels of educational attainment were reported within the minority groups, resulting in a lower level of understanding of diabetes care (Rhodes et al, 2003; Hjelm et al, 2005; Povlsen et al, 2005). The severity of the lack of literacy skills was noted in three studies (Greenhalgh et al, 1998; Rhodes et al, 2003; Lloyd et al, 2008). Audio-visual aids were used to improve comprehension, information retention, patient compliance and understanding if ethnic minority participants could not read or write in their first language. For some participants, lay and oral sources of health information were valued highly because of their low literacy skills (Greenhalgh et al, 1998, 2006; Lloyd et al, 2008). Lay diabetes information sources, such as family or personal experiences, appeared to have had a more profound influence on participants' behaviours than scientific evidence.

Beliefs about health and illness

In total, 11 studies reported various beliefs about health and illness based on religious, individual and societal factors, as well as compromising healthcare service provision and/or concordance with professional advice or treatment (Greenhalgh *et al*, 1998, 2011; Kelleher and Islam, 1994; Duthie-Nurse, 1998; Hjelm *et al*, 2005; Lawton *et al*, 2005, 2006b, 2007; Brown *et al*, 2006; Naeem, 2003; Stone *et al*, 2005; Gonzalez, 2008). Muslim, Hindu and Sikh participants reported that these factors contributed to the way they perceived health and illness. Two sub-themes emerged in relation to perceived beliefs about health and illness, namely causation and the integration of curative and diabetes self-management measures into everyday life.

Causation

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Nine studies discussed perceived beliefs relating to the cause of diabetes (Lawton et al, 2006b, 2007; Greenhalgh et al, 1998, 2011; Kelleher and Islam, 1994; Duthie-Nurse, 1998; Hjelm et al, 2005; Naeem, 2003; Stone et al, 2005). These included heredity, cold weather, unfamiliar western lifestyles, stress, Allah's will and supernatural factors. It was believed that heredity meant that diabetes was unavoidable (Naeem, 2003; Stone et al, 2005). Attributing diabetes onset to 'Allah's will and beyond their control' was common among Muslim participants in six studies (Lawton et al, 2006b, 2007; Kelleher and Islam, 1994; Hjelm et al, 2005; Naeem, 2003; Stone et al, 2005). Health, destiny, illness and death were perceived to be pre-ordained by Allah. Five studies discussed the power of Allah beyond the individual patient's control, often leading to an attitude of resignation at diagnosis (Lawton et al, 2007; Hjelm et al, 2005; Greenhalgh et al, 2011; Naeem, 2003; Stone et al, 2005). In one study (Hjelm et al, 2005), involving ethnic minority and non-ethnic minority Swedish-born female participants, the nonethnic minority Swedish-born participants attributed the cause of gestational diabetes to scientific explanatory concepts, feared developing type 2 diabetes, and sought medical help and advice from healthcare professionals. Their beliefs about health and illness were explained in medical terms. Ethnic minority participants attributed the onset of diabetes to social and supernatural factors which made them reluctant to seek medical advice. In another study, South Asian participants attributed the onset of diabetes to UK lifestyles and/or values, or as a form of punishment for their past religious sins. Other life circumstances, such as poverty, limited access to healthcare services, and family-related stress, were also regarded as causes of diabetes. In contrast, white British participants considered their own lifestyle choices and personal failings, thus adopting an internal locus of control to a greater extent (Lawton *et al*, 2007).

Five studies reported diet and/or lifestyle as factors that contributed to developing diabetes (Greenhalgh *et al*, 1998; Naeem, 2003; Hjelm *et al*, 2005; Brown *et al*, 2006; Lawton *et al*, 2006b), with one aligning 'overweight figures' with the cultural norms of projecting prosperity and well-being in the community rather than a health risk (Naeem, 2003). In two of these studies, participants partially associated physical exercise with diabetes, linking such exercise to worsening of their condition (Greenhalgh *et al*, 1998; Lawton *et al*, 2006b). South Asian participants linked cold weather rather than diet and/or inactivity to the onset of their diabetes, and believed that returning to South Asia would 'cure' them (Duthie-Nurse, 1998; Greenhalgh *et al*, 1998).

Integrating curative and diabetes selfmanagement measures into everyday life

This sub-theme examines the perceived healing paradigms and beliefs about diabetes self-management. In total, 11 studies reported at least one aspect of diabetes self-management, which demonstrated participants' perceptions of diabetes and their daily coping mechanisms. In 10 studies, participants acknowledged that diabetes was a permanent condition and could be controlled, to an extent, through natural or supernatural and/or medicinal means. For example, in the study by Lawton et al (2005), participants reported that if western medicines were taken in excess, they could cause side effects, worsening their condition. In addition, they believed that traditional diets, such as chapatti and curry, had strengthening properties that counterbalanced these side effects of medication. In another study (Lawton et al, 2008), participants acknowledged the detrimental effects on their blood glucose control of some South Asian foodstuffs, such as 'roti', used by most participants to describe complete meals consisting of curries, chapatti and/or rice with side dishes, although its literal meaning is 'chapatti.' However, most of them, especially among the first generation, did not effect dietary changes.

Participants also expressed initial qualms about taking oral hypoglycaemic agents, due to fear of acquiring the 'sick person's identity' (Lawton *et al*, 2005). In one study, Gujarati Muslim men believed in the healing powers of 'allopathic medicine', western medicine and other complementary therapies, especially herbal therapies (Fleming *et al*, 2008). In another, the Puerto Rican participants preferred and perceived better effects of western medicines as opposed to complementary or alternative medicines (Gonzalez, 2008).

Belief in expert and professional support

In seven studies, some participants expressed reduced confidence in health workers, and questioned their competence and the support that they offered (Narayan and Rea, 1997; Greenhalgh et al, 1998; Lawton et al, 2005, 2006a; Rhodes and Nocon, 2003; Rhodes et al, 2003; Brown et al, 2006; Gonzalez, 2008). Participants in three of these studies had confidence in UK doctors and perceived them to be competent and trustworthy. In contrast, doctors from the Indian subcontinent were perceived as untrustworthy, lacking training, and as sometimes giving preferential treatment to the wealthy and to relatives and friends (Lawton et al, 2005, 2006a; Rhodes and Nocon, 2003; Rhodes et al, 2003). One of these studies reported that medicines available in the UK were superior but inherently dangerous compared with those available from the Indian subcontinent (Lawton et al, 2005). Another perceived the purpose of healthcare services to be the prompt detection and treatment of complications, rather than the provision of advice about managing their condition (Lawton et al, 2006a).

In one study (Narayan and Rea, 1997), family members of a Hindu patient with gestational diabetes felt humiliated and embarrassed following their exclusion from her care planning. They saw this as contrary to their customs of involving family members and valuing their contribution to care. In two studies involving African-Caribbeans, South Asians (Brown *et al*, 2006) and Puerto Ricans (Gonzalez, 2008), participants valued one-to-one linguistically and culturally concordant support from their health workers.

Low accessibility of culturally appropriate services and information

Nine studies reported variations in participants' experiences, with negative issues relating to accessing culturally appropriate services or information (Narayan and Rea, 1997; Greenhalgh et al, 1998, 2011; Rhodes and Nocon, 2003; Rhodes et al, 2003; Stone et al, 2005; Brown et al, 2006; Lawton et al, 2006a, 2006b, 2008; Kohinor et al, 2011). These included gender issues, lack of culturally sensitive facilities during clinical consultations, and preferences for same-sex health workers irrespective of language barriers (Rhodes and Nocon, 2003). Some women avoided mixed-sex leisure facilities, such as swimming pools, and male gym instructors (Rhodes and Nocon, 2003; Lawton et al, 2006b), due to social and cultural beliefs about modesty (Greenhalgh et al, 2011). Six studies reported inappropriate and/or lack of culturally appropriate information about diet and foods (Greenhalgh et al, 1998; Narayan and Rea, 1997; Stone et al, 2005; Brown et al, 2006; Lawton et al, 2008; Kohinor et al, 2011). Participants in one study expressed a particular preference for gender-specific diabetes education sessions (Stone *et al*, 2005). Participants in two studies reported having received inappropriate information from healthcare workers that led to non-concordance with dietary and other healthcare advice (Greenhalgh et al, 1998; Rhodes et al, 2003). For instance, some Bangladeshi participants reported receiving leaflets in Bengali despite having very limited literacy skills (Rhodes et al, 2003). A further two studies reported the receiving of culturally insensitive advice (Narayan and Rea, 1997; Lawton et al, 2006a). For example, a Hindu patient was prescribed beef, perceived by Hindus as taboo, which contributed to the patient's non-concordance with the care package recommended by the nurse (Narayan and Rea, 1997).

Low concordance with western professional advice

In total, 11 studies reported that participants did not follow professional advice due to lack of cultural knowledge, religious and language differences, or contextual factors, which were sometimes misinterpreted by health workers (Kelleher and Islam, 1994; Narayan and Rea, 1997; Duthie-Nurse, 1998; Chowdhury et al, 2000; Naeem, 2003; Hjelm et al, 2005; Lawton et al, 2005, 2008; Stone et al, 2005; Fleming et al, 2008; Greenhalgh et al, 2011; Kohinor et al, 2011). Participants expressed a desire for dietary balance, but reported the importance of the traditional norms and beliefs about their foods, which some claimed made them 'weak and not strong enough' (Kelleher and Islam, 1994; Duthie-Nurse, 1998; Chowdhury et al, 2000; Lawton et al, 2008; Fleming et al, 2008). All of these factors contributed to their non-adherence to professional recommendations. Two studies reported conflicting professional dietary advice and prescriptions that were contrary to participants' traditions (Narayan and Rea, 1997; Kohinor et al, 2011). Two studies reported healthcare professionals' lack of cultural awareness resulting in a mismatch between prescribed interventions and the patient's beliefs and values (Narayan and Rea, 1997).

In one study, participants reported deliberately reducing their tablet intake without medical advice and concordance when they were lethargic or unwell, and despite awareness of the importance of prescribed oral hypoglycaemic agents (Lawton *et al*, 2005). In another study (Fleming *et al*, 2008), Gujarati Muslim men noted that contextual factors such as the choice of allopathic or cheaper homeopathic medicines influenced their choices. Stigma associated with having diabetes was reported as a factor contributing to low concordance with professional advice (Lawton *et al*, 2006b, 2007; Greenhalgh *et al*, 2011).

Discussion

The themes identified from this review of different ethnic, cultural and religious groups are participants' strong adherence to culture, religious beliefs, linguistic differences between them and their health workers, low health literacy levels, different beliefs about health and illness, belief in expert and professional support, low accessibility of culturally appropriate services and information, and low concordance with western professional advice. Although we do not claim that our findings are universal, our review has collated and demonstrated significant cultural and linguistic barriers that are perceived by members of ethnic minority groups as compromising diabetes care. There appeared to be gaps in identifying and making reasonable adjustments to meet specific needs which could enhance the engagement of members of ethnic minority groups, increase their personal satisfaction with diabetes service provision, and ultimately improve their health-related outcomes. Only three studies (Lawton et al, 2006a; Sedgwick et al, 2003; Brown et al, 2006) reported specific attempts to seek their opinions of services or their cultural needs (Goody and Drago, 2009; Brown et al, 2002; Hill, 2006). More work is needed to improve cultural competence among health workers to enable them to more effectively empower patients to self-manage their diabetes. Health policies should therefore be directed towards improving cultural competence training to facilitate partnership working between patients and their healthcare providers. This has been shown to improve professional skills, cultural knowledge and attitudes among healthcare professionals, enabling them to work effectively in cross-cultural situations, thereby yielding positive health-related outcomes for their ethnic minority patients (Majumdar et al, 2004; Khanna et al, 2009).

For people with diabetes, knowledge of diabetes can significantly predict their perceptions of the quality of services they receive, as well as their own illness perceptions (Baradaran and Knill Jones, 2004). The inability of members of ethnic minority groups to speak English fluently and low levels of health literacy in their own mother tongue are seen, in the UK context, as factors contributing to increasing social distance and reducing communication, which often threaten trust between patients and their health workers (Audit Commission, 2000; Greenhalgh *et al*, 2011). Appropriate linguistically competent tools have been proposed to provide high-quality diabetes care services to ethnic minority groups (Roy and Lloyd, 2008).

As culture consists of shared but dynamic patterns of behaviours and interactions that remain ongoing among different ethnic groups (Naeem, 2003), caution should be exercised when interpreting these results, due to the heterogeneity of the studies with regard to factors such as place of publication, recruitment setting, study design, studied population, and the cultural barriers explored. In total, 73% (n = 16) of the included studies were published in the UK, which has a significant number of ethnic minority people with diabetes (Zeh *et al*, 2012), and merits substantial investment in researching the cultural differences faced by these populations (Brown *et al*, 2002, 2006). Therefore this review may be more applicable to the UK primary care situation.

Health workers need to acknowledge cultural similarities and differences and build trust that might encourage concordance (Goody and Drago, 2009). Dietary advice and information should not be prescriptive, but rather it should be negotiated, affordable, culturally sensitive, and take account of the importance of food in the individual patient's ethnic and social context, as well as the importance of their religious, cultural, and health and illness beliefs (Brown, 1997; Hill, 2006). Diabetes health workers need to possess culturally competent knowledge of different cultures and ethnic foods, in order to empower patients with diabetes to adopt healthy lifestyles rather than to abandon familiar foods, as the evidence from the studies included in this review demonstrates limited cultural competence in these areas.

Strengths and limitations of the review

The search criteria included all ethnic minority groups with all types of diabetes and all primary qualitative and quantitative studies, excluding randomised controlled trials and quasi-experimental studies (which have been reported elsewhere), that have explored cultural differences globally. We assessed the quality of studies and included any research design to uncover any relevant studies that have explored cultural differences in diabetes. Triangulation of the results from the three included designs (quantitative, qualitative and mixed-methods) was a strength of the review, as they complemented each other, thereby improving the validity and generalisability of the findings. Our design was rigorous compared with previous systematic reviews that limited their search to specific ethnic minority groups, certain study types or specific types of diabetes, and which did not formally assess the methodological quality of the included studies (Brown et al, 2002; Fleming and Gillibrand, 2009).

The limitations of this review include the heterogeneity of the included studies, which causes difficulties in analysing the results or drawing firm conclusions. Some current research involving Eastern European populations within the UK may have been excluded, as only published studies were included. Excluding

randomised controlled trials and quasi-experimental studies from this review may have resulted in the omission of some important information about ethnic minority groups, such as exploration of different aspects of cultural barriers and their effectiveness. However, our aim was to collate and highlight these barriers in order to target appropriate interventions for ethnic minority groups with diabetes. Zeh et al (2012) identified the key elements for such interventions. Further reviews, including both randomised controlled trials and observational studies, may provide more insight into this area. Some cultural barriers may be specific to certain ethnic minority groups. Grouping all ethnic minority groups together may be contentious, as they may differ in terms of health patterns and the effects of interventions, making it difficult to provide generic recommendations (Davidson et al, 2013). In fact the definitions of ethnic minority groups, culture and cultural barriers have been restricted in this review, as they have diverse interpretations. The fact that not all of the studies included participants' health literacy levels may pose training and comprehension problems, and it is difficult to ascertain whether specific cultural barriers pertained to specific ethnic groups and/or age groups, which may have different educational needs. In addition, some vital information about ethnic minority groups may have been missed by excluding other chronic conditions, such as cancer.

Conclusions, implications for practice and recommendations for further research

This review has examined cultural barriers that can affect the quality of life of ethnic minority groups with diabetes and their glycaemic control, including communication problems, religion, health literacy levels and beliefs about health and illness. Understanding these issues may enable health workers to deliver culturally appropriate and individualised care, and thus reduce health inequalities in diabetes service provision. The review has examined some of these cultural issues and offers suggestions to guide the planning and commissioning of culturally appropriate diabetes services for ethnic minority populations. Sustained and targeted actions by health commissioners and partnership with all stakeholders in diabetes management (local authorities, community organisations, diabetes leads in primary and secondary care, academic institutions and service users) are essential for improving diabetes-related outcomes (see Box 2).

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Box 2 Recommendations

- Use the eight themes identified in this review to inform healthcare professional training curricula to develop and deliver culturally competent diabetes services.
- Provide culturally competent training to diabetes health educators who will support the development and implementation of specific community-based interventions, designed to help newly diagnosed patients come to terms with their condition and to facilitate their navigation through healthcare systems (Greenhalgh *et al*, 2011).
- Target recruitment and training of multilingual healthcare professionals to improve their knowledge of diabetes and health literacy.
- Minimise the use of medical jargon and technical terminology, and ensure continuous assessment of patients' understanding during clinical engagements.
- Develop psychological and behavioural interventions to enable individuals to take responsibility for their diabetes self-management.
- Acknowledge the influence of dominant and minority cultures on concordance, and seek to influence those aspects that are perceived to be changeable by the patient through patient-centred education.
- Undertake further research to investigate the effectiveness of community-led interpersonal health information sources and/or centres, including written and audio-visual materials associated with ethnic minority populations' cultural beliefs.
- Conduct randomised controlled trials relating to the themes identified from this review.
- Undertake qualitative explorations of health workers' perceptions and understandings of ethnic minority people's eating patterns (and the reasons for them), and how these might guide the advice that is given to patients.

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REFERENCES

- Alam R, Speed S and Beaver K (2012) A scoping review on the experiences and preferences in accessing diabetesrelated healthcare information and services by British Bangladeshis. *Health and Social Care in the Community* 20:155–71.
- Audit Commission (2000) Testing Times: a review of diabetes services in England and Wales. London: Audit Commission.
- Baradaran H and Knill Jones R (2004) Assessing the knowledge, attitudes and understanding of type 2 diabetes amongst ethnic groups in Glasgow, Scotland. *Practical Diabetes International* 21:143–8.
- Brown K, Dyas J, Chahal P *et al* (2006) Discovering the research priorities of people with diabetes in a multicultural community: a focus group study. *British Journal of General Practice* 56:206–13.
- Brown SA, Garcia AA and Winchell M (2002) Reaching underserved populations and cultural competence in diabetes education. *Current Diabetes Reports* 2:166–76.
- Brown V (1997) Diabetic pregnancy: an inner-city perspective. *Journal of Diabetes Nursing* 1:45–50.
- Bulmer M (1996) The ethnic group question in the 1991 Census of population. In: Coleman D and Salt J (eds) *Ethnicity in the 1991 Census. Volume One. Demographic characteristics of the ethnic minority populations.* London: HMSO. pp. 33–62.
- Chowdhury AM, Helman C and Greenhalgh T (2000) Food beliefs and practices among British Bangladeshis with diabetes: implications for health education. *Anthropology* & *Medicine* 7:209–27.
- Cohen J (1960) A coefficient of agreement for nominal scales. *Educational and Psychological Measurement* 20: 37–46.
- Cone DC, Richardson LD, Todd KH *et al* (2003) Health care disparities in emergency medicine. *Academic Emergency Medicine* 10:1176–83.
- Creswell JW and Plano Clark VL (2007) *Designing and Conducting Mixed Methods Research.* Thousand Oaks, CA: Sage.
- Davidson EM, Liu JJ, Bhopal RS *et al* (2013) Consideration of ethnicity in guidelines and systematic reviews promoting lifestyle interventions: a thematic analysis. *European Journal of Public Health* doi: 10.1093/eurpub/ckt093
- Davies K (2006) Addressing the needs of an ethnic minority diabetic population. *British Journal of Nursing* 15:516–19.
- Department of Health (2001) National Service Framework for Diabetes: standards. London: The Stationery Office.

- Duthie-Nurse G (1998) An anthropological study into the views on diet and disease of a sample of Hindu Gujaratispeaking women with type 2 diabetes. *Practical Diabetes International* 15:109–12.
- Fagerli RA, Lien ME and Wandel M (2005) Experience of dietary advice among Pakistani-born persons with type 2 diabetes in Oslo. *Appetite* 45:295–304.
- Fleming E and Gillibrand W (2009) An exploration of culture, diabetes, and nursing in the South Asian community: a metasynthesis of qualitative studies. *Journal of Transcultural Nursing* 20:146–55.
- Fleming E, Carter B and Pettigrew J (2008) The influence of culture on diabetes self-management: perspectives of Gujarati Muslim men who reside in northwest England. *Journal of Clinical Nursing* 17:51–9.
- Gohdes D (1988) Diet therapy for minority patients with diabetes. *Diabetes Care* 11:189–91.
- Gonzalez L (2008) *Health-care seeking behaviors of Puerto Ricans with diabetes mellitus who live in South Florida: an exploratory study.* Doctoral dissertation. Orlando, FL: University of Central Florida.
- Goody C and Drago L (2009) Using cultural competence constructs to understand food practices and provide diabetes care and education. *Diabetes Spectrum* 22:43–7.
- Greenhalgh PM (1997) Diabetes in British South Asians: nature, nurture, and culture. *Diabetic Medicine* 14:10–18.
- Greenhalgh T (2008) Communicating with people who have limited English. *Diabetes & Primary Care* 10:89–93.
- Greenhalgh T, Helman C and Chowdhury AM (1998) Health beliefs and folk models of diabetes in British Bangladeshis: a qualitative study. *British Medical Journal* 316:978–83.
- Greenhalgh T, Chowdhury M and Wood GW (2006) Storybased scales: development and validation of questionnaires to measure subjective health status and cultural adherence in British Bangladeshis with diabetes. *Psychology, Health & Medicine* 11:432–48.
- Greenhalgh T, Collard A, Campbell-Richards D *et al* (2011) Storylines of self-management: narratives of people with diabetes from a multiethnic inner city population. *Journal of Health Services Research & Policy* 16:37–43.
- Hawthorne K, Mello M and Tomlinson S (1993) Cultural and religious influences in diabetes care in Great Britain. *Diabetic Medicine* 10:8–12.
- Hill J (2006) Management of diabetes in South Asian communities in the UK. *Nursing Standard* 20:57–64; quiz 66.
- Hjelm K, Bard K, Nyberg P *et al* (2005) Swedish and Middle-Eastern-born women's beliefs about gestational diabetes. *Midwifery* 21:44–60.
- International Diabetes Federation (2009) *International Diabetes Federation Diabetes Atlas*. Brussels: International Diabetes Federation.
- Jadad AR, Moore RA, Carroll D *et al* (1996) Assessing the quality of reports of randomized clinical trials: is blinding necessary? *Controlled Clinical Trials* 17:1–12.
- Kelleher D and Islam S (1994) The problem of integration: Asian people and diabetes. *Journal of the Royal Society of Medicine* 87:414–17.
- Khanna SK, Cheyney M and Engle M (2009) Cultural competency in health care: evaluating the outcomes of a

cultural competency training among health care professionals. *Journal of the National Medical Association* 101:886–92.

- Kohinor JE, Stronks K, Nicolaou M *et al* (2011) Considerations affecting dietary behaviour of immigrants with type 2 diabetes: a qualitative study among Surinamese in the Netherlands. *Ethnicity* & *Health* 16:245–59.
- Landis JR and Koch GG (1977) The measurement of observer agreement for categorical data. *Biometrics* 33:159–74.
- Lawton J, Ahmad N, Hallowell N *et al* (2005) Perceptions and experiences of taking oral hypoglycaemic agents among people of Pakistani and Indian origin: qualitative study. *British Medical Journal* 330:1247.
- Lawton J, Ahmad N, Hanna L *et al* (2006a) Diabetes service provision: a qualitative study of the experiences and views of Pakistani and Indian patients with type 2 diabetes. *Diabetic Medicine* 23:1003–7.
- Lawton J, Ahmad N, Hanna L *et al* (2006b) 'I can't do any serious exercise': barriers to physical activity amongst people of Pakistani and Indian origin with type 2 diabetes. *Health Education Research* 21:43–54.
- Lawton J, Ahmad N, Peel E *et al* (2007) Contextualising accounts of illness: notions of responsibility and blame in white and South Asian respondents' accounts of diabetes causation. *Sociology of Health & Illness* 29:891–906.
- Lawton J, Ahmad N, Hanna L *et al* (2008) 'We should change ourselves, but we can't': accounts of food and eating practices amongst British Pakistanis and Indians with type 2 diabetes. *Ethnicity & Health* 13:305–20.
- Lloyd CE, Sturt J, Johnson M *et al* (2008) Development of alternative methods of data collection in South Asians with type 2 diabetes. *Diabetic Medicine* 25:455–62.
- Mainous AG 3rd, Diaz VA, Saxena S *et al* (2007) Heterogeneity in management of diabetes mellitus among Latino ethnic subgroups in the United States. *Journal of the American Board of Family Medicine* 20:598–605.
- Majumdar B, Browne G, Roberts J *et al* (2004) Effects of cultural sensitivity training on health care provider attitudes and patient outcomes. *Journal of Nursing Scholarship* 36:161–6.
- Modood T and Berthoud R (1997) *Ethnic Minorities in Britain: diversity and disadvantage – Fourth National Survey of Ethnic Minorities.* London: Policy Studies Institute.
- Moher D, Liberati A, Tetzlaff J *et al* (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Medicine* 6:e100097.
- Naeem AG (2003) The role of culture and religion in the management of diabetes: a study of Kashmiri men in Leeds. *Journal of the Royal Society for the Promotion of Health* 123:110–16.
- Narayan MC and Rea K (1997) Nursing across cultures: the South Asian client. *Home Healthcare Nurse* 15:460–70.
- NHS Health Scotland (2004) Diabetes in Minority Ethnic Groups in Scotland: a report by the National Resource Centre for Ethnic Minority Health in collaboration with the Scottish Diabetes Group. Glasgow: NHS Health Scotland.
- Oldroyd J, Banerjee M, Heald A et al (2005) Diabetes and ethnic minorities. Postgraduate Medical Journal 81:486–90.
- Pluye P, Gagnon M, Griffiths F et al (2009) A scoring system for appraising mixed methods research, and concomitantly

appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *International Journal of Nursing Studies* 46:529–46.

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- Popay J, Rogers A and Williams G (1998) Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research* 8:341–51.
- Povlsen L, Olsen B and Ladelund S (2005) Diabetes in children and adolescents from ethnic minorities: barriers to education, treatment and good metabolic control. *Journal of Advanced Nursing* 50:576–82.
- Rhodes P and Nocon A (2003) A problem of communication? Diabetes care among Bangladeshi people in Bradford. *Health & Social Care in the Community* 11:45–55.
- Rhodes P, Nocon A and Wright J (2003) Access to diabetes services: the experiences of Bangladeshi people in Bradford, UK. *Ethnicity & Health* 8:171–88.
- Roberts S (2007) *The Way Ahead: the local challenge.* London: Department of Health.
- Roy T and Lloyd CE (2008) Development of audio methods of data collection in Bangladesh. *Diversity in Health and Social Care* 5:187–99.
- Salimbene S (1999) Cultural competence: a priority for performance improvement action. *Journal of Nursing Care Quality* 13:23–35.
- Sedgwick JE, Pearce AJ and Gulliford MC (2003) Evaluation of equity in diabetes health care in relation to African and Caribbean ethnicity. *Ethnicity & Health* 8:121–33.
- Stone M, Pound E, Pancholi A *et al* (2005) Empowering patients with diabetes: a qualitative primary care study focusing on South Asians in Leicester, UK. *Family Practice* 22:647–52.
- Wilson C, Alam R, Latif S *et al* (2012) Patient access to healthcare services and optimisation of self-management for ethnic minority populations living with diabetes: a systematic review. *Health and Social Care in the Community* 20:1–19.
- Zeh P (2010) Delivering diabetes care to ethnic groups: a pilot general practice survey. *Diabetes and Primary Care* 12:280–90.
- Zeh P, Sandhu HK, Cannaby AM et al (2012) The impact of culturally competent diabetes care interventions for improving diabetes-related outcomes in ethnic minority groups: a systematic review. Diabetic Medicine 29:1237–52.

CONFLICTS OF INTEREST

None.

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