A systematic review of research into black and ethnic minority patients' views on self-management of type 2 diabetes

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Abstract

Context Eliciting patients' views of type 2 diabetes self-management provides insights on how policy and services might better support the needs of this population.

Objective To synthesize black and ethnic minority patients' views on the barriers and facilitators influencing the self-management of type 2 diabetes.

Search strategy A systematic search of international literature published in nine electronic databases was undertaken in 2008. Search strategies used both MeSH and free-text terms. Two relevant journals were also hand searched.

Inclusion criteria Any primary empirical study published in the English language since 1986 that reported black and ethnic minority patients' views on type 2 diabetes self-management.

Data extraction and synthesis Data were extracted and study quality was formally assessed. Data were analysed using thematic synthesis.

Main results Fifty-seven studies were included, of qualitative ($n = 54$), mixed-method ($n = 2$) or quantitative ($n = 1$) design. Studies were from North America ($n = 41$), Europe ($n = 14$) and Australia ($n = 2$), including 1735 participants in total. Three analytical themes emerged: 'Importance of identity'; 'Being understood by others' and 'Making sense of condition', all linked conceptually under the overarching theme 'Sense of self'. The quality of the studies varied.

Discussion and conclusions The findings provide insight into what black and minority ethnic people regard as the barriers to, and facilitators of self-management, as opposed to what health professionals, policy makers and trial researchers may have assumed. Recognition of the views of people with diabetes is essential for the design and delivery of patient-centred care and policies.

Introduction

Worldwide the prevalence of type 2 diabetes mellitus (T2D) is increasing[1] and it is now the fifth most common cause of death.[2] In 2009 2.3 million people in the UK had T2D,[3] while globally it is estimated that 171 million people live with the condition and this is expected to increase to 366 million by 2030.[4] T2D is associated with a range of acute and long-term complications, including heart and circulatory disorders, renal failure and sight loss.[5]

Black and minority ethnic (BME) groups are at higher risk of developing T2D,[6] and diabetes outcomes tend to be worse among people from some BME and socially deprived groups.[7,8] One factor contributing to poorer outcomes is an inadequate match of health and social care to the needs of these patient groups; thus designing more appropriate policy and interventions may impact on health inequalities.[9] To do this, patients' views of T2D and the factors that influence their ability to manage the condition, need to be better understood.

By maintaining good glycaemic control the chance of complications of T2D can be reduced and quality of life improved.[10] Self-management is central to diabetes, as it is for many long-term conditions,[11] and has been defined as the behaviours that the patient employs in implementing the treatment regimen within their lifestyle routine.[12] Diabetes self-management requires the patient to make multiple decisions each day regarding diet, activity, glucose monitoring and medicine adherence to prevent hypo- and hyper-glycaemia.[13] Decisions and actions are based on their knowledge, beliefs, attitudes, resources and support systems.[14]

The patient empowerment approach to self-management education interventions was first proposed in the 1990s.[15] It aims to support patients in identifying and achieving their own goals; indeed empowering patients to self-manage has been seen as the cornerstone of T2D management.[16] This suggests that there is merit in health-care systems recognizing those groups most at risk, such as BME communities, and tailoring appropriate programmes to support self-management.[17] Western health systems including the UK[18] have advocated patient-centred care as a key component of health policies for over a decade.[19] Appropriate patient-centred treatment programmes can only be tailored when patients' views on self-management are known and understood.

To our knowledge there are currently only two reviews that have explored culturally relevant issues relating to diabetes self-management and they focused on only one or two BME groups, living in a single country.[20,21] In addition, reviews have evaluated diabetes self-management interventions delivered to BME groups.[22–26] To our knowledge there are no existing systematic reviews that have synthesized research across countries for BME patients' views on multiple T2D self-management behaviours. This review aimed to answer the question, 'What are BME patients' views relating to self-management of T2D?'

Methods

Design

A systematic review and interpretative data synthesis of primary empirical studies reporting patients' views.

This review is one of a linked pair of systematic reviews undertaken in line with the Evidence for Policy and Practice Information (EPPI) Centre's innovative 'mixed-methods framework'[27] in which data from intervention studies (usually trials) are reported alongside data from 'views studies'.[28] The interventions review is currently under review. The EPPI centre's framework enables multiple research questions to be answered because many research designs can be included and multiple syntheses can be undertaken.

The EPPI approach was well suited to this systematic review because it provides clear guidance on synthesizing evidence from 'views' studies that place people's own voices at the centre of analysis. 'Views' studies are usually but not always qualitative. For the purposes of

this review 'views' studies were identified as studies of any design that presented views as data, considering these insights as valuable in themselves, as opposed to presenting these as a strategy for generating variables that would go on to be tested in a model.[29]

As with traditional systematic review methods, the EPPI process incorporates transparent steps to reduce the impact of bias and error that may be present in primary studies as well as in the process of reviewing. These procedural points are detailed in the remainder of the methods section.

Search strategy

A single literature search was undertaken for the two linked reviews. When screening the titles and abstracts of retrieved papers, papers were categorized as being potentially relevant for inclusion in either the 'views' or 'interventions' reviews.

The first step was to identify synonyms for the review's three key components (BME groups, T2D, self-management), using British and North American terms and spellings. The search used both 'controlled vocabulary' (standardized indexed search terms) and 'free-text terms'. In total the search included 159 terms in OVID databases. These search terms have been made available as supporting information for the online edition.

Eight bibliographical databases (MEDLINE, CINAHL, EMBASE, HMIC, AMED, PsycINFO, CSA, Web of Science) and one specialist register (Cochrane Library) were searched to April 2008. Some of the smaller databases did not employ controlled vocabulary, and even in databases that did, these were not standardized. Consequently, a search strategy was initially devised in MEDLINE and then adapted to other databases. Free-text terms were used consistently throughout.

To test search sensitivity, two key journals (*Diabetes Care* and *Ethnicity and Health*) were hand searched from 2000 to 2008. This process did not produce any studies not already identified.

Inclusion and exclusion criteria

The entry criteria were adapted from previously defined study selection criteria:[30] *populations*, *interventions*, *outcomes* and *study designs*. As this review aimed to explore patients' perspectives and not the effects of intervention studies, 'Interventions' was replaced with 'Health issue.'

Population
1. Adults with a diagnosis of T2D.
2. Study samples of whom at least 50% were BME or when studies reported separate findings for BME subsamples.

BME was defined as 'individuals with a cultural heritage distinct from the majority population'.[31]

Health issue
 Patients' perspectives on T2D self-management.

Study design
 Any.

Outcomes
 Any outcome related to T2D self-management.

Exclusion criteria
1. Studies not published in English.
2. Studies of indigenous ethnic groups.

Given the focus of the review, the historical and policy contexts were considered to be influential, so we applied a publication start date of 1986, the date of Lorig's influential paper on self-management in long-term conditions.[32]

Procedure and materials

A screening tool was developed to review the search results. Initially screening was based on title and abstract, conducted by one author (RM) with a second author (CJ or PK) checking the decisions on a 10% sample

for reliability. When the inclusion criteria appeared to have been met, the full paper was obtained and read for potential inclusion by RM.

Data extraction and quality assessment

The next step involved selecting a tool which enabled consistent and accurate data extraction and quality assessment of the included research papers thereby minimizing bias in the interpretation of findings.[33] A key consideration when selecting a critical appraisal tool was that it accommodated both of the linked pair of systematic reviews, one of which focused on data from intervention studies (usually trials) while the other, reported here, focused primarily on qualitative data from 'views studies'.

There is no one 'gold standard' critical appraisal tool. A systematic review on the content of critical appraisal tools was consulted.[34] Katrak *et al.* retrieved 121 tools, 16 of which enabled an assessment of studies of both a quantitative and qualitative design and these tools were reviewed for our purpose. The template developed by Long and Godfrey[35] was selected which served both data extraction and quality assessment.

Long and Godfrey's template was slightly adapted for the purposes of this systematic review. The EPPI Centre's review guidelines for data extraction and quality assessment of intervention studies[36] were also adopted. This amalgamation of the two existing checklists plus the review questions specific to this study formed the basis of the critical appraisal tool developed here. This has been made available as supporting information for the online edition.

Data were extracted by one author (RM) and then checked by a second author (PK or CJ).

Evidence synthesis

It was anticipated that the 'views' data would be highly heterogeneous. In order to organize a large and potentially varied data set, key findings from the primary studies were organized according to the following three questions:

1. What is the meaning of 'self-management' to BME patients with T2D?
2. What helps and what prevents their self-management?
3. What ideas do BME patients themselves identify for what could promote self-management?

The findings of the studies were integrated using thematic synthesis and in so doing, key themes were identified to answer the overall review question 'What are BME patients' views relating to self-management of T2D?' The process of thematic synthesis followed four sequential stages:[37]

1. Line-by-line coding of the key findings of the primary studies was undertaken by RM, and this produced a bank of codes.
2. The data set was organized by RM, according to the three review questions (above). This facilitated the development of 'descriptive themes', which remained proximate to the findings of the primary studies.
3. Generation of interpretative 'analytical themes' enabled additional understanding of the concept by 'going beyond' the primary studies and producing more abstract constructs.[38] To obtain analytical themes, all the study authors considered the descriptive themes in the context of how they answered the review question. Barriers and facilitators to self-management were obtained from patients' views, and the implications of the findings for supporting the development of T2D self-management interventions were considered. Through this process, more conceptual themes emerged that reflected patients' perspectives on their T2D self-management.
4. The relationship between the analytical themes was also carefully considered by all of the study authors until an emergent over-arching theme was identified, which addressed the systematic review question.

Results

Description of studies

The search identified 15 725 articles (see Fig. 1), of which 84 met the inclusion criteria after screening by title and abstract and were retrieved and read in full. Final screening resulted in 57 included studies,[35–95] involving a total of 1723 patients.

One study had used a quantitative design,[60] two were of a mixed-method design[83,88] and the remaining 54 were qualitative studies. Thirty-eight studies were undertaken in the US[39–43,46,47,49–52,54,55,58,59,61,62,64–69,71,77,79–82,84–86,88,92,93,95] and a further three in Canada.[63,83,87] Fourteen studies were from Northern Europe (11 in the UK[44,45,53,60,74–76,78,89–91] and three in Scandinavia[56,57,94]). The remaining two studies were from Australia.[72,73] Because the literature was dominated by North American research, it is unsurprising that most of the BME groups were of African[42,45,47,54,55,62,77,80–82,86,89,91,92,95] or Latino origin.[39–41,43,48,50,61,65–69,71,85,93] The next largest numbers of studies included South Asian[44,53,56,57,60,74–76,78,87,90] and East Asian[51,52,63,70,79] populations. One study included

Figure 1 A flow chart of study selection. *These numbers relate to a broad search strategy that was used to identify studies for this 'views' review and the linked 'interventions' review.

Italian immigrants;[83] the remaining five studies included patients from more than one BME group.[58,64,72,73,88] Nine of the 57 studies included only women,[39,40,46,47,49,53,72,73,86] while one study included only men.[74]
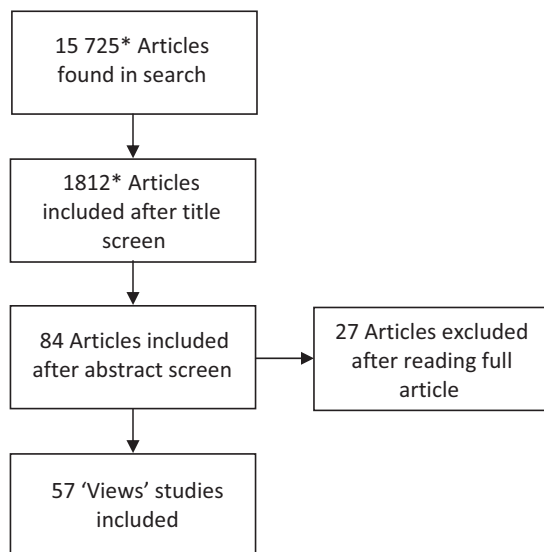
The studies addressed a broad and diverse set of issues relating to T2D self-management, including general lived experience;[39,46,61,70,77,78,92,94,95] lifestyle;[53,55,57,58,76,84,86,89] beliefs about diabetes;[45,48,51,59,60,67,72,79] perceptions of health professionals';[44,57,72,73,82] general self-management;[42,47,65,68,93] diabetes education;[41,43,85,87] alternative treatments;[69,80,88] explanatory models of T2D;[40,52,71] insulin therapy;[63,66] family roles;[49,83] depressed mood;[50,83] culture;[59,91] health-care goals;[64] health service use;[75] medicines;[74] symptoms;[81] social support;[72] fatalism;[54] problem-solving;[62] and empowerment.[90] Three studies[59,72,83] investigated more than one of these issues.

Quality assessment

Methodological quality was assessed according to accepted standards by appraising individual components of each study's: design; procedure; conduct; and analysis. Table 1 summarizes the application of the quality assessment criteria to each study; 26 criteria apply to qualitative (and mixed-method) studies, while only 24 criteria apply to the quantitative studies. Seven studies[41,53,61,67,72,78,89] scored poorly, meeting less than half the criteria. Four of these studies[41,53,67,89] were published over ten years ago, when research quality criteria were less standardized. Since the findings of the seven lower-quality studies did not differ from the higher-quality majority, all studies were retained in the review.

Self-management views

The synthesis identified three analytical themes, 10 descriptive themes with nine subthemes, and an over-arching theme (see Fig. 2); these will now be discussed in turn. Differences that emerged across gender or ethnicity are identified in the findings.

Table 1 Number of studies scoring a 'yes' on quality assessment criteria by study design

|	All (*N*)	%	Qualitative (*n* = 54)	Mixed (*n* = 2)	Quantitative (*n* = 1)
Clear aims	57	100	54	2	1
Clear articulation of rationale	57	100	54	2	1
Clear description of setting	54	95	51	2	1
Explicit theoretical framework	16	28	16	0	0
Clear description of self-management behaviour	48	84	46	1	1
Stated measure of self-management	8	14	5	2	1
Clear description of recruitment procedure	49	86	46	2	1
Clear description of sampling procedure	56	98	53	2	1
States inclusion and exclusion criteria	50	88	47	2	1
State participation rates	16	28	16	0	0
Target sample achieved	14	25	14	0	0
Clear description of sample	51	89	48	2	1
Appropriate sampling	48	84	45	2	1
Provision of recruitment data	22	39	19	2	1
Provision of attrition data	15	26	13	1	1
Clear description of data collection	57	100	54	2	1
Information collected with sufficient detail and depth	50/56	89	49	1	-
Clear description of data analysis	37	65	35	2	1
Reliability and validity of data analysis methods reported	42	74	40	1	1
Evidence of reflexivity	7/56	13	55	1	-
Explicit mention of health literacy	2	4	2	0	0
Interprets findings in context of other studies/theory	51	89	48	2	1
Evidence of consumer involvement	13	23	10	2	1
State implications	51	89	48	2	1
Strengths and limitations stated	45	79	42	2	1
Conclusion justified	55	96	52	2	1
Total (of possible 1486)	1021		962	39	20
% of maximum possible score	69		68	75	83

Analytical Theme 1: Importance of identity
Self-management was largely influenced by how the patients identified themselves. A patient's identity was evidenced in their: emotional outlook, particularly in response to the diagnosis and living with T2D; confidence levels; and roles.

Descriptive Theme 1a: Emotional responses to illness
Patients recalled their emotional responses to their diagnosis of diabetes as overwhelmingly negative including: depression;[46,48,61,62,93] denial;[41,45,46,54,59,62,73,77] anxiety;[72,75,86,90] resignation;[40,48,54,76,77,84,90,92] and pessimism.[39,40,46,52,54,62,75,76,94] Patients described how diabetes was an 'assault' on their identity.

Emotional responses to self-management were also mentioned. Patients reported frustration[62,76,80,93] and anger[46,62,77,93] with the complexity of self-management. Fear of diabetes and its complications[46,47,61,70,71,75,77,84,90,94] added to the difficulties associated with initiating and maintaining good self-management.

A commonly adopted strategy to facilitate self-management was improving emotional well-being. Some people actively sought opportunities to be involved in activities that made them happier and healthier.[52,66,69,70,88,92,95] Others either accepted[42,47,62,68,77] or avoided focusing on[47,54,60,66,72,94] their diabetes so as to improve their emotional well-being. By accepting their diabetes, patients were better able to receive support from others[52,72,84,85,87,92] as
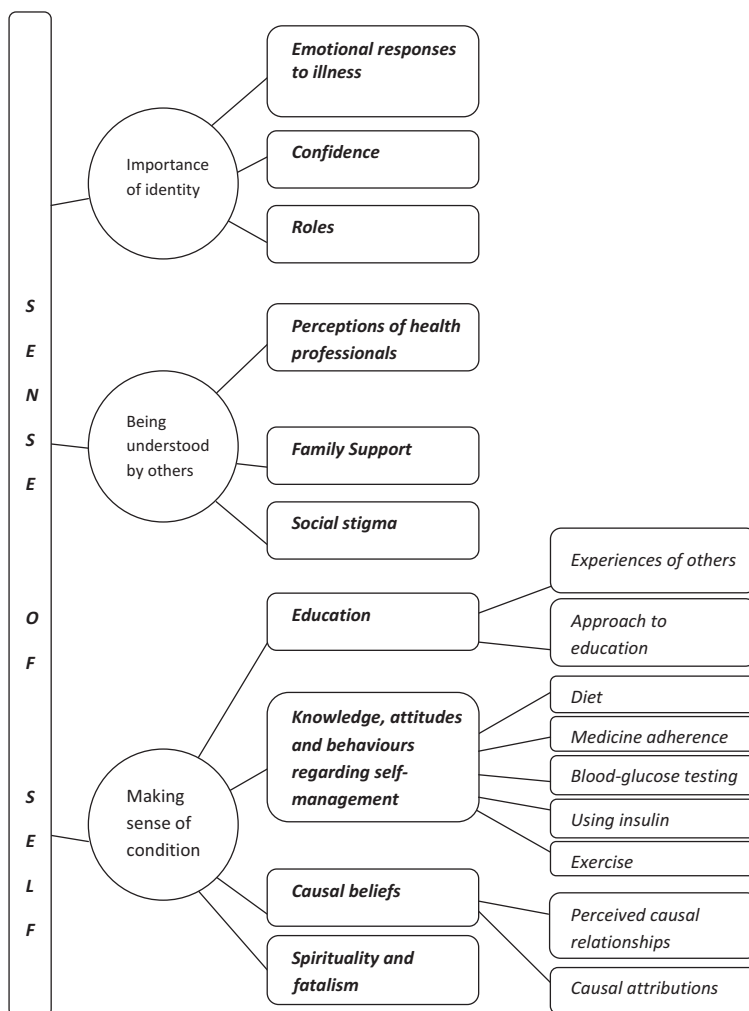
Figure 2 Identified descriptive and analytical themes.

well as help themselves self-manage.[46,47,62,68,84, 85,92,94]

Descriptive Theme 1b: Confidence
Those who accepted their diabetes, demonstrated an empowered perspective to self-management and were able to embrace their new, evolving identity. They emphasized the personal experience of living with diabetes, maintaining that knowledge of their own bodies could not be surpassed in managing the condition.[39,40,42,43,45,47,52,62,67,73,77,94]

For those who experienced a disoriented identity or rejected their new identity, developing diabetes resulted in a loss of confidence in their ability to implement behavioural changes required for self-management.[39,40,43,48,54,72,80] Furthermore, some expressed the view that diabetes was a 'betrayal' by their own body.[39,73,81,95]

Descriptive Theme 1c: Roles
Gender roles were commonly discussed.[39,41,44,47–50,55,58,59,66,72,76–80,83,86,87,90,94,95]
Men focused on how diabetes affected them physically,[50,66,76,77,80,94,95] while women expressed general concerns about having poorer health.[39,50,94,95] Gender was influential with respect to perceived support, with men tending to report significant family support[44,50,59,66,77,95] and women tending to feel unsupported.[50,59,76,86,94]

Cultural norms were more evident in women's discourses.[76,79,87,90] For many women, the role of caregiver affected self-management.[39,41,44,47–49,55,66,72,76,78,80,83,86,87] For some, their family, social and work roles facilitated self-management because they believed it was important to maintain health, so as to retain identity, independence and a sense of normality. For some women, such caregiver roles were a barrier, requiring time and energy that made it physically and emotionally difficult for them to self-manage their T2D.

Health goals were commonly described in functional rather than biomedical terms, that is, being able to continue with aspects of their daily routine.[64,66,68,81,94] Similarly, symptoms were defined in terms of impact on social, familial and working roles.[47,55,61,68,70,76,77,81] Diabetes served to motivate some people to maintain their pre-diagnosis roles in order to preserve their identity within their social, religious and familial groups.[39,42,46,49,53,94] By the same token, patients reported unease with being dependent on others.[47,52,59,74,75,77,81,84,94]

Analytical Theme 2: Being understood by others
Patients' views emphasized a need for their condition to be understood by others in their family and local community. Patients also actively sought health professionals who understood their cultural background.

Descriptive Theme 2a: Perceptions of health professionals
Patients frequently reported seeking guidance from health professionals.[39,42,44,46–48,50,56,62,73,82,95] There was respect for the physician's professional status,[72,87,90] which, for some, meant they never criticized health professionals.[44,56,95] Others even withheld information about their own 'poor' self-management practices.[44,72,73,79,84,95]

Patients were mindful of the health professional's lack of time.[56,60,87] Some patients were critical of the quality and amount of information they received,[72,73] while others accepted that health professionals were busy.[46,92,93] Patients showed high regard for health professionals who offered patient-centred care[39,42,45,95] and communicated in a meaningful way.[39,56,82,85]

Failing to consistently follow health professionals' recommendations because of the challenges of managing daily life within a complex regimen[44,81,92,93,95] and the constraints imposed by comorbidities was not uncommon.[42,44,50,57,61,76,90,92] Professional advice was also not always followed when patients disagreed with the recommendations[39,42,57,63,72,73,93] or viewed health professionals as untrustworthy.[43,45,54,56,72,80]

Patients' perceptions of their health professional were shaped by the cultural and linguistic appropriateness of the health-care exchange; in circumstances when the consultation was perceived to be inappropriate patients referred to health professionals' inability to relate to them.[42,46,56,57,80,84,87,95] For example, patients were critical of health professionals' dietary recommendations that were perceived as expecting the patient to reject culturally traditional foods.[45,56,57,84,94]

The linguistic inappropriateness of the exchange with the health professional was mentioned by patients who understood none or little of the host country language.[50,90] Those who spoke positively of consultations tended to share a common language and culture with their health professional as this made communication easier, more direct and culturally sensitive.[39,53,75,79,84,87] The inadequacy of working through interpreters as compared with direct communication with bilingual staff also emerged.[56,57,59,63,75,87]

Descriptive Theme 2b: Family support
This was a commonly reported descriptive theme to emerge. Interestingly, all statements of family support being 'valued' came from North American studies of African-Americans or Latinos.[41,47,49,71,80,86,92,93,95] Only two studies reported patients resisting family support by concealing their condition, motivated in part to protect family members from worry.[51,72] It was noted that disclosure of the condition elicited emotional[71,72,90,93] and practical support from the family, particularly with diet.[46,49,53,55,58,71,92]

Some patients reported that families lacked understanding of the need for dietary modifications.[39,56,78,90,93,94] Many patients reported that feeling supported by their family depended on the family understanding their condition.[41–43,47,48,50,93]

Although identified less frequently, some views suggested a lack of familial support, which was largely due to poor understanding of the condition.[41,47,85,92] There was a perceived lack of empathy from some families who did not change their expectations of the individual's home responsibilities after diagnosis of diabetes.[86,87]

Descriptive Theme 2c: Social stigma
Several studies identified social stigma as a concern,[39,47,63,70,76,87,92] which at times prevented patients from disclosing their diagnosis, leading to an impaired ability to self-manage. Elsewhere, however, patients talked about diabetes as a common condition and as such they felt comfortable telling people they had it[71,77] with information sharing occurring naturally.

Analytical Theme 3: Making sense of own condition
Despite showing a high regard for education, the majority of views demonstrated a lack of knowledge about, and negative attitudes towards, making lifestyle changes to manage their diabetes. Patients evidenced inaccurate health beliefs, either as a result of misunderstanding the underlying causes and consequences of diabetes or by over-emphasizing cultural health beliefs. Traditional beliefs regarding spirituality and fatalism further impacted on patients' understanding of diabetes.

Descriptive Theme 3a: Education
Two subthemes emerged within this descriptive theme.

Experiences of others. The experiences of others, including family members, with diabetes were seen as a valued, informal source of education and information.[39,40,42,45,46,52,58,62,70,80,85,90,92] The experiences of others also influenced

patients' health-care goals. However, social comparison had negative consequences for some because it led them to believe that poor outcomes of diabetes were inevitable.[39,40,48,54,61,62,76,77,84,90,92] For some, however, exposure to others' poor health facilitated acceptance of their diagnosis[73] and a realization of possible outcomes; as such, it was a motivator to self-manage well.[42,45,50,62] Several studies reported the value attached to having good role models because they inspired hope for a normal life and provided the opportunity for interaction with someone who was successful at self-management and understood the challenges of the condition.[42,84,93]

Approach to education. Some patients sought a non-didactic approach to education,[46,64,69,73,80,85,91–93] and this tended to be reported in American studies. Meanwhile, other patients sought a more didactic approach to education[39,42,44,54,56,60,64,70,73,75,78,85,87,90,93,95] where formal learning techniques were employed, and these tended to be in studies with South Asian samples.

Patients talked favourably of education classes.[46,48,71,84,92] Group education was positively received due to its supportive[58,72,76,84,90,92] and motivational[85] atmosphere. Some sought the inclusion of family members, partly for their support but also so they too could learn how to manage diabetes.[41,56,84,85,93]

Patients sought practical education centred on diet,[46,55,58,83–85,91–93] and culturally appropriate education focused on physical activity.[58,75,76,93] The use of health-care jargon was identified as an educational barrier[57,60,73] as were patients' own literacy limitations.[52,85,91,93,94]

Descriptive Theme 3b: Knowledge, attitudes and behaviours regarding self-management
Studies reported a broad range of knowledge, attitudes and behaviours regarding diabetes self-management. More studies reported negative attitudes and behaviours and a lack of knowledge than did those identifying good knowledge, and positive attitudes and behaviours about diabetes. Patients' knowledge and atti-

tudes towards specific self-management behaviours are now presented in the five following subthemes; ordered according to frequency of occurrence in the primary studies, with the most common presented first.

Diet. Patients spoke of the importance of diet for self-management.[52,58,71,84,86,93,94] However, there was considerable evidence of limited knowledge about what constituted a healthy diet for a person with diabetes.[39,55,57,71,81,84,85,87,93,94] Unsurprisingly, a lack of education was a barrier to achieving and maintaining a healthy diet.[39,77,81,83,90,94]

Identified cultural barriers included a craving for traditional foods recognized as problematic for those with diabetes.[39,46,70,84,92,94] Perceptions of healthy food practices were culturally influenced[41,50,52,59,60,66,70,71,74,80,90,93] leading some to integrate professional dietary advice into their own cultural perception of a healthy diet.[59,71]

There were negative perceptions of the diet recommended to them, including its taste[41,44,55,66,84,94] and expense.[46,55,66,84] Patients reported concerns about protecting the eating experience of the family,[39,44,45,51,55,59,66] at times subordinating their own dietary needs for the sake of the family.[36,41,44,49,54,63,75,81] Some patients reported difficulty in adhering to an appropriate diet during special family occasions.[46,55,60,62,70,78,90,91]

Medicine adherence. The importance of taking medication as prescribed was recognized.[52,64,66,71,74,81,90,92,94] However, there was inconsistent motivation to take medicines,[43,47,67,72] and some would reduce their medicine intake when they felt well.[52,74,77,79]

Traditional cultural beliefs about medicine featured strongly. Some BME samples distrusted Western medicines[45,52] due to side-effects[63,74,79,84,87]; long-term health implications[74,79,92] and its relative recency when compared with traditional therapies such as Chinese medicine.[63] Traditional remedies were referred to frequently by patients across different BME groups[40,41,45,52,63,69–72,74,79,80,84,87,88,91–93] and were used to varying degrees.

Blood glucose testing. Some patients reported that testing their blood glucose daily helped them evaluate the success of self-management[52,60,70,81] and that they knew what to do when blood glucose was too high or low[91] although they did not always have the time or energy to respond.[47,60,68] The relationship between blood glucose and long-term health outcomes was not always recognized.[85,87,93]

Hypoglycaemia was clearly and fearfully described.[46,52,66,71,77] It may be to avoid this outcome that some patients reported maintaining a higher than recommended level of blood glucose.[44,52,77,84] In contrast, descriptions of hyperglycaemia were rare and unclear.[71,87]

Using insulin. Negative perceptions of using insulin were evident, especially among East Asian participants.[52,63,70,79] There was also a stigma concerning insulin use, with people believing that regular use led to addiction,[71] dependency[47,63] or a need for higher doses.[79] The most frequent barrier to insulin use was the dislike of injections.[47,63,71,76,79,86]

There was also considerable apprehension around insulin use in terms of illness progression. A need for insulin was understood to signify severity of the condition[45,47,63,70,78,79] and was thought to be related to more severe complications.[47,71,79,84]

There were two main sets of views favouring insulin. First, that it helped control symptoms, avoid complications and prolonged quality of life;[47] and second, that it was faster acting than oral medicines.[73]

Exercise. The importance of exercise was less frequently identified in comparison with other self-management behaviours. Socio-economic factors were identified as barriers, including prohibitive health club costs,[41,93] fear of walking in high crime neighbourhoods[52,53,66,84] and the difficulty of incorporating activities into busy lives with long working hours.[41,52,76]

Cultural barriers included a lack of culturally relevant information[84,93] or culturally sensitive facilities[76,91] for physical activity. Physical barriers also included the cold climate of the host country,[41,52,77,83,94] comorbidities and pain.[41,52,66,76,83,84]

Descriptive Theme 3c: Causal beliefs
There were two sub-themes within this descriptive theme.

Perceived causal relationships. Many views identified causal relationships between symptoms and complications that were incorrect according to a biomedical framework.

Symptoms of high blood glucose were correctly identified by patients in five studies, in which it was suggested that symptoms could be interpreted and used to adjust lifestyle[71,81] with the aim of avoiding deterioration of the condition.[52,66,70,81] Other patients, however, considered the symptoms of poor self-management to be inevitable[40,61,80,86] and so delayed seeking medical help.[42,80,92]

The causal relationships between prolonged periods of high blood glucose and complications of the condition were correctly identified by patients in two studies only[48,52] with a further two identifying a goal to prevent complications through good self-management.[62,64] Complications were not always understood well.[84,87] As with symptoms, some patients believed that complications were inevitable.[39,40,52,62,70,75]

Causal attributions. Some patients ascribed their T2D to a range of lifestyle factors including diet[45,61,67,70,77], exercise and weight gain.[70,71] Others considered the cause of diabetes to be genetic.[39,40,54,61,67,70,71,76,77,90]

Interestingly, Latino samples tended to attribute diabetes onset to an emotional life event such as a family bereavment.[39,50,59,61,67,71,78,85] Anger,[61,71] general sadness and stress were also identified as causes.[45,48,52,70,79] Some patients made a link with the distress of the migration experience[45,50] or the move to a new environment.[45,52,53,59,70,76,78]

Other causal beliefs included eating too many sweets[40,78,80] and taking medicines

prescribed for other conditions.[74] Spiritual factors[54,76,90] were also cited. Participants in two studies stated that they did not know the cause.[61,70]

Descriptive Theme 3d: Spirituality and fatalism
Spirituality and fatalism were seen to both support and hinder coping. Spiritual beliefs had an important role in providing emotional support.[45,46,48,72,86,90] Prayer was considered to reduce stress.[69,86,88,92] Spiritual beliefs could hinder coping as well as help. For example, there were cases of religiosity where patients did not show sickness, undertake self-management or accept treatment.[47,54] There were also examples of religious considerations prevailing over dietary ones.[53,94]

Others expressed views that while their faith had direct influence on the outcome of their condition it did not absolve them from taking responsibility for self-management.[45,53,69,86,87] In this way, positive fatalistic attitudes helped them accept their condition, and this was associated with improvements in mental health.[52] Negative fatalistic attitudes included patients believing that their actions would not change their future.[39,40,46,52,54,62,75,76,94]

Over-arching Theme: 'Sense of self'
The three analytical themes ('importance of identity', 'being understood by others', 'making sense of own condition') were closely interrelated. An individual's perception of their condition was in part influenced by their self-identity before and after diagnosis. Furthermore, it was important to patients that others understood their (perception of their) condition. As such the over-arching theme was identified as 'sense of self', reflecting the belief that inherent to successful self-management is the interplay between personal resources and the environment.

Discussion

The systematic review aimed to further understanding of BME views on the barriers and facilitators influencing self-management of type

2 diabetes. Data were included from 57 primary studies across a variety of self-management behaviours, populations and settings. While it is accepted that this is a large data set, the method of thematic synthesis was employed rigorously at each of its five stages. This ensured that depth in the analysis was not compromised. The review identified three analytical themes ('importance of identity', 'being understood by others', 'making sense of own condition') and an over-arching theme 'sense of self'.

As discussed earlier, other reviews have explored culturally relevant issues relating to diabetes self-management, but they only focused on one or two BME groups living in a single country.[20,21] To our knowledge, this is the first systematic review to synthesize views about type 2 diabetes self-management across a variety of BME populations in a variety of settings. Moreover, this is the first review on this topic to have synthesized studies, using qualitative research traditions.

Due to the large amount of published primary research, this secondary data analysis was timely. The synthesis drew together data from BME populations in similar Western settings to examine commonalities and differences. This allowed theoretical generalization, which had not been possible from the individual qualitative studies.

In interpreting the findings of the review, it is necessary to recognize four potential limitations. First, the research was included from several countries, and the contextual variation might influence the validity of a synthesis. For example, the issue of language difficulties as a barrier to self-management is very different for first-generation immigrants than for sixth- or seventh-generation African-Americans in the USA. It would be useful to know whether English-speaking and non-English-speaking BME patients experience the same or different barriers. A future review could address this question.

A second potential source of bias was the exclusion of studies of indigenous populations. The rationale was that while indigenous groups may belong to minority ethnic groups, they are not immigrants. It was thought that indigenous and immigrant BME groups are likely to experience different barriers and facilitators to diabetes self-management. This issue warrants an evidence base and is one that a future review might address.

Thirdly, it is possible that the broad literature search (of 240 terms, resulting in 15 275 retrieved titles) lacked specificity. This increased the chance of missing a relevant article during the selection process. The trade-off between sensitivity and specificity in searching for qualitative research has been debated,[96,97] and the conclusion appears to be that there is no fail-safe method.

Finally, the review was limited to studies published from 1986 to 2008, hence relevant studies published outside these dates have been excluded. Nevertheless, we consider that this comprehensive review offers new evidence.

The BME patients' views about diabetes self-management were captured within three analytical themes. First, how patients identified themselves was of great importance to successful self-management. Second, being understood by others facilitated self-management; patients wanted family members to understand their condition and health professionals to understand their culture. Third, patients' own limited understanding of diabetes was a barrier to self-management. These three analytical themes highlighted the complex nature of self-management.

These findings were consistent with previous research. Wilson *et al.*[21] synthesized quantitative and qualitative evidence relating to self-management and access to health services for South Asian and Black African-Caribbean people with diabetes in the UK. They also found barriers at the patient, provider and service levels. Patients lacked knowledge of self-management, which was attributed to language and communication difficulties and a lack of culturally sensitive services.

A key issue in this review not identified in the study by Wilson *et al.*[21] was how living with the condition influenced identity and

'sense of self'. That said, the importance of this theme does resonate with wider views on long-term conditions. For example, long-term conditions have been conceptualized in terms of biographical disruption.[98] This poses the interesting question to what extent the findings of this review are specific to T2D (or to an immigrant, socially and educationally disadvantaged population with T2D) and how much they are generally true of patients living with any long-term condition? The resonance of the over-arching theme 'sense of self' suggests that how patients learn to manage a long-term condition is not necessarily consistent with traditional Western assumptions of how this may be achieved, for example, through formal education classes. Rather the findings suggest that learning is acquired through living with diabetes and experiencing and overcoming situations. This supports the notion of patient-centred experiential learning and the provision of interactive health education interventions.

Two previous systematic reviews synthesized accounts of the experience of diabetes in predominantly non-BME patients, using the meta-ethnographic method.[99,100] A key finding from both reviews was that effective self-management was learnt through experience and experimentation with behaviours over time. As you would expect there is some overlap between these findings and those reported in this systematic review. However, there are also interesting and important differences. For example, previous reviews reported that a majority of patients preferred to take a dynamic position that allowed them to control their own condition and which was not reliant on health professionals. In contrast, many patients in this review sought didactic health education. This systematic review was also novel in its finding of the importance that patients place on maintaining culturally normative social, familial or work roles. An interesting similarity between this review and those of Paterson *et al.*[100] and Campbell *et al.*[99] is the need identified by all patients for receiving support and understanding from others, particularly family and health professionals. However, the emphasis on family

was far greater in the studies included in this review.

The high prevalence of T2D in patients' communities came across in the theme 'making sense of own condition' where patients talked about learning through information sharing with friends and family. However, the dependence on family and friends for information was noted by patients as risky because of its limits and potential for being incorrect.[101] However, there may be advantages to collecting information from various sources and choosing between them, in engendering patient independence.[102] A potential implication for health-care interventions would be to harness naturally occurring peer support groups among high prevalence populations, encouraging upward social comparisons.[103] Social comparison principles refer to how individuals compare themselves with others to evaluate their feelings and abilities, particularly when they are distressed.[104] Such upward comparisons can initiate self-improvement behaviours, while downward comparisons may be used to enhance self-esteem.[103]

An intervention that utilizes existing social support networks would have the same potential advantages as those noted in peer support groups in general: providing condition-specific information[105] and opportunities for social comparison and emotional support;[103,104] reducing subjective uncertainty[106] and being sympathetic to the individual's cultural and social needs.[107] Additional advantages would be practical in enabling patients who know each other to overcome the barriers of transport and language limitations. Moreover, even after the intervention had ended, individuals would continue to support one another.

The review findings suggest that the identified themes were not addressed sufficiently in the development of health-care policy and the delivery of health services. Identifying patients' views from the primary empirical studies has been valuable, not only for understanding the uptake of available interventions, but also for the potential to inform the development of interventions that have more appropriate and

acceptable content and delivery to minority groups.

Acknowledgements

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Data S1 Critical appraisal form (views).

Data S2 Type 2 diabetes & BME & self-management.

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