

**Understanding the Self-management of Type 2 Diabetes in Black and Minority Ethnic Groups Using a Health Literacy Framework**

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The candidate confirms that the work submitted is his/her own and that appropriate credit has been given where reference has been made to the work of others.

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## **Abstract**

### **Background**

The aim of this thesis was to explore the self management of Type 2 diabetes mellitus (T2DM) in black and minority ethnic (BME) groups using health literacy (HL) as the conceptual framework.

### **Study One**

Study One was a multi-method systematic review that aimed to answer the research question: *What is known about the barriers to, and facilitators of, self-management of T2DM amongst BME groups?* There were two review strands. The interventions strand drew together quantitative evidence on T2DM self-management interventions in patients from 28 trials. Secondary analyses demonstrated that interventions were most likely to show a positive effect on self-management if they were culturally competent and based on a theoretical framework. The 'views' strand of the review synthesised 57 predominantly qualitative studies of participants' perspectives on diabetes self-management. Thematic synthesis identified 'Sense of self' as the over-arching theme. Finally, a cross-synthesis of the findings from both review strands was undertaken so as to consider whether barriers and facilitators to effective self-management identified within participants' views had been addressed by available interventions.

### **Study Two**

Study Two was a qualitative interview study with 15 first and second generation immigrant, British-Pakistani women who had T2DM. The study aimed to address the research question: *How does having T2DM affect patients' identity and how does this relate to subsequent self-management?* Thematic analysis identified the over-arching theme, 'Role re-alignment enables successful self-management'.

### **Health literacy**

Studies One and Two had the same subsidiary aim which was: *To refine Nutbeam's conceptual framework of HL (2000) in the context of T2DM.* Using the key findings of both studies, operational definitions were developed for the different levels. Functional HL reflected day-to-day adherence, interactive HL focused on soliciting information and critical HL emphasised acquiring knowledge from experience. A critique was also presented of the conceptual framework focusing on its hierarchical nature and broader applicability.

## **Publications**

The following papers have been presented from the research in this thesis:

Majeed, R., Jackson, C., Cheater, F. & Knapp, P. (2007). Exploring the health-literacy gap in type-two diabetics of the South-Asian community. Leeds Social Science Institute, Leeds.

Majeed, R., Jackson, C., Cheater, F. & Knapp, P. (2009). What are the barriers and facilitators to type 2 diabetes self-management in black and ethnic minority communities? A mixed method review. Fifth Annual International Mixed Methods Conference 2009, Harrogate.

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## **Chapter 1**

### **Introduction**

The aims of this short introductory chapter are threefold. Firstly, this chapter will illustrate the importance of this research by concisely placing it in its wider research context. Secondly, the conceptual framework of health literacy that underpins the research will be introduced. Finally, the structure and overview of the thesis with reference to the research questions are presented.

#### **1.1 Background**

It is recognised that individuals from some black and minority ethnic (BME) groups have poorer general health (health inequalities) than indigenous groups (Bhopal, 2007). There are a plethora of determinants for health inequalities in addition to ethnicity, including poor educational attainment, social deprivation, economic status and employment (Wilkinson and Pickett, 2010). The relationship between these health determinants and health outcomes is complex (Bhopal, 2007).

Evidence in the UK from cross-sectional surveys undertaken over ten years has demonstrated an increasing socio-economic inequality in type 2 diabetes prevalence in women (Imkampe and Gulliford, 2010). Also, in the UK particular ethnic groups are at higher risk of developing abnormal glucose tolerance and type 2 diabetes than the indigenous white population (Riste et al, 2001; Forouhi et al, 2006). People from a South-Asian background living in the UK have a four-fold to six-fold higher prevalence of type 2 diabetes than white Europeans (Mather and Keen, 1985). Moreover, illness onset can be over a decade earlier and the risk of cardiovascular and renal complications are greater in South-Asian patients, morbidity and mortality is significantly higher than in the indigenous white population (Chaturverdi and Fuller, 1996). The predicted rise in prevalence of type 2 diabetes amongst ethnic minorities poses further challenges to healthcare services (Storkey, 1995).

Since the late 1970s when home blood glucose monitoring was introduced, the focus of diabetes management has shifted from doctors to patients (Saudek et al, 2006). Patients are now viewed as being primarily responsible for diabetes management on a daily basis. Type 2 diabetes self-management takes into account one's diet, physical activity, medication administration, blood glucose testing,

smoking behaviour and medical examinations, including inspections of eyes and feet. Ethnic differences in outcomes of diabetes care are recognised (Oster et al, 2006; Lanting et al, 2008)

Studies routinely show that the key to controlling type 2 diabetes is early prevention, education and awareness (Vyas, 2003; Heisler, 2005, Veg, 2006). Snoek and Skinner (2005) consider the only possibility of controlling type 2 diabetes outcomes to be through the provision of culturally appropriate treatment and educational programmes for ethnic groups although they recognise these are challenging to develop.

## 1.2 Conceptual framework

Health literacy has been defined by the World Health Organisation (WHO, 1998, p.10) as:

“...the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health....By improving people’s access to health information and their capacity to use it effectively, health literacy is critical to empowerment.”

Nutbeam (2000) proposes a health literacy framework with three levels. *Functional health literacy*, which refers to the basic reading and writing skills that are necessary for functioning in everyday situations; *interactive health literacy*, which entails more advanced cognitive and social skills that are used to derive meaning from different forms of communication enabling participation in everyday activities; and *critical health literacy*, which includes even more advanced cognitive and social skills which are used to critically analyse information and exert greater control over life events.

Paasche-Orlow and Wolf (2010) have noted that there has been little research in the relationship between health literacy and health inequality. They promoted the exploration of health inequalities by considering the influence of health literacy. In particular they specified that the relationship of health literacy with self-management warranted investigation.

Effective self-management is reliant on the patient's ability to gain knowledge and apply information appropriately to their own daily behaviours. Health literacy skills are considered to be key to making informed health decisions and consequently they play an important role in making efforts in self-management (Selden et al, 2000). There is evidence linking low health literacy to a higher prevalence of type 2 diabetes, poor disease knowledge and sub-optimal self-management (Rothman et al, 2002; Schillinger et al, 2002).

### **1.3. Structure and overview of thesis**

The thesis consists of ten chapters. Chapter 2 is a literature review with two sections, one of these is regarding type 2 diabetes and the other is concerning health literacy. Causes; prevalence; complications; consequences; management and the influence of culture are all considered in regards to type 2 diabetes. The health literacy section reviews current definitions; various frameworks; measures and the policy context. The chapter concludes with the research questions for the two studies that comprise the thesis.

Chapters 3 to 6 comprise Study One which is a multi-method systematic review driven by the research question *"What is known about the barriers to, and facilitators of, self-management of type 2 diabetes amongst ethnic minority groups?"* Furthermore the review evidence is used to address the subsidiary aim which was: *"To refine Nutbeam's (2000) conceptual framework of health literacy in the context of type 2 diabetes."*

Chapter 3 outlines the methodology and the method for the different components of the mixed-method review. In the first section, methodological issues of effectiveness and qualitative systematic reviews are covered before focusing on the adopted multi-method review. The method section provides detail on the search strategy, inclusion criteria, screening tool and approach to data synthesis.

Chapter 4 presents the results for each of the review's components. There are secondary analyses of the interventions data, thematic synthesis of the qualitative 'views' data and a cross-synthesis of both of these sets of findings.



Chapter 5 is the discussion chapter and it provides a critical evaluation of the methods and the results of each of the review's components. Strengths and limitations of the systematic review are noted in this chapter.

Chapter 6 presents an exploratory study which uses the data from the systematic review to develop operational definitions for the different levels of Nutbeam's (2000) health literacy framework within the context of self-management of type 2 diabetes. This chapter has its own introduction, methods, results and discussion sections.

Chapters 7 to 9 comprise Study Two which is a qualitative interview study driven by the research question "*How does having type 2 diabetes affect British-Pakistani women's identity and how does this relate to subsequent self-management?*" Furthermore the interview study has a subsidiary aim: "*To investigate the operational definitions of the three levels of Nutbeam's (2000) health literacy framework as developed in Study One, so as to further refine the conceptual framework in the context of type 2 diabetes.*"

Chapter 7 details and justifies the methods used in this study focusing on data collection and data analysis. Rationale is also provided here of the link between Study One and Study Two.

Chapter 8 presents the results of this primary research. In this chapter characteristics of participants are described and detail on the themes that emerged from thematic analysis are provided. The operational definitions of health literacy are considered amongst the study themes.

Chapter 9 is the discussion chapter. This chapter provides a summary of the results and considers the findings of Study Two in the wider literature. Strengths and limitations of the research are also identified.

Chapter 10 presents an overall discussion which relates to both of the two studies that comprise the thesis. This chapter considers the literature reviewed in Chapter 2 with the findings of Study One and Two. This chapter also reflects on the strengths and limitations of the thesis. Finally, the theoretical and practical implications of the thesis are discussed.

## **Chapter 2**

### **Review of literature**

#### **2.1 Introduction**

A review of published literature on type 2 diabetes and health literacy is presented in this chapter. The purpose of the review is to provide a background on policy initiatives and research evidence and by so doing supply a rationale for the research questions that are addressed in this thesis. The focus of the thesis is on understanding the self management of type 2 diabetes in black and minority ethnic (BME) groups using health literacy as the conceptual framework.

The chapter begins with a section providing an account of the literature on type 2 diabetes. Causes of type 2 diabetes are presented, followed by detail on current rates of prevalence with a focus on the South Asian population who are recognised as having a higher risk of developing diabetes and its complications. Health consequences of the long-term condition are then detailed, as are styles of management and the influence of culture.

The subsequent section begins with some definitions for health literacy. This is followed by an overview of different health literacy frameworks, with a focus on Nutbeam's (2000) framework. Measures of health literacy and the significance of limited health literacy are then considered. Finally, health literacy's policy context is presented. The chapter concludes with the research questions to be addressed in this thesis.

As is evident from the list of headings and subheadings in the literature review, the literature search was a broad and scoping one. Its purpose was to summarise the key literature, thereby identifying and examining gaps in current knowledge. Key sources that were searched were the MEDLINE and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases. Search terms included the following: health literacy, type 2 diabetes, self-management and BME populations. These terms were searched both individually and combined.

## **2.2 Type 2 diabetes**

The section will begin by presenting the causes of type 2 diabetes. Then, information on the global and national prevalence of type 2 diabetes will be provided. Prevalence in the South Asian population will be considered alongside the genetic and socio-economic risk factors for ethnic predisposition to type 2 diabetes. Health consequences and management of the long-term condition will then be detailed. Consideration will be given to the influence culture has on management styles particularly South Asians' health beliefs regarding the causes and self-management of type 2 diabetes. Finally the importance of providing culturally sensitive patient education will be considered.

### **2.2.1 Type 2 diabetes and its causes**

Diabetes mellitus has been recognised as a long-term condition for more than 3,500 years (Loriaux and Lynn, 2006). There are many different beliefs about the causes of diabetes and thoughts about these aetiologies have evolved over centuries. Although advances in genetics and developments in immunology have considerably progressed our understanding, the precise causal nature of the disease remains uncertain and will require new methodologies for its discovery (Dehwah et al, 2009).

There are two primary types of diabetes (Karlsen and Bru, 2002); type 1 diabetes originally labelled 'insulin dependent' or 'early-onset,' and type 2 diabetes previously referred to as 'non-insulin dependent' or 'late-onset'. Distinctions between the two types of diabetes have become increasingly blurred over time. People with type 2 diabetes are now being diagnosed at younger ages (Simsek et al, 2005) and the need for insulin to maintain good health in type 2 diabetes is no longer rare (Garg et al, 2007). It is due to this epidemiological shift that 'type 1' and 'type 2' diabetes have become accepted as the most accurate terminology for these conditions (Patel, 2003).

A related trend to type 2 diabetes being diagnosed at younger ages, has been the emergence of childhood type 2 diabetes. Troiano et al (1995) recognised an increase in childhood obesity across the developed world over a decade ago and Rosenbloom et al (1999) suggested this to be linked to an increasing number of children and adolescents with type 2 diabetes. Indeed, among Japanese children, type 2 diabetes became more common than type 1 diabetes (Kitagawa et al, 1998.)

Originally these reports were predominantly concerned with ethnic minority groups who are known to be at disproportionately higher risk of type 2 diabetes (Fagot-Campagna, 2000) but soon after a similar trend was reported for white English children (Drake et al, 2002).

Both type 1 and type 2 diabetes result from too much glucose in the blood (hyperglycaemia) and this occurs because the body does not metabolise the glucose properly (Tattersall and Gale, 1982). Indicators of marked hyperglycaemia include thirst, large volume of urine, frequent feeling of hunger, feeling of tiredness, blurred vision and weight gain or weight loss (LeRoith et al, 2000).

Glucose is produced from sugar and other sweet foods as well as the digestion of starchy foods such as bread, rice or pasta. Under normal circumstances after a meal the amount of glucose in the blood rises and this triggers the pancreas to release the hormone insulin. Insulin is vital for life and is responsible for regulating glucose levels by moving glucose from the blood into cells, where it is broken down to produce energy (Watkins, 1998). The liver is also stimulated by insulin to absorb and store remaining glucose in the form of glycogen. A second hormone manufactured by the pancreas is called glucagon. This stimulates the liver to release glucose when it is needed, which raises the level of glucose in the blood, a key symptom of diabetes (Watkins, 1998). Whilst both types of diabetes are associated with the regulation of glucose in the body, the causes of this vary in type 1 and type 2 diabetes.

Poor regulation of glucose associated with type 1 diabetes is the result of destruction of the beta cells in the pancreatic Islets of Langerhans, which causes a loss of insulin production. This is widely believed to be a combined result of environmental and genetic factors triggering an autoimmune attack in susceptible individuals (Patel, 2003). Type 2 diabetes, the focus of the research presented in this thesis, has a less clear aetiology. Risk factors in type 2 diabetes can be classified into those that are modifiable, for example obesity, lack of physical activity, smoking and alcohol intake, and the non-modifiable such as age, ethnicity, genetic factors, family history of diabetes and pregnancy (Lassko, 2009). The relative importance of these factors is still very much a matter of debate (see section 2.2.2.1). While the pathogenesis of type 2 diabetes is complex, it is well recognised that insulin levels and pancreatic beta-cell dysfunction are key factors in the

succession of normal glucose tolerance to impaired glucose tolerance to type 2 diabetes (Steppel and Horton, 2004).

An underlying mechanism causing type 2 diabetes is said to be either a diminished insulin secretion by the pancreas or increased peripheral resistance to the action of insulin (Watkins, 1998). Obese people tend to have high insulin levels as a result of insulin resistance but often insufficient insulin remains, preventing restoration of blood glucose to normal, leading to type 2 diabetes (Patel, 2003). It has been shown that glucose tolerance deteriorates as body weight increases (Campbell and Gerich, 1990). Excessive food intake is also detrimental to insulin sensitivity and its effects are considered to some extent to be independent of fat accumulation (Ferrannini et al, 2008).

As with type 1 diabetes, a combination of environmental and genetic factors are considered to influence progression of insulin resistance to type 2 diabetes. There are several popular theories regarding the mechanisms for impaired beta-cell function. One theory claims that sustained levels of hyperglycaemia (Leahy et al, 1992) or chronic levels of hyperglycaemia diminish the beta-cell response and this is termed 'glucose toxicity' (Kaneto et al, 2001). Another theory proposes that high levels of fatty acids, evident in obese people, directly damage the pancreatic beta-cells and this leads to 'lipotoxicity' (Unger and Zhou, 2001).

Furthermore, it is hypothesised that the increased demand of insulin as a result of increased insulin resistance, hastens beta-cell failure (Steppel and Horton, 2004). This is supported by evidence from the United Kingdom Prospective Diabetes Study (UKPDS) (Turner et al, 1999) longitudinal clinical trials which showed a 50% reduction in beta-cell function at diagnosis and this figure continued to decrease alongside the duration of type 2 diabetes, suggesting it is a progressive condition.

### **2.2.2 Diagnosis and prevalence of type 2 diabetes**

The World Health Organisation (WHO) (2006) states the diagnostic criteria for type 2 diabetes is either, a fasting plasma glucose of  $\geq 7.0$ mmol/l (126mg/dl) or a venous plasma glucose two hours after oral ingestion of 75g of glucose of 11.1mmol/l (200mg/dl). This is based on information derived from the population

distribution of plasma glucose and risks associated between plasma glucose levels and microvascular complications (WHO, 2006).

Since the prevalence of type 2 diabetes is increasing worldwide it has been described in the literature as a 'global epidemic' (Bonow and Gheorghide, 2004) and has come to be considered as a health priority by international health organisations (Magnusson, 2007). According to the World Health Organisation about 171 million people live with diabetes in the world and this estimate is expected to increase to 366 million by 2030 (WHO, 2007). In 2009, over 2.3 million people in the UK had type 2 diabetes (Diabetes UK, 2010). The number of people with type 2 diabetes is projected to further increase from the current 4.7% to 6.5% of the population by 2025 (National diabetes support team, 2008).

One explanation of the rising incidence and prevalence of type 2 diabetes is the increasing longevity in many societies. Declining glucose tolerance and insulin secretion alongside increasing insulin resistance (which accompanies progressive weight gain), have been shown to increase markedly with age (Watkins, 2003).

#### **2.2.2.1 Prevalence of type 2 diabetes in South Asian populations**

At the most recent census the South Asian communities residing in Britain formed 4% of the population, representing the largest minority ethnic group and constituting half of the nations total minority ethnic population (National Office of Statistics., 2001). South Asian immigrants in Great Britain have mainly come from the north of the Indian subcontinent but they are not a homogenous population. There are four main groups and three main religions: Urdu and Punjabi speaking Muslims from Pakistan; Sylheti and Bengali speaking Muslims from Bangladesh; Hindi and Gujarati speaking Hindus from the Gujarat in India and Punjabi speaking Sikhs from the Punjab in India (Tattersall and Gale, 1982).

Traditional diets vary between communities, but are typically based on wheat (chapattis) or rice (Burden, 1994), and are rich in dairy products (butter, ghee, yoghurt) and other sources of fat (Misra et al, 2001; Cornish, 2006). There is also an inter-generational difference in food choices of first generation immigrants, who tend to favour more traditional foods and their children who typically mix this with western foods particularly convenience foods (Tattersall and Gale, 1982).

Simmons et al (1992) conducted a cross-sectional study with 4395 South Asians residing in Coventry who represented five communities: Punjabi Sikhs, Punjabi Hindus, Gujarati Muslims, Gujarati Hindus and Pakistani Muslims. Although they found differences in anthropometry, socioeconomic circumstances and migratory patterns between the five communities, all groups displayed a higher prevalence of risk factors and type 2 diabetes than their counterparts of European descent. Regardless of education and medical interventions however, the prevalence of type 2 diabetes continues to increase and its complication rates remain high (Shaw and Cummings, 2005).

Since chain migration of South Asians to Britain was predominantly in the 1950s and 60s (Shaw, 1998) currently British ethnic minorities have a relatively young age distribution despite which prevalence of type 2 diabetes is significantly higher in people of South Asian descent that are living in the UK than in the white population (Forouhi, 2006). It is anticipated that, as the South Asian population ages, the prevalence and impact of type 2 diabetes will rise further, since diabetes is more common among older people (Storkey, 1995). This makes the identification of the mechanisms involved in the incidence of type 2 diabetes in ethnic minorities a public health priority (Abate, 2001).

Epidemiological research provides valuable indications about disease aetiology. Studies that have endeavoured to disentangle the genetic from the environmental causal factors of type 2 diabetes will be discussed here. The particular relevance of genetics and environment for type 2 diabetes; a pathogenically heterogeneous disease demonstrating marked ethnic variation, including diverse responses to pharmacotherapy, different risk factors and complications is detailed in this section. It has been suggested that the accumulative effect of such variables may begin to explain health inequalities in type 2 diabetes outcomes between ethnic groups (Karter, 2003) and these will also be explored here.

### **Genetic predisposition**

Little is known about the genetics of type 2 diabetes although it is suggested that there is a strong familial component. Jensen et al (2002) examined 531 non-diagnosed first degree relatives of patients with type 2 diabetes across four ethnic groups (African-American, Asian, White and Hispanic). Of these 19% were given a

new diagnosis and a further 36% were found to have either impaired fasting glucose or impaired glucose tolerance. Similarly, Reaven (1995) found non-diabetic relatives of individuals with type 2 diabetes to also be insulin resistant and concluded that this suggested a strong genetic component although the search for a 'candidate gene' has proved fruitless to date. Insulin resistance is the precursor of type 2 diabetes that people of South Asian origin are more likely to be as compared to white British people, this is considered to be as result of a genetic predisposition that becomes evident in particular environments i.e. in western society (McKeigue et al, 1991).

The UKPDS (1994) was an early piece of research that examined patients from three major ethnic groups: white, South Asian and African-Caribbean. Insulin resistance was found to be highest in the South Asian population and lowest in the African-Caribbean communities. Beta cell dysfunction was worst in African-Caribbean communities and least evident in South Asians. This raised the questions, why do South Asians develop more severe insulin resistance than people of European and African-Caribbean descent yet display the least evidence of beta cell dysfunction? What is the relative impact that environmental and genetic factors have on these observed pathogenic differences among ethnic groups?

Abate (2003) comments that the UKPDS study (1994) identified ethnic groups that may possess a predisposition to developing type 2 diabetes, possibly as a result of different aetiology since they demonstrated higher levels of susceptibility, even when sharing the same environment with other ethnic groups. He argues that this observation suggests a possible racial or ethnic susceptibility to type 2 diabetes.

It is conceivable that South Asians have a genetic predisposition to develop insulin resistance and understanding genetic mechanisms and their interaction with acquired factors, particularly fat accumulation, may explain the high prevalence of type 2 diabetes within this ethnic group (Abate, 2001; Abate, 2003). British South Asians are prone to developing central obesity, occurring when the main body fat deposits are located around the abdomen (McKeigue et al, 1991). Abdominal fat is associated with insulin resistance and is said to be a key factor determining the rising incidence of type 2 diabetes although these impaired mechanisms are incompletely understood (McKeigue et al, 1991). Conversely it has also been



suggested that obesity or fat distribution alone does not explain the excessive insulin resistance observed in South Asians. Chandalia et al (1999) demonstrated that even after adjustment for total body fat, men of South Asian origin living in America had significantly lower glucose disposal rates, a marker for insulin resistance, when compared with similarly overweight white Americans.

Neel (1962) famously hypothesised that the tendency to develop insulin resistance was unlikely to be a genetic disorder but rather a 'thrifty genotype' that was advantageous in primitive life aiding survival during episodes of 'feast and famine' but was now detrimental in the context of modern lifestyles and diet. However, Lazar (2005) highlights inadequacies with the thrifty gene hypothesis, emphasising that although there is a strong association between obesity and insulin resistance, the causal relationship remains ambiguous. Nonetheless, insulin resistance's apparent major role in the pathogenesis of type 2 diabetes in South Asians, is in itself an important finding in the quest for treating and preventing type 2 diabetes in British South Asians (Abate, 2001).

### **Environmental determinants**

Although studies using genetic markers have shown the disease trait insulin resistance to vary by ethnicity (Gower et al, 2003) they can be criticised as having methodological weaknesses. For example, it is likely that environmental factors that are known to determine insulin resistance including sedentary lifestyle, diet and socio-economic status fluctuate within the sample (Abate, 2001; Simmons et al, 1992). Environmental inequity as result of living in an adverse physical and social environment is considered to contribute to the higher risk of diabetes and its complications as experienced by some BME and socio-economically disadvantaged groups (Blackwell, 2009). Issues include circadian stress, living in unhealthy environments with poor access to physical activity venues, healthy food supply or health providers; moreover such residents typically have poor literacy and numeracy, poor sense of autonomy and low self-efficacy (Ershow, 2009).

Epidemiological studies have focused on potential causal factors of environmental origin including the recurring suggestion that a sedentary lifestyle promotes development of insulin resistance (Belloc and Breslow, 1972; Bell, 1997). There is evidence that a lifestyle with increased physical activity improves glucose

tolerance and insulin sensitivity, which can arguably prevent or delay the onset of type 2 diabetes (McAuley, 2002; Watkins, 2003; Corpeleijn et al, 2006; Shaw et al, 2009).

Migration studies also indicate a potential weakness in the genetic argument and give support to the ecological perspective, a framework that considers the influence of environmental factors on health and health related behaviours. This methodology enables the genetic variables to be minimised between study groups whilst the environmental variables remain different enough to allow meaningful inferences.

Sasaki et al (2006) compared the prevalence of type 2 diabetes amongst Tibetan monks and Tibetan migrants living in Nepal; both groups shared similar genetic origins but had different lifestyles. The Tibetan migrants were found to have a significantly higher prevalence of type 2 diabetes suggesting that environmental factors associated with the 'westernisation' phenomena, namely weight gain and sedentary lifestyles, may influence the emergence of type 2 diabetes.

Studies conducted in Southern India also reflect these westernisation trends since the prevalence of type 2 diabetes is approximately 2% in rural areas and 12% in urban areas (Ramachandran et al, 1997). The main difference observed between the two populations was that the urban population had largely sedentary occupations whereas the rural population engaged in routine and strenuous manual labour. Ramachandran (2001) also observed that the prevalence of type 2 diabetes in urban Indians has increased from 3% in the 1970s to a rate of 12% over three decades.

Since these trends in both lifestyle and incidence of diabetes are predicted to continue, it has been estimated that by 2025 the Indian sub-continent will have more than 60 million people with diabetes making up one fifth of the entire world's diabetic population; three quarters of whom will be from the developing countries (King and Rewers, 1993). This phenomenon is frequently attributed to the changing demographic, nutritional and socio-economic profile of countries experiencing economic transition (Yajnik, 2004).

Unsurprisingly this phenomenon extends, and is arguably more pronounced, in South Asian migrants in the UK. The UKPDS (Zhang et al., 1996) compared

diabetes patients of different ethnicities and found that migrant South Asians lead the most sedentary lives amongst the ethnic groups, highlighting its role as a risk factor in migrants.

Increasing body fat content is linearly and inversely related to insulin resistance (Karter et al, 1996). Wing et al (1987) demonstrated that weight loss of 5-10% of body weight leads to an increase in insulin sensitivity which results in an improvement of blood pressure. Although this relationship between obesity and type 2 diabetes is well-established it remains complicated. Research suggests that type 2 diabetes is a disease of national affluence where an improvement in prosperity is associated with inactivity and obesity (Ramachandran, 2001). However, this causal relationship is complicated as illustrated in the British population where the prevalence of obesity and type 2 diabetes both have a well-documented inverse relationship with household income (Sundquist and Winkleby, 2000). That is to say, people of a low socio-economic status demonstrate ill health behaviours and people of a high socio-economic status demonstrate good health behaviours, suggesting a complex combination of societal and individual causations.

Marked socioeconomic disparities in ethnic groups in the west support the claim that socioeconomic status is related to the prevalence of type 2 diabetes (Abate, 2003). Hippisley-Cox et al (2004) conducted a large scale study of clinical evidence from electronic general practitioner records of over 50,000 British patients with type 2 diabetes and found ethnicity and deprivation to be important indicators. They also identified poorer diabetic care for women, patients from deprived areas and people from ethnic minorities. This work suggests that the people most in need of health care resources may be the least likely to receive them which may in turn increase health inequality amongst different ethnic groups. Health inequality is often explained by social determinants of health, one of which is poor access to healthcare but Hippisley-Cox et al (2004) were unable to draw any such conclusion due to incomplete data entry in the records they surveyed. Social determinants of health are discussed in more detail in the context of health literacy (see section 2.3.5.1).

Unequal access to quality health care is also often offered as an explanation for the variations in incidence of micro-vascular complications among different ethnic

groups. However, when Karter et al (2002) examined disparities in rates of diabetic complications within an ethnically diverse sample of more than 62,000 Californian patients, ethnic differences persisted despite the entire sample having uniform healthcare coverage. Relative to whites, incidence rates for end stage renal disease was significantly higher for blacks, Asians and Latinos (112% [P<.001], 44% [P<.001] and 41% [P=0.004] respectively). During follow-up, relative to whites, Asians and Latinos had a 36% (P<.001) and a 32% (P<.001) lower incidence of congestive heart failure respectively, whereas the rates for blacks and whites were not significantly different. This was the first large-scale study that controlled the variable access to healthcare, suggesting the link between ethnicity and type 2 diabetes complications might be more consistent than researchers had previously considered. The persistence of ethnic disparities when controlling for demographic, socioeconomic, behavioural and clinical factors gives further weight to the explanation for type 2 diabetes in some high risk populations being of possible genetic origin, although the likelihood of a contribution from other unmeasured environmental factors cannot be disregarded.

Schofield and Ashworth (2010) examined health inequalities in a large scale study in Lambeth, an inner London Borough which used over 100,000 patients records at each of two time points (2006 and 2009). Lambeth is an area of contrasting social deprivation and has a large ethnic population, mostly black. Schofield and Lambeth tested a range of bio-medical measures that represented healthcare goals relating to four long-term conditions including diabetes. Results demonstrated very little health inequality in terms of social deprivation other than for smoking status. There was however, a clear ethnic inequality in the results for blood pressure and glycaemic control (HbA1c). This showed health inequalities were more strongly related to ethnicity than social deprivation.

Essentially, the debate is about understanding when ethnicity is a genuine variable and when it is masking underlying causal factors. Though long standing it remains a contentious issue and one popular debate is that metabolic susceptibility and predisposition of complications are dependent on genetic determination, but particular environmental factors are required for their expression.

### **2.2.3 Health consequences of type 2 diabetes**

Type 2 diabetes is the fifth most common cause of death in the world (Roglic et al, 2005). Moreover, there are a variety of acute and long-term problems associated with type 2 diabetes. Three major acute complications include hyperglycaemia, diabetic ketoacidosis and hyperglycaemic hyperosmolar non-ketotic syndrome (Smeltzer et al, 2007). The long-term complications of type 2 diabetes can be classified as microvascular (nephropathy and retinopathy), macrovascular (cardiovascular, cerebrovascular disease) and neuropathy problems (peripheral such as feet and legs, autonomic) (Guthrie and Guthrie, 2002). Long-term complications can lead to serious problems including heart disease, stroke, blindness, renal failure and amputation (Davis et al, 2008).

Whilst type 2 diabetes is recognised as the disease without a cure, secondary prevention can be achieved through good glycaemic control. By maintaining near normal glucose levels complications associated with the disease can be delayed, minimised or even prevented, and quality of life can be improved (Watkins, 2003).

The first convincing evidence in the UK that good glycaemic control prevents the development of diabetes-related complications and maintains health was provided by the UKPDS (Turner et al, 1999). This was a 20-year trial which recruited over 4,000 patients. The study showed that intensive treatment i.e. multiple therapies including diet and medication, improved blood pressure and blood glucose control thereby reducing the risk of micro-vascular and cardiovascular complications that cause morbidity and premature mortality in patients with type 2 diabetes.

According to the UKPDS (1998), the reduction of 1% in Haemoglobin A<sub>1c</sub> (HbA<sub>1c</sub>) in a 10 year-period was associated with a 21% reduction of type 2 diabetes related deaths, a 14% reduction in myocardial infarctions and a 37% reduction of microvascular complications. HbA<sub>1c</sub> is an effective indicator of glycaemic control in type 2 diabetes reflecting the previous two to three months of control (Sacks et al, 2002). An HbA<sub>1c</sub>  $\geq$  6.5% is considered diagnostic of type 2 diabetes, and an HbA<sub>1c</sub>  $\geq$  6.0% and  $<$  6.5% as hyperglycaemia (The International Expert Committee, 2009).

### **2.2.3.1 Healthcare for type 2 diabetes**

Mulnier et al (2006) reported that in the UK mortality in patients with type 2 diabetes was twice as high as those without type 2 diabetes. A survey undertaken on 800 people with type 2 diabetes across Europe revealed those in the UK as having the worst blood glucose control (Liebl and Eschwege, 2002). It is unsurprising then that 40% of UK patients with type 2 diabetes have a high risk of diabetes complications (NDA, 2010).

Type 2 diabetes places a rapidly increasing economic burden on the UK healthcare system accounting for more than £9 billion each year which is a tenth of NHS budget (Suhrccke et al, 2006). The statistics show that in the UK 0.5% of all admissions, 0.8% of emergency admissions and 0.7% of all bed days relate to type 2 diabetes (DH 2004b). However, the admissions and the length of stay can be reduced by relevant patient education (Fedderson and Lockwood, 1994), appropriate treatment and nursing care (Davies et al, 2001). While the organisation of type 2 diabetes care has improved in recent years with advances in target-driven clinical management this has resulted in a change in the pattern of complications with fewer microvascular complications while the risk of cardiovascular disease in type 2 diabetes is considerable and growing (Shaw and Cummings, 2005; Holt, 2009). Hence the need for early interventions to prevent complications developing in patients is necessary suggesting there are still vast limitations in service provision.

The Department of Health (DH) (2002) has recognised and reflected in the 'National Service Framework (NSF) for Diabetes' a necessity to take steps to improve type 2 diabetes prevention, identification, clinical care, management of type 2 diabetes care and screening. The NSF for type 2 diabetes (DH, 2001) has set service standards for patient care. From this, seventeen quality measures including blood pressure, smoking status and Body Mass Index (BMI) were included in the new General Medical Services (GMS) contract (2004) however deprivation and ethnicity were not specifically accounted for. The GMS contract is the UK-wide contract between general practices and primary care organisations for delivering primary care services to local communities. Hippisley-Cox et al (2004) did a cross-sectional survey of over 54,000 electronic general practice records and found all of the quality indicators to be adversely associated with either ethnicity or deprivation,

strongly suggesting the omission of ethnicity and deprivation to be a severe oversight since practices in areas of high deprivation and high ethnicity will find it more difficult to achieve the quality indicators for diabetes, and it is possible that the practices most in need of the resources will be least likely to achieve them. This may be a contributing factor to type 2 diabetes disparities.

Diabetic health outcomes are known to be worse for people from some BME and socially deprived groups (Mather and Keen, 1985; Riste et al, 2001; Forouhi et al, 2006; Imkampe and Gulliford, 2010). Health inequalities, both within and across minority ethnic groups, need to be considered as to whether they can be reduced or eliminated. One way to do this would be by designing interventions that are appropriate to the needs of the community. To do this, the extent to which disparities are a result of social, environmental or genetic differences needs to be better understood. This is essential for formulating appropriate public health policy and establishing adequate public health resources for prevention and effective management of the condition (Abate, 2003).

The predicted rise of type 2 diabetes amongst ethnic minorities poses a particular set of challenges to healthcare services including patients' language barriers and the provision of culturally sensitive policies. Studies routinely show that the key to controlling type 2 diabetes is early prevention, education and awareness (Vyas, 2003; Heisler, 2005; Veg, 2006). This suggests that there is merit in a national health care system that recognises those groups, including ethnic minorities, who are most at risk and develops culturally appropriate treatment programmes (Simmons, 1992; Hawthorne, 2001). Tailoring treatment strategies and educational programmes for ethnic groups, although challenging are considered by some as the only possibility of controlling type 2 diabetes outcomes (Snoek and Skinner, 2005).

Whilst strict glycaemic control to prevent diabetic complications remains the optimal goal, secondary prevention through early detection is also an important aspect of management explaining the emphasis that some international health bodies place on regular screening (Engelgau, 2000). Research conducted in the UKPDS (Zhang et al., 1996) showed that by the time of diagnosis, approximately half of people with type 2 diabetes show some evidence of diabetic tissue damage. Due to

the irreversible nature of type 2 diabetes and the severity of long-term complications that can arise if the condition remains unmanaged, missed diagnosis remains an area of concern in public health. In direct response to such concerns, the WHO (1999) has produced diagnostic criteria for people presenting with symptoms of type 2 diabetes. This has been endorsed by the Department of Health (2002) although there is presently no national screening policy in the UK to identify type 2 diabetes.

#### **2.2.4 Managing type 2 diabetes**

It was questioned towards the end of the 1970s, whether the traditional “medical model” was still effective for dealing with the growing prevalence of long-term conditions (Lorig and Holman, 2000). In the medical model, patient education is viewed as ‘prescriptive’ with an assumption that health professionals know best, and that efforts should be focusing on encouraging patients to adhere with medical recommendations (Funnell and Anderson, 2004). The 1980s saw growing attention being paid to research in long-term conditions and self-management (Tobin et al, 1986). This trend has continued with self-management being considered to be an integral part of care of long-term conditions (Kennedy and Gask, 2005).

The concepts *self-care* and *self-management* are often used interchangeably. However, distinctions do exist between the terms. In *self-care* patients are involved in their care and this can be with or without the presence of healthcare professionals (Becker 2004) whereas in *self-management* patients are involved in collaboration with peers, health professionals and support networks (Barlow et al, 2002; Loeb, 2003). Furthermore self-care refers to preventive strategies undertaken by healthy people (Clark et al, 1991) while self-management refers to more specific strategies to gain control such as shared decision making (Lorig et al, 1993) thereby requiring fewer visits to doctors (Lorig et al, 1998) due to improved physical health status and functioning (Gallant, 2003). Wilson argues that self-management is more specific than self-care because patients are undertaking responsibilities that are the traditional responsibility of health professionals (Wilson et al, 2006).

Self-management recognises the individual’s role as central to the management of a long-term condition and it has been defined as the behaviours that the patient employs in implementing the treatment regimen within his or her lifestyle routine (Lorig and Holman, 2003). Type 2 diabetes self-management requires the patient to



make multiple health decisions daily regarding their complex treatment regimen of diet, physical activity, glucose monitoring and adherence to medication to prevent hypo- and hyper-glycaemia (American Diabetes Association, 2008); based on their knowledge, beliefs, attitudes, resources and support systems (Sakraida and Robinson, 2009).

The patient empowerment approach to self-management education interventions was proposed as a new philosophy for programmes in the 1990s (Funnell et al, 2008). Funnell and Anderson (2003) explain this approach as “to inspire, inform, support, and facilitate their efforts to identify and attain their own goals”. In this approach, patients themselves have ultimate responsibility for their diabetes care.

A growing body of literature, including several systematic reviews (Norris et al, 2001, Norris et al, 2002a) and meta-analyses (Norris et al, 2002b; Gary et al, 2003; Fan and Sidani, 2009) have demonstrated that type 2 diabetes self-management education is effective and can improve clinical outcomes predominantly in the short term. Education has also been shown to improve quality of life (Steed et al, 2003); knowledge and self-care behaviours (Norris et al, 2001; Fan and Sidani, 2009) as well as cost and demand on healthcare services (Robbins et al, 2008; Duncan et al, 2009).

Achieving good type 2 diabetes control is heavily reliant on self-management on a day to day basis (Funnell et al, 1991). It is estimated that annually patients with type 2 diabetes have approximately three hours contact with a health professional (DH, 2005), and as much as 98% of diabetic care is carried out by the patients themselves and their family (Anderson, 1995). Type 2 diabetes self-management is based on five main areas namely: diet, physical activity, blood-glucose monitoring, adherence to medication and education (Smeltzer et al, 2007). Effective self management prevents or reduces the need for medical interventions thus containing healthcare costs (Watkins, 2003). Type 2 diabetes is typically in the first instance non-insulin dependent, and can be treated with a change of diet and lifestyle alone (Tattersall and Gale, 1982).

The main objective in the dietary management of type 2 diabetes is control of blood glucose, lipid levels and blood pressure (Conlon, 2001). Exercise has also

been shown to be effective in both the prevention and treatment of type 2 diabetes. It can lower blood glucose and cardiovascular risk factors through increasing the uptake of glucose by muscles and increasing insulin sensitivity (Nathan et al, 2005).

As described previously obesity worsens insulin resistance and hinders effective management of type 2 diabetes and has been found to significantly affect morbidity and mortality, largely as a result of its contribution to cardiovascular disease (Snoek and Skinner, 2005). Intensive lifestyle changes, namely dietary modifications and increased physical exercise are needed to control obesity and put the patient in a position to self-manage (Watkins, 2003), and react appropriately to many pharmaceutical treatments for type 2 diabetes that cause weight gain as a side effect.

Empowering patients to self-manage is considered the cornerstone of type 2 diabetes management (Snoek and Skinner, 2005). Education for type 2 diabetes self-management is accepted as key to diabetes care and is a lifelong and ongoing process (American Diabetes Association, 2010). The aim of type 2 diabetes education is to improve metabolic control, quality of life, and prevent diabetes complications (Norris et al 2002b). While early education programmes initiated in the 1930s were largely didactic and focused on providing information (Bartlett, 1986; Mensing and Norris, 2003) it is now believed that although type 2 diabetes knowledge is a prerequisite to maintain glycaemic control (De Weerd et al, 1990) it alone is not sufficient for behaviour change (Coates and Boore, 1996; Davis et al, 2008; Khunti et al, 2008b).

### **2.2.5 Influence of culture on type 2 diabetes management**

Biomedicine continues to focus on individual level risk factors emphasising lifestyle modification (Lawton, 2007) despite epidemiological evidence that type 2 diabetes is more prevalent amongst some ethnic minorities, the elderly and socially disadvantaged. Hence assessing factors in the form of patients' health beliefs and exploring the role of culture are becoming increasingly recognised as important (Tan, 2004). This is especially true as many Western societies have become multi-cultural and multi-lingual (Hjelm et al, 2003). This has made an increased awareness of health beliefs and their impact on self management practices necessary.

### **2.2.5.1 Health beliefs of type 2 diabetes in South Asians**

Understanding of what is healthy and unhealthy can vary by culture, for example Asian food may be classified as 'hot' or 'cold' according to traditional medical teachings (Bhopal, 1986). A disease considered 'hot' is treated with a 'cold' food and vice versa. Religion adds another dimension to this already composite relationship. As a result of these complexities, interventions to improve diabetes management need to be culturally appropriate (Tattersall and Gale, 1982). In this section the South Asian populations' health beliefs on the causes and self-management of type 2 diabetes are discussed.

#### **Beliefs about causes**

Lawton et al (2007) analysed causal accounts of type 2 diabetes in interviews with white and South Asian respondents who had type 2 diabetes living in Scotland. Most prominent were the within-group consistencies regarding allocation of responsibility for disease onset. South Asian respondents emphasised the influence of life circumstances, particularly those arising from migration where they had encountered health inequalities by virtue of being poorer and less well educated than the majority population. As such their type 2 diabetes condition was viewed as 'inevitable'. In contrast, white respondents largely implicated their own lifestyle choices and personal failings in the onset of the condition, thus depicting themselves and not their circumstances as to blame. The authors suggest that by internalising responsibility white respondents expressed Western individualism. Conversely, South Asians, by attributing their condition to external factors, conveyed a general experience of their life being dictated by circumstances.

Greenhalgh et al (1998) attributed South Asian's fatalistic health beliefs to the religious values normally held by this population. Lawton et al (2006a) however considered this absence of responsibility for self management to be reinforced by the style of the western healthcare service, for example the routine physical tests, as opposed to those in the South Asian sub-continent. Similarly, other research also conducted by Lawton et al (2005) investigated South Asian patients' perceptions and experiences of taking oral hypoglycaemic agents and found that 'misinformed' ideas about medicine derived from the subcontinent influenced adherence.

This section demonstrates British South-Asians patients to hold a set of traditional health beliefs about their diabetes that can have a negative effect on self-management behaviours.

### **Beliefs about self-management**

In this section the suggestion that achieving effective type 2 diabetes management is complicated by the strong familial component in South Asian populations will be discussed. Exposure to type 2 diabetes related morbidity and mortality factors in their kin and community can result in South Asian patients expecting that their health will deteriorate (Lawton et al, 2006b). Similarly, Stone et al (2005) reported that a frequent family history of type 2 diabetes provided emotional support but may also be partially responsible for a lack of motivation to seek additional support such as educational initiatives.

Research suggests that although many South Asian patients with type 2 diabetes articulate a high regard for education, their knowledge of self care behaviour is poor and they lack the motivation to attend educational sessions (Stone et al, 2005). In a qualitative study with white patients and patients of Indian origin living in Leicester with type 2 diabetes, Stone et al (2005) identified both shared and culturally specific issues in their attitudes and lifestyles. For example, whilst diet was an issue for both groups, South Asians felt their traditional diet presented particular problems in its typical high use of fats and sugars. One explanation for this population seeking to maintain their traditional diet could be that it acts as an important assertion of identity in migrant populations (Jobanputra and Furnham, 2005).

In a qualitative study by Lawton et al (2006b) South Asian patients' views of exercising were explored as part of their diabetes self care and a plethora of practical considerations which were recognised barriers to physical activity irrespective of people's ethnic group were discovered. These were interwoven and complicated by the effect of social rules such as against exercising outdoors and cultural obligations such as family responsibilities causing time restraints.

The inter-generational effect in the British South Asian population adds another dimension to the already complex relationship of type 2 diabetes and

migration. Studies give mixed and often conflicting results. Lawton et al (2006b) observed a gender difference to barriers to physical exercise including restrictions on women leaving the home and a lack of socialisation through sport and other outdoor activities. These authors hypothesised that the influence of these factors will decline as subsequent generations become increasingly acculturated. However, contrary to their hypothesis, Jobanputra and Furnham (2005) found that young British Gujarati Indians held the same supernatural health beliefs as older British Gujarati Indians, an ethnic minority population which is comparable to the native white British population in terms of educational attainment. The authors had defined supernatural beliefs quite broadly to include God, destiny and karma as well as witchcraft, the evil eye and voodoo. These findings are a useful illustration of the complex and often poorly understood nature of health beliefs.

### **2.2.6 Culturally appropriate patient education**

Culturally appropriate patient education can be understood in terms of content through the use of familiar language and contexts or in terms of delivery, targeting specific issues for high risk populations. Although culturally appropriate health education has been shown to improve knowledge and glycaemic control in British Pakistani women with type 2 diabetes (Hawthorne, 1999), limited research on health beliefs means health professionals are less well placed to develop culturally appropriate patient material (Scott, 2001).

Previous studies of type 2 diabetes in ethnic minorities have mainly focused on living with the disease and its consequences, and have largely ignored behaviours or attitudes of the ethnic minority population (Hjelm et al, 2003). Scott (2001) suggests this to be an oversight since health beliefs could be usefully incorporated into patient education.

A successful example of this is when Greenhalgh et al (1998) explored the experiences of diabetes management in British Bangladeshis, an ethnic group typically composed of recent immigrants living in a deprived urban environment. The research focus was on underlying attitude and belief systems driving observable behaviour. Greenhalgh et al (1998) discovered that their British Bangladeshi sample valued informal oral explanations from friends and relatives and this led the authors to further investigate these findings in a group intervention. Greenhalgh et al (2005)

found the Bangladeshi sample compared their blood glucose results with one another which led to reflection and understanding within the group, this was unlike what the biomedical model implies, that people compare their blood glucose with their own previous results. This illustrates that although BME groups' health beliefs may be different to biomedical constructions they have their own functional value on the lives of the people adopting them. This highlights their importance of developing culturally sensitive patient education (Scott, 2001).

Smith et al (2003) conducted a qualitative investigation following the introduction of a diabetes shared care service. They did not report the ethnicity of the participating patients but all interviews were conducted in English. Lawton et al (2006a) undertook a similar study with an ethnic minority population. Comparisons between the two studies reveal interesting observations. Both populations identified busy doctors and poor communication as key themes but each group's approach to such statements differed markedly. The South Asian sample assessed British type 2 diabetes services using services on the Indian subcontinent as a benchmark which led to a feeling of gratitude for the free services in the UK and an enhanced awareness of time constraints on busy health professionals whereas the white participants were directly critical of the services in their commentary. However, these studies were developed to explore experiences of newly structured type 2 diabetes care services as opposed to health beliefs more generally.

Furthermore, it should be noted that many barriers to successful health outcomes discussed in this section are similar to those in studies of other disempowered groups, often relating more to structural and material barriers than ethnic or religious customs. Nazroo (1997) has argued that access to services, socio-economic status and lifestyle choices largely explained ethnic differences in type 2 diabetes outcomes. This makes the case that the well documented relationship between poverty and health inequalities should not be ignored by focusing too much on the influence of culture and ethnicity on health beliefs.

Moreover, Greenhalgh et al (1998) also reported similarities in health beliefs between the ethnic minority group and the indigenous population. This suggests, that although ethnic differences are of considerable anthropological interest, it is imperative to realise the practical importance of the often understated similarities in

the health beliefs and behaviours between minority groups and the host culture. By considering this when designing an intervention one ensures it is not only biomedically effective but also culturally acceptable. Some studies focusing on disadvantaged groups can be criticised for interpreting findings exclusively in terms of folk models (Holy and Stuchlik, 1981). Nevertheless Greenhalgh et al (1998) concluded that health education which is concordant with folk models will be better employed than education contradicting such models.

### **2.2.7 Choice of terms used in the thesis: ethnicity; culture; South Asian and immigrant**

While it is accepted that the terms 'race' and 'ethnicity' have limitations, they are frequently employed within health research and the dominant discourse (McKenzie and Crowcroft, 1994). Problems with the use of the categories of race or ethnicity are that they are rarely defined and their use is inconsistent and at times arbitrary (Sheldon and Parker, 1992). 'Race' is often used interchangeably with the terms 'ethnicity' or 'culture', though race is biologically determined and ethnicity and culture are social constructs which are characterised by the behaviour and attitudes of a social group, making them more difficult to measure (Fernando, 1991).

The contested meanings of the terms 'race', 'ethnicity' and 'culture' continue to change over time because of trends and politics (McKenzie and Crowcroft, 1994). Given that ethnicity is now most often self-classified, perhaps due to high levels of diversity in the British population, the dynamic nature of ethnicity and culture is accepted and it is considered unlikely that an agreed taxonomy can be achieved (McKenzie and Crowcroft, 1996). However, to enable researchers to compare results of studies now and in the future reporting of ethnic or cultural groups is necessary. McKenzie and Crowcroft (1996) advised that names are descriptive clearly reflecting how these groups were distinguished. They further advised researchers to describe how ethnic groupings were assigned in the methods and warned not to draw conclusions that went beyond the data.

Another criticism in the reporting of research with ethnic groups is a lack of specificity. For example, the broad term "Asian" has been used to describe people who have come to the U.K. from many different parts of the world including India, Pakistan, Bangladesh, Uganda, Kenya, and Tanzania. These people are variously

from peasant, urban or middle class backgrounds; furthermore they have different religions, languages, castes, kinship obligations, diets, clothing, health beliefs and practices (Bhopal et al. 1991). Moreover, Pfeffer (1998) noted that context is crucial to terminology. Using the example "Asian" again, the term has different meanings in the U.K. and the U.S. In Britain, 'Asian' has come to be used to describe individuals and groups whose ancestry can be traced to an area often called South Asia, which is composed of the three nations that were formed as a result of British imperialism: India, Pakistan, and Bangladesh. In the U.S., Asian is a term connected with countries of the Pacific region, such as Japan, Malaysia and China. Similarly, the presence of such 'Asians' in the U.S is the outcome of the country's economic and political history.

Within the thesis, in Study One (the systematic review) ethnic groups are reported as they had been in the primary studies. In Study Two (the primary empirical work) the advice of McKenzie and Crowcroft (1996) will be heeded, to clearly describe how the ethnic group was distinguished. A range of information will be collected that helps describe the group. Information will be provided on the participants' country of birth, parents' country of birth, mother tongue, religion and years living in the UK. Information on socioeconomic status will also be collected as this is noted to be an often neglected confounder when drawing comparisons between ethnic groups (Senior and Bhopal, 1994).

Related to the way that ethnicity assumes meaning within the thesis is the use of the word 'immigrant'. It is misleading when words and phrases such as 'immigrants' and 'ethnic minorities' are used interchangeably and indiscriminately, particularly when an adequate definition is not provided (Donovan, 1984). Often the term 'immigrant' is not provided with detail of individual circumstances and experiences, including the length of time in the country, legal status, and socio-economic background (Orellana et al., 2003).

In administrative and media contexts, the term 'immigrant' is a collective noun that is used to describe different categories of people with a foreign background of some form (Back and Soininen, 1998). Even in research an examination into the use of the term 'immigrant' reveals considerable confusion, since it has been defined in a variety of ways, with the result that use of the term is problematic. Desai and



Subramanian (2000) argued that the term is acceptable if the term is strictly used to refer to members of society that have not been through the legal process of becoming national citizens. Ferrada-Noli (1997) adopted its definition to mean all persons born in foreign countries irrespective of citizenship. This definition excluded second-generation immigrants and refugees applying for asylum. Donovan (1984) used the term to denote all foreign born ethnic groups and also individuals with foreign born ancestry. All of these researchers agreed that the label 'immigrant' is inappropriate when simply used to describe individuals that are not white. Skellington and Morris (1992) further argue that the term 'immigrant' is inappropriately used to refer to people of a different colour, when the vast majority of migration is amongst white groups.

The term immigrant can be applied appropriately when it is used to refer to an individual's or group's relatively recent arrival in a country. This is how it will be used in this thesis. The children of immigrants will be referred to as second generation immigrants.

## **2.3 Health literacy**

### **2.3.1 Definition of health literacy**

Health literacy is a term increasingly used in healthcare research (De Walt et al., 2004) and policy (see section 2.3.7). The label 'health literacy' was first applied within the framework of school health education and social policy (Simonds, 1974). Since then the term has expanded in scope. Many definitions of health literacy have come to exist that share the same concept (Ishikawa and Yano, 2008). There is no agreed definition on what constitutes health literacy or limited health literacy (Clement et al, 2009) and it has come to mean different things over time (Zarcadoolas et al, 2003). Most of the existing health literacy definitions have conceived it narrowly to mean word recognition, reading comprehension and numeracy (Ad hoc committee on Health Literacy, 1999; USA Department of Health and Human Services, 2000; Institute of Medicine, 2004).

A broader and now heavily cited definition however has been proposed by the World Health Organisation (WHO, 1998, p.10):

“Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people’s access to health information and their capacity to use it effectively, health literacy is critical to empowerment.”

The range of skills listed in the WHO definition highlight how health literacy has come to mean much more than comprehension and compliance. The WHO definition encompasses elements of the empowerment philosophy which has become a recurring theme within health literacy research (Shohet, 2002). Empowerment in the context of healthcare refers to a patient’s ability to increase control over their health (Hayward, 1996). Using this broader perspective, health literacy is consistent with the health promotion principles that support health education efforts (Speros, 2005). It is based on this definition and a want to broaden the traditional understanding of health literacy from just the capacity to read and write that Nutbeam (2000) introduced his health literacy framework (see section 2.3.3.1).

It is important to note that the terms ‘literacy’ and ‘health literacy’ are not automatically interchangeable. As demonstrated in the WHO (1998) definition, there is some overlap since ‘health literacy’ does encompass the ability to read and write but, unlike ‘literacy’ it also involves understanding information to a level which enables the individual to take an active role in the management of their own health. Sullivan (2000, cited in Sihota and Lennard, 2004) noted that literacy is contextual and not necessarily related to years of education or reading ability. That is a person may be literate within a familiar semantic and lexical context but functionally illiterate when required to comprehend unfamiliar vocabulary and concepts such as those encountered in healthcare settings. This suggests that a person’s health literacy level is likely to be worse than their general literacy level (Speros, 2005).

### **2.3.2 Is health literacy a new concept?**

Nutbeam (2000) suggests that health literacy is a novel concept in health promotion and one that describes a range of health education outcomes. The

challenge is whether it is necessary to introduce yet another term and concept to the already complex lexicon of health promotion (Kickbusch, 2002). Indeed, some experts have questioned the utility of the concept of health literacy.

Tones (2002) argues that Nutbeam's framework of health literacy (see section 2.3.3.1) is too ambitious, incorporating all of the major psychological, social and environmental constructs that influence individual health choices. He adds that it is unclear how this conceptual framework improves on many of the previously well-researched frameworks that describe empowered health-related decision-making. These include Gagne (1985, as cited in Tones, 2002) on problem-solving and Janis and Mann (1977, as cited in Tones, 2002) on the process of decision-making.

Nutbeam (2000) contends that health literacy is a concept both new and old that essentially requires some 'repackaging' of established ideas concerning the relationship between education and empowerment. He makes the case that the importance of health education required rediscovery with an emphasis on extending health intervention methods since education as a tool for social change had had limited success in contemporary health promotion. This suggests that Nutbeam's framework in its current form is open to criticism and it may benefit from being further developed.

The Scottish Government commissioned a recent report (2009) to identify potential policy responses to health literacy. The report recommended against pursuing a separate health literacy policy as it was felt this would be counter-productive since existing key policies were considered to already address the complex and diffuse concepts that underpin health literacy. These key policies included those on health inequalities, patients' rights, patient safety, self-management of long-term conditions, anticipatory care as well as adult literacy and numeracy. This remains a contentious topic with some countries incorporating health literacy (see section 2.3.7) in their policies and others not.

### **2.3.3 Health literacy frameworks**

In this section detail will first be provided on Nutbeam's framework (2000) including a rationale for its selection in the thesis. However, just as there are numerous health literacy definitions, there are also several frameworks that exist for

health literacy. Four other health literacy frameworks will then be briefly presented and contrasted to Nutbeam's (2000) health literacy framework.

### 2.3.3.1 Nutbeam's framework of health literacy

As a direct response to the WHO's broader definition of the term 'health literacy' Nutbeam (2000) proposed a framework with three levels of health literacy. *Basic/functional health literacy*, which is having sufficient basic skills in reading and writing to be able to function effectively in everyday situations; *interactive health literacy*, entailing more advanced cognitive and social skills which can be used to participate in everyday activities, to extract information and derive meaning from different forms of communication and to apply new information to changing circumstances; and *critical health literacy*, which includes more advanced cognitive skills which, together with social skills can be applied to critically analyse information and to use this information to exert greater control over life events.

A strength of Nutbeam's (2000) framework is that it helps distinguish between educational programmes which are designed to achieve one of the three different levels of health literacy. These levels distinguish between adherence with a prescribed behaviour (i.e. *functional health literacy*); self-management of problems in partnership with health professionals (i.e. *interactive health literacy*) and empowerment, (i.e. *critical health literacy*) (Jahan, 2000). Recognising functional health literacy interventions is relatively straightforward since it is facilitated by precise definitions and developed measures (see section 2.3.4). However, distinguishing between an educational programme as promoting and enabling interactive or critical health literacy is less simple since there are currently no developed measures for either of these levels and the concepts themselves are less well defined.

Wang (2000) provided the following useful differentiation of Nutbeam's (2000) framework. Functional health is a top-down approach to disseminating information regarding health while critical health literacy is a bottom-up approach to health promotion and is more participatory in nature empowering people to seek and analyse health information. Nutbeam's (2000) hierarchical framework indicates that health literacy levels progressively allow for greater autonomy in decision-making and personal empowerment consistent with health promotion principles. The

concept is novel since it identifies health literacy not only through comprehension and numerical skills, as early definitions suggest, but also in terms of the capacity to use information in healthcare decision-making.

Nonetheless, through utilising Nutbeam's (2000) health literacy framework a shift in health education and health promotion interventions is enabled. This means the focus moves from the simple transmission of knowledge to the more active process of empowerment, in which an individual develops skills to seek out information, assess the reliability of that information and use it to make well-informed health decisions and exert greater control over their own health.

The scope of currently available health literacy research to inform the goal of 'empowerment' has remained fairly narrow. A common response of researchers and health professionals to the problem of limited health literacy has been to evaluate the readability of health information and to recommend the use of plain language (Parker and Kindig, 2006). Medical journal articles repeatedly confirm that health education material is written at a level above average patient reading ability, which has been measured using the REALM or the TOFHLA (Kirsch, 1993; Williams, 1998; Ratzan, 2001; Shohet, 2002 and Mayer and Villaire, 2003). The Institute of Medicine (IOM) report (2004) (see section 2.3.7.1) included a survey of the systematic approaches to health literacy being used and found that vast majority were focused on simplifying materials. While simplifying written language is important it is not sufficient (Zarcadoolas et al, 2003).

However, an over-reliance on plain language in health education to deal with the issue of low-literate patients should be questioned. As Shohet (2002) maintains, written information should be secondary to verbal communication, only supplementing the exchange between the patient and health professionals. Measures for interactive and critical health literacy need to be developed if we are to move away from this trend. Nutbeam (1999) believed community based educational outreach would help people develop confidence and be central in achieving a shift towards critical health literacy.

Nutbeam's conceptual framework has been well employed in research as detailed in this section, it has also been employed in health policy (see section 2.3.7). However it has not been empirically tested.

### 2.3.3.2 Other health literacy frameworks

Four other health literacy frameworks: Zarcadoolas et al (2003); Freedman et al (2009); Von Wagner et al (2009) and Kwan et al (2006), will now be presented and contrasted to Nutbeam's (2000) health literacy framework.

Zarcadoolas et al (2003) proposed a multidimensional framework for public health literacy. This framework is characterised by four domains: fundamental literacy, which refers to the skills necessary for reading, writing, speaking and interpreting numbers; science literacy, which relates to a persons' awareness and competence with science and technology; civic literacy, which relates to awareness of governmental processes and public health; and cultural literacy, which means recognising and interpreting collective beliefs and social identity.

In comparing the two frameworks, Nutbeam's (2000) framework's functional health literacy level seems to map directly reflect the fundamental literacy domain of the framework as developed by Zarcadoolas et al (2003). The interactive and critical health literacy levels could be interpreted to encompass the other three domains of health literacy as proposed by these authors.

Freedman et al (2009) proposed a more comprehensive framework of health literacy, one that included a component of public health literacy as well as individual level health literacy. These authors define public health literacy as 'the degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community.' Three dimensions of public health literacy are identified. The first is the conceptual foundations which include the basic information that is required for understanding public health concerns. The second dimension is the critical skills required to obtain, evaluate and act on information so as to make public health decisions. The third dimension is civic orientation which ensures the community remains the focus in public health literacy.

When compared to Nutbeam's (2000) framework what is immediately clear are the parallels between the conceptual foundation dimension of Freedman's framework with the functional health literacy level, and the critical skills dimension of Freedman's framework with the critical health literacy level. A clear difference

between the frameworks is that while the framework developed by Freedman et al (2009) is targeted at groups of people, the first two levels of Nutbeam's (2000) framework focus on the benefit to individuals, critical health literacy is stated to focus on individual and community benefits.

Von Wagner et al (2009) outline a complex wider framework of health action that incorporates health literacy within it. The framework takes into account individual influences such as cognitive ability and external influences such as formal educational opportunities on health literacy. The framework also considers psychological determinants in a motivational and volitional phase between health literacy and action. It is clear that the framework of Von Wagner et al (2009) is more complex than Nutbeam's three level health literacy framework. There is similarity in both frameworks as they are based on a hierarchy of skills, from basic ones of decoding to more complex cognitive strategies.

Finally, Kwan et al (2006) developed a conceptual framework to understand health literacy and its role in Canadian society. They validated their framework using interview data. Similar to the framework of Von Wagner et al (2009), Kwan et al (2006) placed four health literacy skills in a wider health information context. The context was of health knowledge and health related goals. This represents the circumstances in which health information is encountered and could be processed in. A host of personal and external influences were also recognised. The four health literacy skills were to: access to relevant health information; understand the meaning of health information; appraise credibility of health information and communicate health information so as to enable care for self or share knowledge with others. There is a key similarity between the framework of Kwan et al and Nutbeam. Kwan et al give consideration to the public and population health context that health literacy skills must be applied within while Nutbeam (2000) contextualised health literacy as health goal. Moreover, although the functional and interactive health literacy levels focus on individual benefit, the critical health literacy level was clearly also linked to population benefit.

### **2.3.4 Measures of health literacy**

As previously discussed health literacy is a broad concept that is defined in various ways. These conceptual differences inevitably translate into measurement

difficulties. It is likely as result of the different health literacy definitions and frameworks that measures have focused on functional health literacy skills which are easier to operationalise. A benefit of health literacy measures is that they facilitate comparisons between populations and enable them to be related to other variables such as income, education levels, age groups and ethnicity. This section will consider available measures for functional health literacy first and measures for wider health literacy skills second.

#### **2.3.4.1 Functional health literacy measures**

Rootman et al (2006) identified fourteen health literacy measurement instruments. Of these, two measures, the Rapid Estimate of Adult Literacy in Medicine (REALM) developed by Davis et al in 1991 and the Test of Functional Health Literacy in Adults (TOFHLA) produced in 1995 by Parker et al, were the most applied in research. The REALM comprises a reading recognition test that measures an individuals' ability to correctly pronounce 66 medically-related words of increasing difficulty. The TOFHLA tests a patient's ability to read passages and phrases containing numbers using materials from an American healthcare setting and it is therefore understood to have face validity (Davis, 1991). Since unlike the REALM, the TOFHLA also tests numeracy it is considered to be the most reliable functional health literacy measure available (Davis et al 1998).

A limitation of both tests is that since they were developed in the USA their applicability for use in other countries is potentially limited. Additionally all empirical referents measuring health literacy that are validated are only available in English with the exception of the Spanish-TOFHLA. The additional significant barriers to assessing patients' literacy using the TOFHLA is that its development was methodologically weak since a convenience sample of 256 patients was recruited from only one Los Angeles hospital, raising issues about its generalisability.

Other difficulties with both the TOFHLA and REALM measures are that their execution is problematic. No formal training is provided to make an assessment despite the test being specifically designed to meet clinical and research needs of health care providers (Davis, 1995). This situation is exacerbated since health professionals notoriously work under considerable time constraints. The



acceptability of such tests is also questionable as there is some evidence that direct assessment can cause embarrassment and increase anxiety for the patient (Williams et al, 1995). This is especially true with the REALM, where patients are asked to read medical words aloud so as to assess pronunciation. Mancuso et al (2009) reviewed and criticised functional health literacy measures for focusing on medical terms and materials in healthcare settings and criticised them for not looking at health literacy materials and processes outside of there.

In the work by Rootman et al (2006) which retrieved fourteen health literacy measurements, 11 of the remaining 12 measures used the REALM and the TOFHLA for validation purposes. Since both tests remain routinely employed empirical referents of health literacy and are cited most frequently in publications, they have become accepted as the 'gold standard' measures in spite of their limitations. Paasche-Orlow et al. (2009) noted that the REALM and TOFHLA are not testing health literacy as it is typically defined and can be more accurately regarded as testing basic literacy skills within a healthcare context.

Existing measurement tools have been useful for identifying a high risk population but they have been limited in their capacity to measure health literacy and are more accurately literacy measures in a healthcare context (Paasche-Orlow et al, 2009). A further consideration remains that if health literacy is accepted to mean more than functional health literacy then measures are required for these wider definitions. While most definitions regard health literacy to be a process requiring skills to transform information into knowledge, most measures for health literacy do not relate it to knowledge (Pleasant and Kuruvilla, 2008). A person's ability to correctly pronounce or select a word from multiple choice options does not mean the significance of the instruction is understood, as researchers routinely infer. Wider health literacy measures are needed to assess an individual's ability to gain access to context-specific information from various resources, discriminate between information sources and assess an individual's ability to apply relevant information so as to benefit them.

#### **2.3.4.2 Wider health literacy measures**

Kwan et al (2006) have developed a measure based on four health literacy skills: access; understand; appraise and communicate. The measure comprises two

short passages for the participants to read, one is a text passage describing a self-management programme for a long-term condition and the second passage describes good and bad fats and includes a food label. Comprehension is tested by posing nine questions regarding the two passages. The measure developed by Kwan et al was found to have validity and more variability than REALM, on which all the participants scored highly. Despite these encouraging findings Kwan et al concluded that although their work had shown progress, health literacy was still not adequately defined and even less well measured.

More recently, Ishikawa and Yano (2008) developed a reliable and valid 14-item psychometric test for diabetic patients. This was the first scale of its kind to measure the functional, interactive and critical levels of health literacy as conceptualised by Nutbeam (2000). Functional health literacy was assessed based on difficulty patients experienced in reading leaflets from hospital. Interactive health literacy was assessed by focusing on how well patients were able to extract and communicate type 2 diabetes since their diagnosis. While critical health literacy was assessed by considering to what extent patients were able to critically analyse information and then utilise this information to make health decisions.

In conclusion, whilst there has been progress in understanding, defining and assessing health literacy, current measures remain limited since they still do not consider all facets of health literacy. A first step towards a more meaningful measurement of health literacy is agreement on its key components. A starting point would be clearer definitions of interactive and critical health literacy from Nutbeam's (2000) framework.

### **2.3.5 Impact of limited health literacy**

This section discusses the consequences of low health literacy both in terms of the individual and the wider healthcare context.

#### **2.3.5.1 The individual**

This section will begin by providing general literacy statistics from the UK. The negative health consequences of limited health literacy for the individual will then be emphasised. It will then be noted that health literacy is not an issue limited to the individual. Finally, related to this an argument will be presented of the need

for British health professionals to become more aware of these low literacy levels in the general population.

Von Wagner (2007) noted there had been no study of the prevalence of functional health literacy in the British population, which had not been limited to a specific patient cohort. Using a modified version of the TOFHLA the prevalence of functional health literacy was investigated in 759 adults with particular examination of its association with health behaviours. Limited health literacy was reported to be more likely in men, older people and people without formal education. Higher health literacy levels were associated with people who reported eating healthily, not smoking and doing exercise. This study demonstrated high rates of limited health literacy in Britain (11.4%) and highlighted the need for health literacy research outside USA.

While it is accepted that literacy is not the same as health literacy, in the absence of health literacy data for the UK, literacy data is provided. International Adult Literacy Survey showed general literacy in England to be amongst the lowest in Western Europe (Carey, 2000). The Basic Skills Agency (Bynner and Parsons, 1997) suggested that men and women with limited literacy are more likely to be unemployed or working for low incomes in unskilled jobs. It also states that these men and women are more likely to report symptoms of poor physical and mental health, experience low self-esteem and be dissatisfied in life. The Skills For Life survey (DFES, 2003) reported limited literacy skills in 16% and limited numeracy skills in 47% of working age adults. The same survey reported that deprived areas in the north-east of England have lower general literacy levels than the less deprived south-east of England. This is particularly unsettling since inadequate literacy is most prevalent amongst those reporting poor health, suggesting those with the greatest need for healthcare have the least ability to read, understand and act on information needed to function in a healthcare 'consumer' role.

Freedman et al (2009) have critiqued the formulation of the health literacy concept for being limited to the individual as is reflected by the health literacy measures. It is argued that individual-level health literacy initiatives do not tackle what can be considered as the root causes of health illiteracy such as socio-economic disparity and unequal access to quality education (Baker, 2006; Goldberg, 2007).

The IOM report (2004) contextualised health literacy as a healthcare challenge and not a patient problem. Kalichman et al (1999) suggested that people need to overcome other challenges such as lack of access to care and treatment as well as find the necessary time and finances that may be related to these behaviours.

In their editorial Paasche-Orlow et al. (2009) note interesting duality in health literacy research. The first regarding the knowledge and skills a person needs, addressing the individuals' cognitive and psychosocial skill set. The second regarding the improvement of barriers in the health system and the outreach required from health professionals. In Nutbeam's (2008) recent publication, comments in a similar vein were delivered on the evolving concept of health literacy. It was suggested that health literacy emerged from a clinical care root as a 'risk' and the public health root as an 'asset.' The clinical care root had resulted in a body of research developing screening for poor literacy. The public health root, which focuses on health education skills that enable individual's to exert more control over their health, has remained less well developed. Pleasant and Kuruvilla (2008) remark on the distinction between the clinical approach and the public health approach to health literacy research and practice. They commented that the clinical approach was largely developed in the USA so as to encourage patient compliance and improve patient communication. Health literacy diagnostic measures were developed as result of this orientation whereas public health research is more international and concerned with health promotion and progressing with conceptual frameworks and theories.

Practitioners over-estimate patients' health literacy (Lindau, 2002; Hardin, 2005) particularly of BME patients (Kelly and Haidet, 2007) or display a lack of awareness of their patients' low health literacy levels (Ad Hoc Committee on Health Literacy, 1999). Rootman (2005) argues that if health-care providers' communications and instructions are unhelpful or potentially harmful for some patients then attending to this problem should be a priority. Poor communication between the health professional and the patient exacerbates any difficulties encountered by low-literate patients trying to navigate the increasingly complex healthcare system.

The documented contribution of healthcare professionals in Britain to the field of health literacy has been limited. British physicians should be more concerned with limited health literacy because of their well documented negative health consequences to the individual (Von Wagner et al, 2009). These included associations with less knowledge of condition and self-care (Williams et al, 1998), poorer self-management skills (Levin-Zamir, 2001; Rothman, 2004), lower medication compliance rates (Kalichman, 1999; Safeer, 2005; Cuban, 2006), shame (Safeer, 2005; Parikh, 1996), higher rates of hospitalisation (Baker et al, 1998; Lindau, 2002; Vastag, 2004) and feelings of vulnerability (Williams et al, 1995).

This understanding has made the identification of patients with limited health literacy, and therefore at risk of poor health outcomes, the health professionals' responsibility (Jeppesen et al, 2009). In a recent publication Phillips (2010) questions whether it is simply a case of people with low health literacy making poor lifestyle choices or whether health professional's interaction styles in fact contribute to these problems. While the improvement of health professional's communication skills is considered important it is suggested health benefits for the patient must be tangible and immediate if emotionally rewarding behaviours are to be changed.

### **2.3.5.2 The healthcare context**

Having presented the issues surrounding health literacy and the individual, this section will consider health literacy in its wider healthcare context.

When patients are faced with complex information and treatment decisions there is a range of health literate behaviours required to firstly locate health information and then evaluate credibility of the source, weigh up risks and benefits of treatment, calculate dosages and interpret test results. Such complexities of the modern healthcare system can create barriers to healthcare delivery, especially for vulnerable populations such as the chronically ill, migrant communities, socially deprived and the elderly (Kickbusch and Ratzan, 2001).

The pervasive problem of inadequate health literacy acting as a barrier to successfully navigating the system and functioning successfully in a health-care 'consumer' role is not warranted enough attention by health care organisations (Neilsen-Bohlman et al, 2004). Health literacy research has focused mainly on

healthcare delivery barriers related to access and cost, such as use of available services and health outcomes (Lindau, 2002), medication use and adherence (Ratzan, 2001), compliance with physician orders (Schillinger, 2004) and with management of long-term conditions (Levin-Zamir, 2001). This indicates a challenge in the orientation of health literacy research from a focus on individual barriers to contextual facilitators.

The consequences of good health literacy have been shown to include lower health care costs because of shorter hospitalisations and less frequent use of health services (Baker et al, 1998; Lindau, 2002; Vastag, 2004). Suggesting a health literate population does not only enjoy better quality of life but also more effectively utilises healthcare resources. Although Lee et al (2004) recognise that health literacy affects health status and health service utilisation, they comment that causal pathways are unclear. They critique the focus on health literacy as an individual trait and suggest that the wider context, namely the amenability of the health services to utilisation, should be investigated.

### **2.3.6 The association between social factors and health literacy**

The WHO (2007) recently stated that literacy is crucial to determining health inequalities in both rich and poor countries. Coulter and Ellins (2007) considered health literacy as central to involving patients in their own care and thereby reducing health inequalities.

One in five British people cannot interpret basic health information and this poor functional health literacy is associated with socioeconomic disadvantage (Sihota and Lennard, 2004). People with poor health literacy have been shown to be less able to make informed health decisions and are more likely to have poor health (DfES, 1999). While the relationship between social factors and health is well established (Goldman, 2004) it is the precise mechanisms linking the two that are unclear. According to the American Medical Association (1999) health literacy is a more accurate predictor of a person's health status than any other socio-economic variable.

However, this seems too simplistic an assumption since such a claim would need to be supported by research controlling for socio-economic variables and these

constructs are difficult to disentangle. It is difficult to report the causal direction between social determinants and health outcomes because the accumulative or additive correlations make the association complex.

De Walt et al (2004) systematically reviewed 44 papers that explored the relationship between health literacy and health outcomes. A key review question was whether literacy skills were related to disparities in health outcomes according to culture, age or ethnicity. While their findings were inconclusive, low literacy was considered to be directly associated with several adverse health outcomes and indirectly associated with unemployment and low income. De Walt et al recommended future researchers examine this important relationship, so as to aid identification of clinical markers for high risk patients and to inform the development of effective interventions.

### **2.3.7 The policy context**

Health literacy has recently been identified as an international public health priority. In 2009, the WHO hosted the 7<sup>th</sup> Global Conference on Health Promotion and health literacy was one of the five pre-determined themes of address. Clement (2009) relates that health literacy has been a focal point of North American research since the 1990s while becoming more recognised in Europe and elsewhere more recently. While health literacy is increasingly becoming introduced in national health policies across the west, in the USA health literacy has been considered a key healthcare challenge for several years (Carmona, 2006). For these reasons USA policy on health literacy will be considered in the following section. UK policy on health literacy will also be detailed.

#### **2.3.7.1 USA policy**

In the USA, the IOM produced a globally influential report 'Health Literacy: A prescription to end confusion' (Nielsen-Bohlman et al, 2004). This report was used to generate research and action. It is argued in the IOM report that research and intervention efforts should be based on a 'socio-environmental' approach to health promotion. Nutbeam's framework supports this orientation, with a focus upon communities, not just individuals (Ratzan, 2001). The IOM report concluded that health literacy and the self-management of conditions are two of the most important cross-cutting opportunities to improve health in the USA. Since medical discoveries

have out-paced efforts in patient education it is imperative for these advances in knowledge to be converted into a healthier society (Adams and Corrigan, 2003).

Developmental targets for health literacy were set for the first time by the USA Department of Health and Human Services (2000) in the report 'Healthy People 2010' founded on the fact that there were no baseline data of health literacy (Department of Health and Human Services, 2000) which lead to a dependence on general literacy surveys being used instead.

#### **2.3.7.2 UK policy**

To date, the USA has pioneered health literacy policies and dominated health literacy research despite similar trends of 'health disparity' in the UK and elsewhere. In the UK there has been disappointingly little health literacy research (Protheroe, Nutbeam and Rowlands, 2009). The National Consumer Council reported health literacy to be low in lower socio-economic groups, ethnic minorities, the elderly and those with disability or long-term conditions (Sihota and Lennard, 2004). Although overall health in the UK is improving, with people living healthier and longer lives in the UK, this change is variable across the population (DfES, 2003) and the 'inequalities gap' between society's most and least disadvantaged is increasing (DH, 2008).

The UK government's public health white paper 'Choosing Health: Making healthy choices easier' (DH, 2004a) implicitly considered health literacy when it identified inequality in health as a key public health issue and recognised the need to assist individuals in making informed health decisions if existing inequalities were not exacerbated. Health literacy was only recently being explicitly introduced as a term in NHS policy documents. The NHS is presently promoting patient health literacy using Nutbeam's health literacy continuum, with an emphasis on greater autonomy in informed decision-making (DfES, 2007) and supporting patient choice (DH, 2004a; DH, 2006).

#### **2.3.8 Health literacy and type 2 diabetes**

The focus of the thesis was on understanding the self management of type 2 diabetes in BME groups using health literacy as the conceptual framework. The health literacy framework seemed to be a logical choice for the investigation of type



2 diabetes self-management, which is composed of various complex skills that necessitate patient motivation. The health literacy framework was also well suited to the investigation of diabetes self-management particularly in BME groups who are known to suffer disproportionately from the consequences of poor self-management which include chronic complications, co-morbidities and even death. It is plausible that the health literacy framework may help explain some of the reasons for the evident health inequality. Furthermore, by supporting health literacy in these populations it is proposed that their diabetes self-management can also be improved. For health literacy to be supported it needs to be better defined and better measured. It was anticipated that type 2 diabetes would act as an exemplar condition for the analysis of Nutbeam's (2000) health literacy framework and by so doing it would serve to clarify its meaning.

## 2.4 Summary

In the UK some BME groups have significantly greater rates of prevalence, of type 2 diabetes than the indigenous white population (Riste et al, 2001; Hewitt and Gallen, 2004; Banerjee et al, 2004; Forouhi et al, 2006). Similar patterns are seen in BME groups living in other westernized countries (Karter et al, 2002; Vines and Godley, 2004). Ethnic differences in the outcomes of diabetes care are also recognized and these are partly attributed to poor self-management (Oster et al, 2006; Lanting et al, 2008).

The relationship of low health literacy with a higher prevalence of type 2 diabetes, poor disease knowledge and sub-optimal self-management is recognised (Rothman et al, 2002; Schillinger et al, 2002). Health literacy skills are considered essential for making informed health decisions and self-managing appropriately (Selden et al, 2000). While the link between health literacy and health inequalities has been recognised (Hippisley-Cox et al, 2004; Volandes and Paasche-Orlow, 2007) there has been limited research of the relationship between these two variables (Paasche-Orlow and Wolf, 2010). This thesis will address this research gap.

Study One (presented in Chapters 3 to 6) is a multi-method systematic review driven by the research question "*What is known about the barriers to, and facilitators of, self-management of type 2 diabetes amongst ethnic minority groups?*" Furthermore it is anticipated the review evidence will be used to address

Study One's subsidiary aim which was: "*To refine Nutbeam's conceptual framework of health literacy (2000) in the context of type 2 diabetes.*" This process is expected to be achieved in part by identifying effective diabetes self management behaviours for the three levels of health literacy.

Interesting findings from the systematic review are pursued in Study Two (Chapters 7 to 9). Study Two is a qualitative interview study driven by the research question "*How does having type 2 diabetes affect British-Pakistani women's identity and how does this relate to subsequent self-management?*" Furthermore the interview study has a subsidiary aim: "*To investigate the operational definitions of the three levels of Nutbeam's (2000) health literacy framework as developed in Study One, so as to further refine the conceptual framework in the context of type 2 diabetes.*"

## **Chapter 3**

### **Methodology and methods**

This chapter presents the methodological issues and the method relating to Study One, the systematic review.

### **3.1 Methodological issues and systematic reviews**

#### **3.1.1 Introduction**

This section introduces and discusses conceptual and theoretical issues surrounding the systematic review, it precedes and sets the context for the subsequent methods section. The methods section in turn deals with issues relating to how the systematic review was conducted.

In this section a brief history of systematic reviews will be presented. This will begin with the origin of systematic reviews which was to assess the effectiveness of clinical interventions, using evidence from randomised controlled trials (RCTs). Subsequently developments in synthesising evidence from different study designs will be discussed. Following this an overview of the increasing number of different approaches available for synthesising qualitative evidence will be presented, highlighting some of the ongoing debates in this area. This section will conclude with a rationale for choosing The Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI Centre) approach as the method of choice in conducting the systematic review presented in this thesis. The rationale for using thematic analysis for the qualitative data synthesis within the review is also presented.

#### **3.1.2 Systematic reviews of effectiveness**

The health sciences have enjoyed a long history of reviewing literature to summarise available knowledge in an area, identify any gaps in research as well as gain fresh insights through accumulating the results of multiple studies (Oakley, 2000). Although these narrative reviews collated literature on a chosen topic, their methods were commonly not replicable since information was rarely provided on the selection, assessment and integration of existing studies. This meant clinicians and medical researchers could not be confident in the results of narrative reviews as to whether a treatment was harmful, beneficial or neither.

It was not until the late 1980s that the limitations of these narrative reviews and potential bias' in their recommendations were presented (Mulrow, 1987; Teagarden, 1989). Moreover a requirement for a systematic approach was emphasised in 1992 when Antman published a landmark paper that reported the effectiveness of clot busters after heart attacks. This work emphasised that if the original studies had been previously systematically reviewed, the benefits of clot busters would have been recognised two decades earlier. Findings such as these spearheaded the research community's movement towards producing high quality systematic reviews using transparent and rigorous methods.

The early 1990s saw the establishment of the International Cochrane Collaboration and the York Centre for Reviews and Dissemination amongst other similar organisations in the UK and internationally. These organisations originated so as to prepare and maintain systematic reviews on the effectiveness of clinical interventions in the health field based primarily on evidence from RCTs. Their task was to synthesise and build on the evidence base about the clinical effectiveness of health interventions, keeping in mind Archie Cochrane's (Cochrane, 1989) original research questions about clinical medicine. These were: Do we know whether an intervention works? Do we know whether the intervention does any harm? What is the best way to determine whether it works or does any harm? And do we know the costs?

Originally, systematic reviews set out to assess the effectiveness of a treatment through combining the numerical data of existing intervention studies. This drawing together of evidence was frequently achieved through a statistical meta-analysis, which produces one estimate of effect which is more reliable than the results reported in any single study. These types of effectiveness systematic reviews have proved valuable in establishing whether findings were consistent and could be generalised whilst also explaining discrepancies, such as why a treatment is only effective within a particular setting or among a certain population (Mulrow, 1994).

Although effectiveness reviews proved to be useful they are not without limitations. The Health Development Agency (HDA) when it was originally set up in 2000 to collate evidence and policy advice for improving health and reducing health inequalities (now subsumed under NICE), identified four main limitations with synthesising evidence from RCTs for systematic reviews of effectiveness.

Firstly, there was the issue of missed data since only a small amount of research relates to interventions (Millward et al, 2003). Secondly, there was recognition that not all questions about 'what works', particularly in terms of some public health questions, would necessarily be amenable to investigation using a randomised controlled trial design. Thirdly, there was the issue of 'process bias' particularly with regard to implementation, as data concerning how interventions were or were not implemented were often excluded from trial reports. Fourthly, 'artefact bias' was considered to be an issue. Meaning the investigators' preoccupation with employing RCTs as the method meant that issues which were a real priority for users may have been overlooked. From these observations, Kelly and Swann (cited in Dixon-Woods, 2004) concluded that questions of central importance to patients were often not asked in effectiveness reviews and to be able to do so, reviewers needed to also make use of other research designs and methods.

### **3.1.3 Post systematic reviews of effectiveness**

Although the bulk of systematic reviews continue to be focused on answering questions about 'what works' and drawing together evidence on the effectiveness of interventions, this is not the exclusive approach. More recently other kinds of questions that are not amenable to Cochrane Reviews are being asked. These questions are concerned with the cost-effectiveness, appropriateness, acceptability and transferability of interventions (Popay and Roberts cited in Popay, 2006). It is becoming progressively more common for reviewers to address complementary issues regarding the feasibility of successful implementation of an intervention outside of a research context (Popay et al, 1998).

With respect to drawing together the evidence on the effectiveness of clinical interventions the Cochrane approach to systematic reviews provides a transparent and robust process to ensure the quality of the review, based on a clear set of criteria. When questions other than those of effectiveness are asked (like those noted in the previous paragraph) a complex array of issues faces researchers (Harden et al, 1999; Boaz and Ashby 2003). These issues include: How can evidence from a diverse range of studies that do not ask exactly the same question or use exactly the same methods be combined? How can research quality and rigour be seriously considered whilst acknowledging the inevitable judgement that underpins the synthesis of assorted research designs? How can any judgements adhere to the

norms of scientific transparency or accountability? Does replication play any role in these reviews?

The Campbell Collaboration, which was launched in 1999, attempted to foster and disseminate systematic reviews of interventions addressing education, crime and justice, and social welfare. These studies most frequently relied on non-experimental study designs diverging significantly from RCTs, the 'gold standard' for evaluating the effectiveness of clinical interventions in health. While the Campbell Collaboration follows largely similar steps to a conventional effectiveness review, other approaches take a very different stance. It is important to note that there is no one accepted approach to undertaking systematic reviews which ask research questions other than clinical effectiveness, as a result the emphasis is more on the skills of the reviewer and less on achieving methodological 'gold standards' (Dixon-Woods et al, 2004; Thomas et al; 2004). An increasing number of 'other' types of evidence reviews are emerging. For example, Pawson (2005) presents 'realist synthesis' which focuses on the causal mechanisms and the theory that underpins the success of an intervention with the intention to understand the context that facilitates an effective intervention. This is to ensure that relevant questions are asked and meaningful answers are produced, not just to generate rigorous reviews in a 'pointless effort' to imitate effectiveness reviews (Petticrew and Egan, 2006).

As methods for reviewing and synthesising research not concerned with effectiveness are still young, they have methodological challenges to overcome so as to enhance their approaches to data synthesis. Petticrew and Egan (2006) highlighted that while systematic reviews of clinical interventions have focused on evidence of effectiveness and as such have a common outcome, other systematic reviews for example, those regarding the appropriateness of interventions often have more broadly defined or multiple goals which make it more difficult to produce definite results.

### **3.1.4 Synthesis styles**

While methods for synthesising studies of effectiveness are sophisticated the synthesis of non-effectiveness data has been developed later and more slowly. For the synthesis of quantitative research the term 'meta-analysis' is routinely employed

whereas for the synthesis of qualitative research the number of terms are far greater and are on the increase (Barnett-Page and Thomas, 2009).

This following section will focus on synthesis of qualitative research. It will begin with rationale for the synthesis of qualitative research. Then from the assortment of techniques available some of the more popular approaches for qualitative synthesis will be considered, followed by some of the challenges that are associated with qualitative synthesis.

#### **3.1.4.1 Rationale for the synthesis of qualitative research**

There has been a growing enthusiasm for integrating qualitative research traditions into systematic reviews (Dixon-Woods et al, 2001; Dixon-Woods et al, 2004; Britten, 2002; Campbell et al, 2003). This was in part a response to the four limitations identified in systematic reviews of effectiveness as detailed at the end of section 3.1.2, since these were partially overcome by drawing on qualitative research methods. For example, the issue of missed data since only a small amount of research addresses interventions (Millward et al., 2003) was overcome by drawing on qualitative research methods.

Moreover, from around the mid 1990s debates began emerging about the need to find ways to synthesise the findings from multiple qualitative studies on the basis that their combined findings would be more 'transferable' (Estabrooks et al, 1994; Sandelowski and Barroso, 1997). As such the synthesis of multiple studies would have a greater impact on the building of theories than any single study. This is partly because a qualitative synthesis would enable access to a larger sample than a single qualitative study would (Sherwood, 1999) which is particularly important when rare events (Thorne, 1994) or hard-to-reach populations are the subject of research (Dixon-Woods et al, 2004). This is in addition to the more practical rationale of optimising available qualitative studies which are valuable sources of evidence and are routinely the product of time-intensive research methods (Thorne, 1994).

#### **3.1.4.2 Approaches to the synthesis of qualitative research**

Noblit and Hare (1988) conceptualised the distinction between integrative and interpretive reviews. Integrative reviews were considered suitable for synthesising

quantitative studies since they were thought to be primarily concerned with accumulating data and making predictions around the phenomena of study. Interpretative reviews were thought to be suitable for synthesising qualitative studies since their focus was on studying and understanding connections.

Dixon-Woods et al (2004) elaborated on Noblit and Hare's original distinction. Rather than identifying integrative with quantitative, they suggested that integrative synthesis was when the focus was on summarising data of well-specified and fixed variables and they give the example of influenza uptake in old people. Similarly, rather than identify interpretative with qualitative, they suggested that interpretative synthesis was related to the expansion of concepts, and from these the generation of theories. Furthermore, they did not consider both types of syntheses as completely separate but as primarily interpretative or integrative with elements of the other.

In the same report Dixon-Woods et al presented a selection of the increasing available methods of qualitative synthesis and grouped them according to their epistemological and ontological foundations as well as whether they were primarily interpretative or integrative. These methods of qualitative synthesis were not completely distinct and showed some overlap. Clustering towards the interpretative end were narrative summary, grounded theory, meta-ethnography and thematic analysis. At the integrative end were content analysis, case survey and qualitative comparative analysis.

#### **3.1.4.3 Challenges associated with the synthesis of qualitative research**

Since qualitative synthesis in contrast to quantitative synthesis involves reinterpretation of published findings and not primary data a central point to the debate of whether qualitative studies should be included in systematic reviews is the different philosophical positions that underpin different qualitative designs and whether these are amenable to a single synthesis. Non-effectiveness systematic reviews include methodologically mixed and highly diverse research designs which may be based on different philosophical positions whereas traditionally effectiveness reviews only include studies of a RCT design.

It has been contested whether it is acceptable to synthesise qualitative studies at all on the grounds that the secondary analyst can neither understand the



epistemological or the ontological positions of the primary research, nor the relationship between the researcher and his data (Fielding and Fielding, 2000; Estabrooks et al, 1994; Jensen and Allen, 1996; Sherwood, 1999). On the other hand, a counter argument suggests that just as it is true that qualitative researchers should deliberately consider negative cases collected from a single data set so as to explore the boundaries of theoretical explanations, it is appropriate to analyse different sources of data when reforming theory (Barbour, 1998). Furthermore, researchers have also noted that primary papers frequently misreport their employed approach meaning a disparity of epistemological approaches is unavoidable to some degree (Paterson et al, 2001; Campbell et al, 2003). Similarly, Dixon-Woods et al (2004) emphasised in a recent report that attempts should be made to resolve practical health problems rather than become overly captivated by what was regarded to be distortions of philosophical concerns.

### **3.1.5 Multi-method research (qualitative and quantitative)**

In addition to the focus on how best to synthesise qualitative findings is enthusiasm in the arena of mixed-methods design and data analysis (Dixon-Woods et al, 2001) and how best to integrate qualitative findings with quantitative findings within a systematic review (Harden, 2006). In many ways the rationale for multi-method primary research also applies as a rationale for multi-method secondary research. Multi-method primary research involves using more than one type of research technique within a study and can be viewed as a way to satisfy complex questions (Dixon-Woods et al, 2004). Researchers have provided a strong rationale for employing multi-method designs, namely that it provides a more rounded and in-depth account of the phenomenon under investigation (Campbell and Fiske, 1959; Duffy, 1987; Bryman 2001).

Hammersley (1981) summarised how the concern surrounding multi-method research pivoted on whether one method was considered more valid than another. In response to this he highlighted three approaches where the sum of multi-method research was greater than its parts. The strategy of 'triangulation' can be employed to verify the results of one method, to some extent, by using another method; 'facilitation' is where one method supports another and 'complementarity' is where two strategies are used to investigate different aspects of the same research question.

Roger et al. (1997) distinguished between the 'difference model' and 'enhancement model' to explain the role of qualitative research in healthcare. They criticised the trend of qualitative research methods being primarily used in an 'enhancement role', which was viewed as supplementary to quantitative research methods rather than in the 'difference role', which would give emphasis to the independent contribution of qualitative research methods to evidence-based practice. However, more recently Dixon-Woods et al (2004) have commented on an encouraging shift as qualitative research is increasingly playing both difference and enhancement roles and in doing so is increasingly challenging historical assumptions about the role of qualitative research.

A lively debate continues about the process of incorporating evidence from qualitative synthesis into multi-method research (Dixon-Woods et al, 2004). This is in part due to there being not one preferred approach for synthesising qualitative data currently available or any widely 'accepted' guidance. As detailed in section 3.1.4.2 there are various methods to select from and the process of synthesising evidence from qualitative study designs is evolving.

### **3.1.6 Selection of review method for this systematic review**

The overall systematic review question posed in this research was "*What is known about the barriers to, and facilitators of, self-management of type 2 diabetes amongst ethnic minority groups?*" and this was addressed by answering three sub-questions.

Sub-question one was "How effective are existing interventions in supporting self management of type 2 diabetes in ethnic minority patients?" This question aimed to assess the effectiveness of interventions for self management of type 2 diabetes by drawing on integrative techniques.

Sub-question two asked "What are ethnic minority patients' views surrounding self management of type 2 diabetes?" This question sought to directly assess patients' perspectives and as such necessitated an interpretative synthesis approach in a component of the systematic review.

Sub-question three “How appropriately do the existing interventions address the identified views of ethnic minority patients and communities?” focused on the interactional effect of sub-questions one and two.

This systematic review therefore, assessed the effectiveness of the trials of type 2 diabetes self management interventions as well as the appropriateness of these interventions from the patients’ perspective. A diverse range of study designs was included in the review and so a mixed methods approach was required.

### **3.1.6.1 Evidence for Policy and Practice Information and Co-ordinating Centre approach**

The Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI Centre) has been engaged in developing methods for systematic review since 1993 (Harden and Thomas, 2005) and, in this time amongst a large body of secondary research they have made leading methodological advancements in the area of systematic review.

The EPPI Centre has developed an innovative and flexible framework for conducting systematic reviews that is quite different from traditional systematic reviews. Their approach aims to answer traditional questions about the effectiveness of interventions as well as assess their appropriateness by judging how the interventions have addressed participants’ perspectives (Rees et al, 2006). In the context of the EPPI-centre framework the term ‘appropriateness’ is considered to be an all encompassing word describing a range of process outcomes including: acceptability, accessibility, delivery and implementation of an intervention. EPPI reviews are able to answer several research questions because they can include many research designs and undertake multiple syntheses.

As with traditional systematic review methods, the EPPI process incorporates steps to reduce the impact of bias and error that may be present in primary studies as well as in the process of reviewing, for example through retrieval bias. The entire process is recorded and transparent. The EPPI process of conducting a systematic review is more complex than conventional effectiveness reviews and as a result other methodological challenges were also addressed in the process of conducting this review. For example, the inclusion of various study designs complicates the extraction of data, assessment of quality and synthesis of the evidence.

There were four reasons for selecting the EPPI approach for this systematic review. These were as follows:

1) The EPPI approach goes beyond effectiveness and accommodates diverse review questions, such as those posed in this systematic review and consequently collates and reviews evidence from different study designs, not only RCTs.

2) Oakley (1999) notes, Cochrane reviews have traditionally tended to prioritise the perspective of health professionals in terms of the clinical questions asked. Oakley suggests, for example, that very different issues and research questions would be identified in maternal care if the perspectives of mothers were drawn upon, rather than those of doctors. EPPI provides clear guidance on synthesising evidence from 'views' studies that place people's own voices at the centre of analysis. This reasoning was well suited to this systematic review where 'views' studies prioritising BME participants' perspectives and experiences associated with the self-management of type 2 diabetes were to be analysed.

3) Reviewers at EPPI recognise there to be scope for examining their methods with other topics. This meant, using the EPPI Centre's approach to undertake the systematic review offered up opportunities for contributing to the evolving debate about how to combine evidence from different study designs. The consideration of adding something to the ongoing debate of mixed methodology and furthering development of this innovative area was additional motivation for selecting the EPPI Centre's approaches in undertaking the systematic review presented in this thesis.

4) It was anticipated that the findings from the systematic review would inform the topic guide for the empirical qualitative work in the second study of the thesis (as reported in chapter 7.5.1). This was a novel aspect of the research because although systematic reviews are associated with securing fresh insights and identifying gaps in the research, to the best of our knowledge this would be the first time that an identified question from a systematic review using the EPPI Centre's approach, would be subsequently investigated in a primary study.

### **3.1.7 Synthesis method for the 'views' data**

Although the EPPI Centre's approach which involved a 'mixed method' synthesis had been selected, how best to synthesise the qualitative studies (from the

'views' component of the systematic review – sub question 2) had yet to be identified because EPPI were not prescriptive about this. An overview of the methods of synthesis that are currently available were outlined earlier in section 3.1.4.2 according to whether they were primarily interpretative or integrative. To recap, integrative reviews are most appropriate when the focus was on synthesising fixed concepts and interpretative reviews related to the expansion of concepts, and from these the potential generation of theories. Since the research questions posed by this systematic review lay at the interpretative end of the spectrum, the potential methods of evidence synthesis to choose from included narrative summary, grounded theory, meta-ethnography and thematic analysis. The following section provides the rationale as to why thematic analysis was considered to be the synthesis method best suited to the 'views' data.

### **3.1.7.1 Thematic Analysis**

Thematic analysis can be described as a research approach that identifies, major recurrent themes from the literature. These themes are subsequently summarised under descriptive and then analytical headings. Detail on the process of undertaking thematic analysis is provided in section 4.3.3.

Dixon-Woods (2004) presented a critique of a range of qualitative synthesis methods (including thematic analysis) and identified their advantages and disadvantages. Advantages of thematic analysis were: ability to cope with diverse types of evidence; clear identification of prominent themes; organised and structured way of dealing with the literature under these themes and an approach that provides reviewers with some flexibility. The EPPI process regularly employs thematic analysis in the synthesis stage of their 'views' studies, making it a natural choice for the 'views' synthesis in this thesis. Moreover, Garcia (2002) reported applying thematic analysis to the synthesis of women's views of ultrasound in pregnancy. This application of the method supports the rationale that it is well suited to research where the participant's voice is central.

Amongst the disadvantages of thematic analysis reported by Dixon-Woods et al (2004) was a deficiency in procedural explicitness leading to a lack of transparency. For example, they said it was unclear whether the analysis structure should reflect the frequency of the reported themes or the weight of them. Thomas

and Harden (2008) have recently produced a detailed publication on the method of thematic synthesis of multiple qualitative studies in systematic reviews which has addressed this deficiency in procedural explicitness. Another disadvantage of thematic analysis that Dixon-Woods et al (2004) presented was that it does not offer theoretical structure from which to develop categories that go beyond what is already identified. Again, Thomas and Harden's (2008) publication goes some way in overcoming this. In this research, efforts were made to further overcome both of these limitations. The success of this is detailed in (see section 10.2.2)

## **3.2 Method**

### **3.2.1 Introduction**

As detailed in the previous section, the decision was made to undertake the systematic review in line with the 'mixed-method framework' developed by the EPPI Centre (Harden and Thomas, 2005). The EPPI Centre's approach has been previously described in detail (see section 3.1.6.1). In brief, the basic principles of EPPI involve collecting data from health promotional 'intervention studies,' which by rigorous evaluation distinguish effective, ineffective and harmful interventions; alongside 'views studies' which are predominantly qualitative studies examining patients' views and describing associated factors (Oliver et al, 2005).

In this section each step of the review will be detailed in terms of how it was developed and how it was undertaken. These steps were the: search strategy; additional searches; inclusion and exclusion criteria; screening tool; critical appraisal tool; and finally synthesis of the findings.

### **3.2.2 Search strategy**

As outlined above, this review involved two components with common points of enquiry, one related to intervention studies and the other to 'views' studies. For the purpose of efficiency, since the sub-question relating to each strand addressed the same overall review question, the search strategy was executed once in April 2008 and utilised for both review strands, designed to retrieve relevant 'views' and intervention studies in the same search. When screening the titles and abstracts of retrieved papers it was clear which articles were concerned with the 'views' strand

and which were concerned with the intervention strand. In this way both the intervention and the 'views' components had their own separate review strand.

The first step in defining the search strategy was to systematically identify a list of synonyms for the systematic review's four conceptual components (BME groups, type 2 diabetes, self-management, health literacy). British and North American terminology and spelling issues were also considered. The search strategy that was employed, used 'controlled vocabulary' which were the standardised search terms indexed in each database that served to describe study content alongside 'free-text terms' which were any words that may appear in the title, abstract and/or any other field. The search strategy included in excess of 240 terms in OVID databases (see Appendix 3.1).

Following a meeting with two information scientists, the decision was made to search eight bibliographical databases (MEDLINE, CINAHL, EMBASE, HMIC, AMED, PsycINFO, CSA, Web of Science) and one specialist register (Cochrane library) relevant to the area of review. Some of the smaller databases did not employ a range of controlled vocabulary, and even in databases that did, these were not standardised. Consequently, an appropriate search strategy was initially devised in MEDLINE and then translated and adapted to other databases. Free-text terms were employed consistently throughout this process.

As in any systematic review, sensitivity and specificity of the search was considered. The use of truncation, adjacency, exploding and using link words was applied to the search terms. Boolean operators were employed to link and formulate the search algorithm, the range of controlled vocabulary and free-text terms, reflecting the four conceptual components were linked by: 'ethnic minority groups' AND 'type 2 diabetes' AND ('self-management' OR 'health literacy'). In the literature review the idea that 'health literacy' is necessary for of self-management was presented hence these two terms were linked with OR. Search terms were employed to reflect the entire health literacy continuum, i.e. from critical health literacy with words like 'empowerment' to interactive health literacy with terms such as 'communication' to functional health literacy using terms that reflected 'reading' 'writing' and 'numeracy'. Details on the health literacy component of the systematic review are provided in Chapter 6.

A decision was made not to employ methodological filters for design of the primary studies despite the procedure being recommended for evidence-based medicine (Dickersin, 1995). There were two reasons for this. Firstly, this review used one search strategy for both the intervention and 'views' strands, study design restrictions required for the effectiveness review would mean excluding the range of study types that would fit the 'views' review's inclusion criteria. Secondly, shortcomings of this restricted search have been previously documented even when conducting an effectiveness review alone. For example, Peersman et al (1999) demonstrated that using specific search terms e.g. 'randomised controlled trial' or 'controlled clinical trial' restricted a search, and studies were missed.

### **3.2.3 Additional searches**

In addition to the database searches which were limited to published articles in journals, a range of additional searches were planned to enhance the likelihood of retrieving all relevant studies. These included hand searching of key journals, scanning the grey literature and contacting key authors and organisations to gain access to any unpublished studies fitting the inclusion criteria. This is recognised as good practice since the comprehensiveness of a systematic review search strategy is one factor that affects its validity (Mays and Pope, 1995).

To test sensitivity, two journals identified as publishing a high volume of papers that were directly relevant to the review were hand searched. These journals were Ethnicity and Health (from 2000 volume 5, issue 12 to 2008 volume 13, issue 5) and Diabetes Care (from 2000 volume 23, number 12 to 2008 volume 31, number 4). A decision was made to extend these dates should studies not already identified through the electronic searches be identified through hand searching. However, this technique did not produce any additional studies fitting the inclusion criteria. From this exercise it was concluded that the search strategy demonstrated an acceptable level of sensitivity i.e. the majority of relevant studies were being identified through electronic searches.

'Grey' literature (including reports, conference proceedings, newsletters, discussion papers) was considered important to include in the review so as to capture the unpublished data relevant to the review question. Additionally, consumer/voluntary groups do not always disseminate via traditional publishing



routes and given the 'views' strand in particular, identifying studies through non publication routes was initially considered to be important. However, once the search had been executed and the large volume of relevant primary research identified, in the interests of time constraints a decision was made to exclude the inclusion of these additional searches. For the same reason, it was decided against contacting key authors and organisations to gain access to any unpublished studies. These decisions may have prevented some relevant unpublished studies from being included in the review.

### **3.2.4 Inclusion and exclusion criteria**

The purpose of defining inclusion and exclusion criteria is to ensure two things: first, that the search strategy identifies research studies that directly address the review questions and second, that the process is replicable. Since the sub-question relating to each strand addressed the same overall review question, the inclusion and exclusion criteria, which served to identify and classify studies, were developed in parallel for both review strands. Khan et al (2003) have developed study selection criteria which are defined in terms of the *populations, interventions, outcomes* and *study designs* of interest. Defining selection criteria using the categorisation of Khan et al (2003) was adopted for this review. These selection criteria were identified a priori to reduce selection bias. Detail on these criteria now follows.

#### **3.2.4.1 Interventions strand: Inclusion criteria**

##### **The population**

The inclusion criteria were:

- People with a diagnosis of type 2 diabetes aged 18 years or over.
- Study samples of whom 50% or more were from ethnic minorities and where studies reported separate findings for sub-samples of ethnic minorities.

This criterion was specified to increase the homogeneity across studies to increase the possibility of conducting a subsequent meta-analysis. In the context of this review, ethnic minority group was defined as 'individuals with a cultural heritage distinct from the majority population' (Manthorpe and Hettiaratchy, 1993).

### **The intervention**

The inclusion criteria was:

- Any intervention targeting the self-management of type 2 diabetes, through individual, group or community means.

### **The outcomes**

The inclusion criteria was:

- 'Effective self management' outcomes across a broad range of physiological indicators (e.g. HbA1c change, BMI) and self-reported measures (e.g. knowledge, attitude, behaviour).

Since any intervention targeting self-management was included, the effectiveness of self-management was understood to be measured in a variety of ways in the published literature depending on the focus and theoretical perspectives of each study. For the purpose of this review it was therefore decided not to be prescriptive in terms of the included outcomes. This approach ensured that outcomes not anticipated at the outset could be found and included.

### **The study design**

The inclusion criterion was:

- The need for a trial design.

This criterion was specified for the purposes of being able to assess consistency or equally, explain discrepancies amongst included studies, for example why an intervention was only effective in particular settings or among certain populations (Mulrow, 1994).

#### **3.2.4.2 'Views' strand: Inclusion criteria**

##### **The population**

As for interventions strand.

##### **The intervention**

The inclusion criterion was:

- Any study that addressed the patients' perspectives on self management of type 2 diabetes.

As the aim of the views strand of the review was to explore patients' perspectives on self-management of type 2 diabetes the Khan et al (2003) categorisation was adapted slightly as the strand did not include intervention studies. For this reason the criterion '*Interventions*' was replaced here with '*Health issue*.'

### **The outcomes**

The inclusion criterion was:

- Any outcome related to self-management.

The 'views' component potentially allowed for identifying the types of outcomes that are of value and not of value to patients. This aspect of the review in particular was anticipated to be potentially the most advantageous in informing practice since it elicited information on a multitude of issues concerned with self-management including, how patients perceive the information they receive, their support from health professionals, making health decisions etc. This, similar to the intervention strand, can be measured in an assortment of ways and it would not have been possible to develop an exhaustive list in advance of conducting the review.

### **The study design**

The inclusion criterion was:

- Any study that reported participants' views surrounding self-management, irrespective of study design.

#### **3.2.4.3 Interventions and 'views' strands: Exclusion criteria**

The exclusion criterion were:

- Studies not published in the English language.
- Studies published before 1982.

All research published in English was included without restriction placed on the country in which the research was undertaken. However, due to resource limitations (preventing translation) foreign language papers were excluded. Although it is possible that this may have excluded some relevant studies it was anticipated that most of the key literature was retrieved. It was clear from the studies retrieved from the search strategy that research on type 2 diabetes self-management in ethnic minority groups was predominantly from the USA.

An appropriate cut off date for excluding studies was considered to be those published before 1982. This decision was because, as identified by Bury et al (2005), this date corresponded with the first published study concerned with a ‘self-management’ intervention *per se* (Lorig et al, 1986). Detail on the importance of self-management to type 2 diabetes is provided in the literature review (see section 2.2.4).

### 3.2.5 Screening tool

The inclusion criteria informed the development of the screening tool (Figure 3.1). The screening tool was used to review the studies identified through searching the nine electronic databases. First titles were screened, then abstracts and then the full paper was read. 10% of the total studies (circa 1500) were quality assured by a supervisor (CJ) to ensure the screening tool was being applied consistently. All of the studies that were identified as included or excluded were verified by the supervisor.

Inclusion criteria	Tick if applicable
1. Published in the English language.	
2. Published 1982 onwards.	
3. POPULATION: Sample includes adults aged 18 or over and with a diagnosis of type 2 diabetes where: - 50% of whom are of a BME group. - data for the BME sub-sample are reported separately.	
4. HEALTH ISSUE: Study focus is type 2 diabetes.	
5. OUTCOMES: Relating to self-management.	
6. STUDY DESIGN: Intervention strand- Studies of a trial design that evaluate a self-management intervention and employ a control or comparison group.  ‘Views’ strand- Patient centred studies that examine self-management and report views.	

**Figure 3.1** Screening tool

### 3.2.6. Critical appraisal tools

Having identified studies that met the review’s inclusion criteria, the next step involved selecting or developing a critical appraisal tool. Employment of a critical appraisal tool enabled consistent and accurate data extraction and quality assessment of the included research papers thereby minimising bias in the interpretation of findings (Canberra, 2000.) The critical appraisal tool deconstructed the articles and

subsequently reconstructed it into standardised parts. These standardised parts facilitated synthesis.

Since there is no consensus regarding the most appropriate critical appraisal tool a decision was made after careful deliberation on the intent and properties of available tools. A key consideration when selecting a critical appraisal tool was that it accommodated the two strands contained in this systematic review. The intervention strand included studies with a trial design, while the 'views' strand included studies of qualitative and mixed method design. It seemed preferable for reasons of consistency to select a tool that could be applied to both of the review strands.

A large number of tools were available from which to make the choice. Katrak et al (2004) conducted a systematic review on the content of critical appraisal tools that address allied health care. They retrieved 121 different English language critical appraisal tools. From these 121 tools, 1475 items were extracted which were then grouped into 173 different items. 104 of these 121 critical appraisal tools were design specific i.e. focused on methodological issues unique to one research design. The remaining 16 were generic tools i.e. those that enabled synthesis from a range of quantitative and qualitative designs. Since the systematic review presented incorporates the assessment of a variety of study designs from RCTs to qualitative studies only the 16 generic critical appraisal tools that enabled synthesis from quantitative and qualitative designs were appropriate for use with this systematic review. This meant a careful selection from the suitable pool of 16 generic critical appraisal tools remained.

It was desired that the selected tool would incorporate both data extraction and quality assessment items, as opposed to having two different tools for each of these components. This brought the search to a template developed by Long and Godfrey (2002). The tool provided a series of questions that served to summarise the content of retrieved studies as well as determine design quality, methodological issues and quality of evidence.

The template developed by Long and Godfrey (2002) was slightly adapted for the purposes of this systematic review. For example, specific review questions regarding the additional health literacy dimension were added. Also, some of the

EPPI Centre's review guidelines for data extraction and quality assessment of intervention studies (1997) were adopted. This amalgamation of the two existing checklists plus the review specific questions formed the critical appraisal tools developed here (see Appendix 3.2).

Methodological quality was assessed according to accepted standards by appraising individual aspects of each study's: design; procedure; conduct; and analysis. All open questions allowed for comment and closed questions had a list of potential answers to select from- yes, no, unknown, and not applicable. By looking at the template of the tool (see Appendix 3.2) it is clear that the tool was composed of a mixture of data extraction (DE) and quality assessment (QA) items ordered in the way they would typically arise in a research article. Eventually these quality assessment scores were totalled and presented with the review results (see Table 4.50).

### 3.2.7 Synthesis of findings

The systematic review process included: two search strands - intervention and 'views'; and three syntheses - a narrative synthesis of the intervention strand, a thematic synthesis of the 'views' strand and a cross-synthesis. The three sub questions of the review were addressed by each of the syntheses (see Figure 3.2).

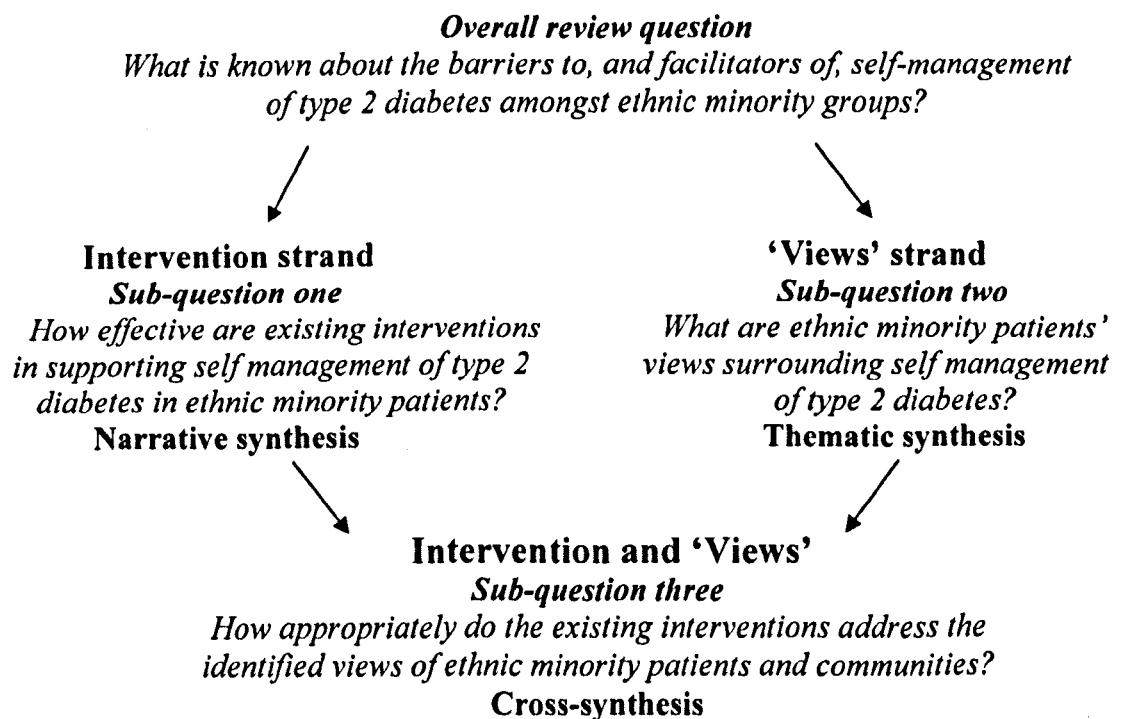


Figure 3.2 The systematic review process

### **3.2.7.1 Synthesis of the interventions strand**

The purpose of this strand was to draw together quantitative evidence on self-management interventions for type 2 diabetes in BME patients from existing trials. Due to the heterogeneity of the included intervention studies, regarding: study design; quality; population; setting; type of intervention; outcome measures and comparison groups it was thought unlikely that a formal quantitative meta-analysis would be appropriate. Instead, a narrative synthesis would be performed to address the effectiveness component of the review.

### **3.2.7.2 Synthesis of the 'views' strand**

The purpose of this strand was to gain an in-depth understanding of patients' experiences and perspectives of the barriers and facilitators to effective self management support for diabetes. It was anticipated that the included 'views' studies would be more heterogeneous than the intervention studies. 'Views' studies were expected to be of a range of study designs and have greater variance in their research questions. To overcome this, it was proposed that, since the review's overall review question was concerned with the barriers and facilitators of type 2 diabetes, key findings would be organised to answer the following questions:

- (i) What does the term 'self-management' mean to ethnic minority patients with type 2 diabetes?
- (ii) What helps and what prevents ethnic minority patients actively self-manage their condition?
- (iii) What ideas do ethnic minority patients themselves identify for what could or should be done to promote self-management of type 2 diabetes?

Using the above questions was expected to be a useful technique for organising a large and potentially varied dataset. These questions were kept broad so as to not direct the thematic synthesis. Detail is provided on how thematic synthesis was undertaken in sections 3.1.7.1 and 4.3.3. This was an additional step to the EPPI Centre's approach that had been developed specifically for this review.

### **3.2.7.3 Cross-Synthesis of the intervention and 'views' strand**

The purpose of the cross-synthesis was to enable an assessment of the appropriateness of available interventions by answering: (I) to what extent have interventions tackled type 2 diabetes self-management barriers identified by BME

patients and (II) to what extent have interventions built on type 2 diabetes self-management facilitators identified by BME patients? This involved looking across the syntheses of the intervention and the 'views' strands so as to deal with the third review question "How appropriately do the existing interventions address the identified views of ethnic minority patients and communities?"

Based on EPPI methodology (Thomas et al, 2003) three specific questions served to juxtapose the findings from 'views' studies against the findings of intervention studies, thereby guiding the cross-study synthesis. These were as follows:

- (i) Which interventions designed to support type 2 diabetes self-management in ethnic minority patients' match the recommendations derived from ethnic minority patients' views and experiences?
- (ii) Do those interventions which match patient' views show bigger effect sizes in their evaluations than those which do not?
- (iii) Which recommendations derived from participants' views have yet to be addressed by interventions?

The cross-synthesis was achieved in two steps. First, the analytical themes identified from the thematic synthesis of the 'views' strand data were individually considered in the context of the barriers and facilitators they posed for achieving effective type 2 diabetes self-management. By considering the barriers and facilitators to self-management for each of the analytical themes, potential implications for intervention development were proposed.

In the second step, outcomes of the synthesis of the 'views' strand were used to derive nine potential interventions for the design of interventions, these were reviewed alongside the outcome of the effectiveness synthesis. Since heterogeneity in the trials prevented a meta-analysis the outcome of the effectiveness synthesis was the eleven sub-sets of trials e.g. culturally competent versus not culturally competent (see section 4.2.5.1). Results on how the outcomes of the 'views' and intervention strands mapped onto one another in terms of matches and gaps were provided in narrative form.

In short, the cross-synthesis drew together all the studies in the review to provide evidence on what works, what may not work, what may be harmful and what requires more good quality evidence to make a decision.



## Chapter 4 Results

### 4.1 Introduction

This chapter presents the results of the systematic review. It will first present an overview of the study selection. Following this, results for the effectiveness synthesis of the intervention strand and the thematic synthesis of the 'views' strand will be presented. Finally, the results for the cross-synthesis of the two strands will be reported.

#### 4.1.1 Study selection

A total of 15,725 articles were identified which were then screened initially by title and then by abstract. From reading titles and abstracts it was clear whether papers, meeting the inclusion criteria, related to the 'views' or the intervention strand. A total of 137 studies met the inclusion criteria after title and abstract screen, these papers were read in full. Finally 28 intervention studies and 57 view studies were included. Figure 4.1 gives a break down of this study selection process.

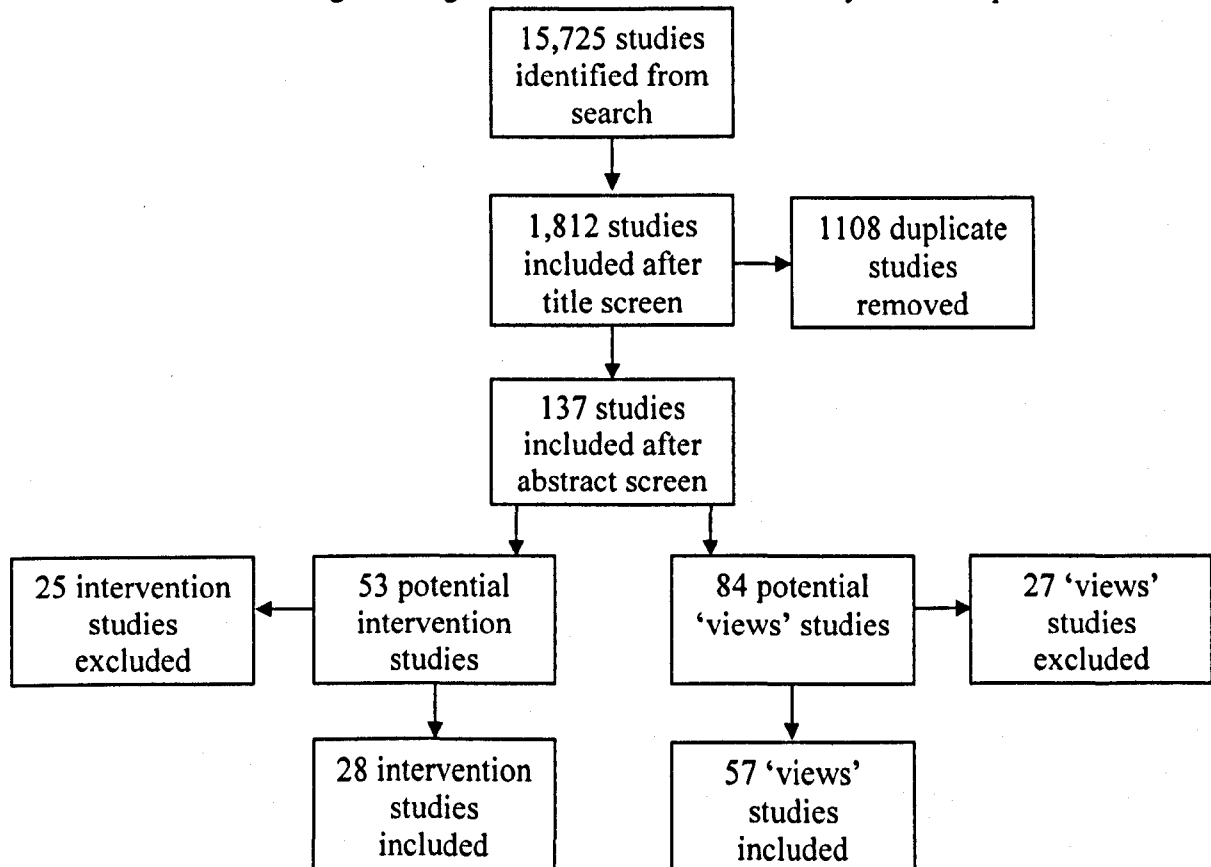


Figure 4.1 A flow chart of study selection

### 4.1.2 Included studies

Tables 4.1 and 4.2 provide the details of the 28 intervention and the 57 'views' studies that were included in the systematic review. Each study has been given an identification number which will be employed throughout the remainder of this thesis.

**Table 4.1** Author, date and title of included intervention studies and their related identity numbers

<b>Author</b>	<b>Date</b>	<b>Title</b>	<b>Id. No.</b>
AGURS-COLLINS	1997	A randomized controlled trial of weight reduction and exercise for diabetes management in older African-American subjects	1
ANDERSON	2005	Evaluating a problem-based empowerment program for African Americans with diabetes: results of a randomized controlled trial	2
ANDERSON-LOFTIN	2005	Soul food light: culturally competent diabetes education	3
BARADARAN	2006	A controlled trial of the effectiveness of a diabetes education programme in a multi-ethnic community in Glasgow	4
BORGES	2008	Improving foot self-care behaviors with Pies Sanos	5
BROWN	2002	Culturally competent diabetes self-management education for Mexican Americans: the Starr County Border Health Initiative	6
BROWN	2005	Dosage effects of diabetes self-management education for Mexican Americans: the Starr County Border Health Initiative	7
BROWN	2007	Health beliefs of Mexican Americans with type 2 diabetes: the Starr County Border Health Initiative	8
CLANCY	2007	Further evaluating the acceptability of group visits in an uninsured or inadequately insured patient population with uncontrolled type 2 diabetes	9
CLANCY	2007 b	Group visits: Promoting adherence to diabetes guidelines	10

GARY	2003	Randomized controlled trial of the effects of nurse case manager and community health worker interventions on risk factors for diabetes-related complications in urban African Americans	11
GREGG	2007	Improving Diabetes Self-Management Through Acceptance, Mindfulness, and Values: A Randomized Controlled Trial	12
GUCCIARDI	2007	Assessment of two culturally competent diabetes education methods: individual versus individual plus group education in Canadian Portuguese adults with type 2 diabetes	13
HAWTHORNE	1997	One-to-one teaching with pictures: Flashcard health education for British Asians with diabetes	14
HENDRICKS	2000	The effect of diabetes self-management education with frequent follow-up on the health outcomes of African American men	15
JABER	1996	Evaluation of a pharmaceutical care model on diabetes management	16
KEYSERLING	2002	A randomized trial of an intervention to improve self-care behaviors of African-American women with type 2 diabetes: impact of physical activity	17
LUJAN	2007	Promotora diabetes intervention for Mexican Americans	18
MAYER-DAVIS	2004	Pounds Off With Empowerment (POWER): a clinical trial of weight management strategies for black and white adults with diabetes who live in medically underserved rural communities	19
MIDDELKOOP	2001	Effectiveness of culture specific diabetes care for Surinam South Asian patients in the Hague	20
NOEL	1998	Patient choice in diabetes education curriculum - Nutritional versus standard content for type 2 diabetes	21
NOTHWEHR	2001	Sequencing diet and exercise programs for African American women with diabetes.	22

ROSAL	2005	Diabetes self-management among low-income Spanish-speaking patients: a pilot study	23
ROTHMAN	2005	A randomised trial of primary-care based disease management program to improve cardio-vascular risk factors and glycated hemoglobin levels in patients with diabetes	24
SKELLY	2005	Symptom-focused management for African American women with type 2 diabetes: a pilot study	25
VAZQUEZ	1998	Buena Alimentacion, Buena Salud: a preventive nutrition intervention in Caribbean Latinos with type 2 diabetes	26
VINCENT	2007	A feasibility study of a culturally tailored diabetes intervention for Mexican Americans	27
ZIEMER	2003	A simple meal plan emphasizing healthy food choices is as effective as an exchange-based meal plan for urban African Americans with type 2 diabetes	28

**Table 4.2** Author, date and title of included 'views' studies and their related identity numbers

Author	Date	Title	Id. No.
ADAMS	2003	Lessons learned from urban Latinas with type 2 diabetes mellitus	29
ALCOZER	2000	Secondary analysis of perceptions and meanings of type 2 diabetes among Mexican American women	30
ANDERSON	1998	Using focus groups to identify diabetes care and education issues for Latinos with diabetes	31
ANDERSON-LOFTIN	2000	Long-term disease management needs of southern African Americans with diabetes	32
BENAVIDES-VAELLO	2004	Using focus groups to plan and evaluate diabetes self-management interventions for Mexican Americans	33
BISSELL	2004	From compliance to concordance: barriers to	34

		accomplishing a re-framed model of health care interactions	
BROWN	2007	Health beliefs of African–Caribbean people with type 2 diabetes: a qualitative study	35
BURNS	2005	African American women with type 2 diabetes: meeting the daily challenges of self care	36
CAGLE	2002	Mid-life African-American women with type 2 diabetes: influence on work and the multicaregiver role	37
CARBONE	2007	Diabetes self-management: perspectives of Latino patients and their health care providers	38
CARTER-EDWARDS	2004	"They care but don't understand": family support of African American women with type 2 diabetes	39
CHERRINGTON	2006	Examining knowledge, attitudes, and beliefs about depression among Latino adults with type 2 diabetes	40
CHELSEA	2005	Accommodating type 2 diabetes in the Chinese American family	41
CULHANE-PERA	2007	"We are out of balance here": a Hmong cultural model of diabetes	42
DUTHIE-NURSE	1998	An anthropological study into the views on diet and disease of a sample of Hindu Gujarati-speaking women with type 2 diabetes	43
EGEDE	2003	Diabetes self-management in African Americans: an exploration of the role of fatalism	44
EL-KEBBI	1996	Identify barriers to dietary therapy among low-income individuals with non-insulin-dependent diabetes mellitus	45
FAGERLI	2007	Health worker style and trustworthiness as perceived by Pakistani–born persons with type 2 diabetes in Oslo, Norway	46
FAGERLI	2005	Experience of dietary advice among Pakistani-born persons with type 2 diabetes in Oslo	47
FEATHERS	2007	The Development, Implementation, and Process Evaluation of the REACH Detroit Partnership's	48

		Diabetes Lifestyle Intervention	
HADWIGER	2005	Acculturation and diabetes in a new Hispanic community	49
HAWTHORNE	1999	Pakistani moslems with Type 2 diabetes mellitus: effect of sex, literacy skills, known diabetic complications and place of care on diabetic knowledge, reported self-monitoring management and glycaemic control	50
HEUER	2006	Living with diabetes: perceptions of Hispanic migrant farmworkers	51
HILL-BRIGGS	2003	A qualitative study of problem solving and diabetes control in type 2 diabetes self-management	52
HO	2006	Cultural barriers to initiating insulin therapy in Chinese people with type 2 diabetes living in Canada	53
HUANG	2005	Self-reported goals of older patients with type 2 Diabetes Mellitus	54
HUNT	1997	NIDDM patients' fears and hopes about insulin therapy: the basis of patient reluctance	55
HUNT	1998 a	How patients adapt diabetes self-care recommendations in everyday life	56
HUNT	1998 b	Porque me tocoa a mi? Mexican Amerocan diabetes patients' causal stories and their relationship to treatment behaviours	57
HUNT	1998 c	Contrasting patient and practitioner perspectives in type 2 diabetes management	58
HUNT	2000	Herbs, Prayer, and Insulin Use of Medical and Alternative Treatments by a Group of Mexican American Diabetes Patients	59
JAYNE	2001	Application of Leventhal's self-regulation model to Chinese immigrants with type 2 diabetes	60
JEZEWSKI	2002	Mexican Americans' explanatory model of type 2 diabetes	61
KOKANOVIC	2006 a	Social support and self-management of type 2 diabetes among immigrant Australian women	62

KOKANOVIC	2006 b	Exploring doctor-patient communication in immigrant Australians with type 2 diabetes	63
LAWTON	2005	Perceptions and experiences of taking oral hypoglycaemic agents among people of Pakistani and Indian origin: a qualitative study	64
LAWTON	2006 a	Diabetes service provision: a qualitative study of the experiences and views of Pakistani and Indian patients with type 2 diabetes	65
LAWTON	2006 b	"I can't do any serious exercise": barriers to physical activity amongst people of Pakistani and Indian origin with type 2 diabetes	66
LIBURD	2004	Views from within and beyond: illness narratives of African-American men with type 2 diabetes	67
MACADEN	2006	Risk perception among older South Asian people in the UK with type 2 diabetes	68
MULL	2001	Vietnamese diabetic patients and their physicians: what ethnography can teach us	69
PARRY	1996	Use of folk treatments for diabetic plantar ulcers among African Americans with Type II diabetes	70
PHINNEY	2003	Recognizing and understanding the symptoms of type 2 diabetes	71
POLZER	2007	African Americans and diabetes: spiritual role of the health care provider in self-management	72
PONZO	2006	Gender, ethnocultural, and psychosocial barriers to diabetes self-management in Italian women and men with type 2 diabetes	73
QUATROMONI	1994	Use of focus groups to explore nutrition practices and health beliefs of urban Caribbean Latinos with diabetes	74
ROSAL	2004	Views and Preferences of Low-Literate Hispanics Regarding Diabetes Education: Results of Formative Research	75
SAMUEL-HODGE	2000	Influences on day-to-day self-management of type 2 diabetes among African-American women:	76

		spirituality, the multi-caregiver role, and other social context factors	
SANGHERA	2000	Deterrents to participation in diabetes education: perspectives of elderly Indo-Canadians	77
SCHOENBERG	2004	Complementary and alternative medicine use among a multiethnic sample of older adults with diabetes	78
SCOTT	1997	Culture, food, diet and diabetes: the West Indian perspective	79
STONE	2005	Empowering patients with diabetes: a qualitative primary care study focusing on South Asians in Leicester, UK	80
STONE	2006	Making education in diabetes culturally appropriate for patients	81
UTZ	2006	“Working hard with it”: self-management of type 2 diabetes by rural African Americans	82
VINCENT	2006	Using focus groups to develop a culturally competent diabetes self-management program for Mexican Americans	83
WALLIN	2007	Diabetes: a cross-cultural interview study of immigrants from Somalia	84
WENZEL	2005	"Plenty of sickness": descriptions by African Americans living in rural areas with type 2 diabetes	85

## 4.2. Interventions strand results

### 4.2.1. Summary of evidence base according to selection criteria

Twenty-eight studies, including a total of 5622 participants, met the inclusion criteria for the interventions strand of the systematic review.

Whilst only empirical studies of a trial “design” were included, the otherwise broad inclusion criteria were a source of heterogeneity among the retrieved trials. A detailed description of the characteristics of the interventions in the included trials is presented in Appendix 4.1. The “population” inclusion criterion included samples composed of any black and ethnic minority (BME) group. However, since North American research dominated (one Canadian and 24 USA studies) it was not



surprising that the most commonly researched populations were Afro-American (n=14) and Latino (n=9), with one USA trial including both. The Canadian trial studied a Portuguese population. The remaining three trials were all European and researched a South Asian population. Two of these trials were in the UK and one was in Holland.

No distinction was made on the type of “intervention” other than it must relate to type 2 diabetes self-management. Self-management has a broad definition in the context of type 2 diabetes, a complex and lifelong condition (see section 2.2.4). Seventeen trials were reportedly concerned with general self-management. Elsewhere, objectives relating to self-management differed between trials. Four trials were concerned with dietary behaviours, one was concerned with dietary behaviours alongside physical activity, while another investigated physical activity alone. Another trial looked at physical activity alongside weight management while one trial considered weight management alone. One trial researched foot care specifically; while another was concerned with blood glucose control; and another considered symptom focused management.

**Table 4.3** Trials tabulated according to number of participants, host country, BME group and self-management focus as reported in trial

<b>Trial Id No.</b>	<b>No. of participants randomised</b>	<b>Country</b>	<b>BME group</b>	<b>Self-management focus</b>
1	64	USA	African-American	Weight loss and physical activity
2	239	USA	African-American	Empowerment
3	97	USA	African-American	Dietary behaviours
4	145	Scotland	South Asian	General self-management
5	167	USA	Mexican-American	Foot care
6	256	USA	Mexican-American	General self-management
7	216	USA	Mexican-American	General self-management
8	216	USA	Mexican-American	General self-management
9	186	USA	African-American	Perceptions of care
10	186	USA	Black	General self-management
11	186	USA	African-American	Improve general control and reduce risk of complications

12	81	USA	African-American, Hispanic, Pacific-Islander and Arab	General self-management
13	61	Canada	Portuguese	General self-management
14	201	England	South Asian	General self-management
15	30	USA	African-American men	General self-management
16	45	USA	African-American	General self-management
17	200	USA	African-American men	Physical activity
18	150	USA	Mexican-American	General self-management
19	152	USA	Black	Weight management
20	113	Holland	South Asian	General self-management
21	596	USA	Hispanic	Nutrition
22	23	USA	African-American women	Diet and physical activity
23	25	USA	Hispanics	General self-management
24	217	USA	African-American	Improve risk factors
25	41	USA	African-American women	Symptom focused management
26	38	USA	Caribbean-Latinos	Nutrition
27	17	USA	Mexican-American	General self-management
28	648	USA	African-American	Dietary behaviours

#### 4.2.2 Multiple outcome measures reported

As can be seen in Table 4.3, trials reported effects on various outcome measures related to aspects of type 2 diabetes self-management. Since only four trials were single component (11, 12, 14, 28) and the vast majority were multi-component (n=24) where more than one constituent of the intervention was delivered at the same time (e.g. a peer support programme nested within an educational class) there was the additional challenge of trials reporting on multiple outcomes (see Table 4.4). A decision was made to only analyse the trials according to their primary outcome measure, so as to reduce the 'noise' and enable any effect to be seen. Primary outcomes were separated according to whether they related to attitude, behaviour, knowledge or physiological measures. No trials assessed cost-

effectiveness so this was not used as an outcome measure. A useful conclusion of the review is that health economic evaluations are needed in this area.

**Table 4.4** Trials tabulated according to all outcome measures that they reported effects on

	<b>Attitudinal measures</b>	<b>Behavioural measures</b>	<b>Knowledge measures</b>	<b>Physiological measures</b>
	2 4 5 6 8 9 12 13 15 17 18 23 25 27	1 3 4 5 11 12 13 14 15 16 17 21 22 23 25 26 27 28	1 2 4 5 6 7 12 14 15 17 18 21 23 25 27	1 2 3 6 7 8 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 27 28
<b>Total</b>	<b>14</b>	<b>18</b>	<b>15</b>	<b>24</b>

Where the focus of a trial was clearly on one outcome then this was a straightforward selection as the primary outcome. When two outcome measures were listed together in the abstract, suggesting them to be of equal weighting, the one listed first was selected as primary. In cases where the trials reported effects on three or four outcome measures and the author(s) did not explicitly stipulate one primary outcome measure, a judgement was made according to how the study aim had been reported. After this exercise each trial's reporting on only one designated primary outcomes was considered in all further analyses. Physiological measures were the most commonly reported primary outcome measure (see Table 4.5.)

**Table 4.5** Trials tabulated according to all primary outcome measures and control or comparison group

	<b>'Usual care' control</b>	<b>Comparison group</b>
<b>Physiological measures</b>	1 2 3 6 10 11 16 19 20 23 24 25 28	7 12 15 18
<b>Attitudinal measures</b>	9 27	8
<b>Behavioural measures</b>	5 17 26	13 21 22
<b>Knowledge measures</b>	4 14	

#### 4.2.3 Multiple measures reported per primary outcome

Having selected a designated primary outcome for each trial, the next issue to consider was how best to select a single measure for that outcome. Researchers frequently reported effects on multiple measures for the primary outcome and the

need to select only one measure for analyses needed to be considered. With physiological measures this was relatively straightforward as all trials reported HbA1c which is recognised as the 'gold standard' measure for long-term measure of blood glucose (NICE, 2002). There were two cases (1, 19) when HbA1c was not the most appropriate measure since the focus of the trial was specifically on weight management (see Table 4.3). In these cases weight was selected as the primary outcome measure.

'Knowledge' was straightforward since both trials (4, 14) that included it assessed it by questionnaire. 'Attitude' was assessed by three trials 8, 9 and 27. Trial 8 assessed attitudes using an instrument with six sub-scales reported separately, one of which was control of diabetes. Trial 27 only assessed self-efficacy whereas Trial 9 evaluated patients' sense of control, patients' perception of doctor and patients' satisfaction in under served communities. Since sense of control was the measure common to all three trials albeit assessed differently, it was adopted in all secondary analyses.

This process was more difficult with the 'behaviour' outcomes where there were six trials. Here, trials 13 and 26 each assessed behaviour using only one measure. Trial 26 assessed nutrient intake through fat and calories consumed while trial 13 measured adherence to nutrition management using a validated questionnaire. Therefore, regardless of what measures the other four trials used, no common measure could be employed here in the same way as had been done with attitudinal outcomes. Instead, it was decided that the best way to organise the behavioural measures was to individually select the measure that best reflected each trial's research objective in assessing effectiveness of the intervention. Whilst remaining mindful that different behavioural measures were being included, they were considered comparable for review purposes.

#### **4.2.4 Sub-sets of trials**

In addition to the broad selection criteria and diversity in reported primary outcomes, there were other important sources of heterogeneity and these are detailed later in section 4.2.6. All of these differences between the trials meant that meta-analysis was not appropriate. Therefore different styles of analyses were considered.

For the purpose of analysing the review's findings the interventions themselves were classified into suitable sub-sets. These sub-sets had not been decided *a priori*, rather the process by which they were arrived at was an iterative one. From having critically appraised the 28 included trials the researcher became familiar with their characteristics and after some deliberation was able to select what were considered to be the most appropriate groupings based on the intervention's focus and method of delivery.

The sub-sets were assessed in a number of ways, while some involved reviewers' interpretation, e.g. didactic versus instructive, others were defined as they were reported in the trial, e.g. culturally competent versus not culturally competent. Definition of each sub-set is presented along with its results, later in the chapter. Trials of self-management interventions were classified according to eleven sub-sets, these were as follows:

- Culturally competent versus not culturally competent
- Intervention based on theoretical framework versus not
- Educational versus educational and practical
- Interventions delivered to individuals, groups or both
- Care setting
- Length of intervention
- Delivered by health professional(s) versus other
- Single self-management behaviour versus multiple self-management behaviours
- Didactic versus interactive versus both
- Lifestyle versus general self-management versus health service use versus single self-management behaviour
- BME group

The final six sub-sets were classified differently to the first five because limited evidence prevented a reliable conclusion in these cases.

#### **4.2.5 Graphical presentation of results**

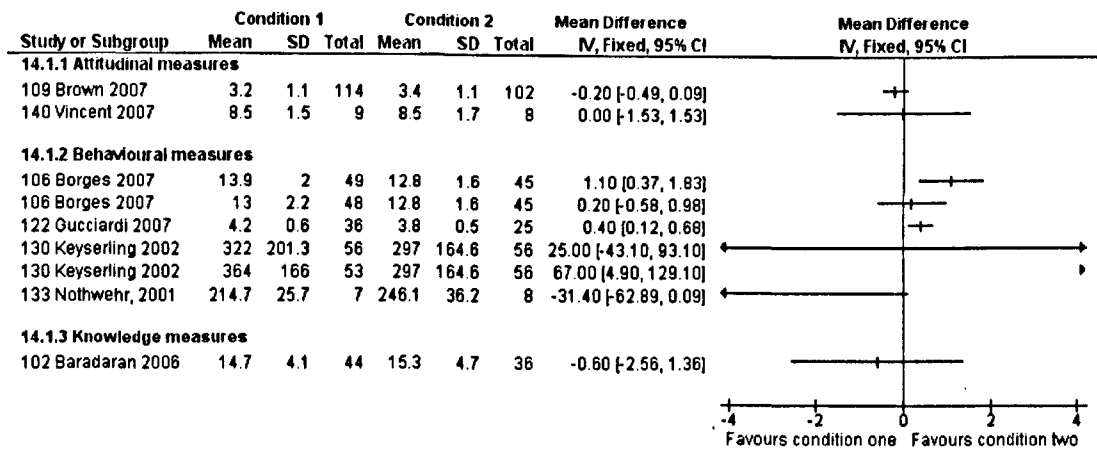
It was thought that a graphical presentation of the results would help illustrate this large and complex dataset and thereby help recognise patterns in the data (or their absence, if none were there). Revman 5.0 (2008) was employed to produce

Forest plots, using mean difference scores between study groups. Forest plots illustrate trial data, with a point and horizontal line corresponding to each trial. The width of each line represents the estimated 95% confidence intervals around the mean. A vertical line represents the line of no effect i.e. that associated with a relative risk of 0. Trials that employed comparison groups rather than usual care controls were not directly comparable and as such were not mapped onto the same forest plots. For detail on this see section 4.2.6.1.

Seven trials could not be plotted because there was limited reporting of information that prevented secondary analyses. For detail on this see section 4.2.6.4. In these cases, the probability values (p-values) reported in the trials were combined in the narrative analysis although the evidence had less weighting due to the limitations of p-values (see section 4.2.6.4). Related to this, there was deliberation over whether different arms of a three or four-arm intervention using the same control group would be presented on one forest plot. Ultimately this was allowed since a meta-analysis was not being conducted.

As can be seen from Table 4.5, there were a total of eleven trials that reported on attitudinal, behavioural or knowledge measures as their primary outcomes. Of these only seven trials had the necessary information for the calculation of effect size and the subsequent graphical presentation. For detail on missing information (see section 4.2.6.4). It was therefore decided to present these seven trials only once for references purposes in the figure below since they do little to illustrate the findings. For the eleven sub-sets of trials (listed in the previous section) graphical presentation of results will only be provided for the physiological measures outcome. The comparisons are reported narratively for the attitudinal, behavioural and knowledge measures.

The results for the eleven sub-sets of trials will now be presented. For each sub-set the findings will be presented separately for physiological measures, attitudinal measures, behavioural measures and knowledge measures. For each outcome measure the trials with 'usual care' controls and trials with comparison groups are presented in turn.



**Figure 4.2** The effects on attitudinal, behavioural and knowledge outcomes of type 2 diabetes self-management interventions

#### 4.2.5.1 Culturally competent versus not culturally competent

This sub-set refers to interventions where researchers made explicit mention of understanding, communicating and interacting effectively with BME participants due to an awareness of their different cultural practices and health beliefs.

#### Physiological measures

	'Usual care' control	Comparison group
Culturally competent	1 2 3* 6 11** 16 18 20 23 25*	7
Not culturally competent	10 19* 24	12 15 28

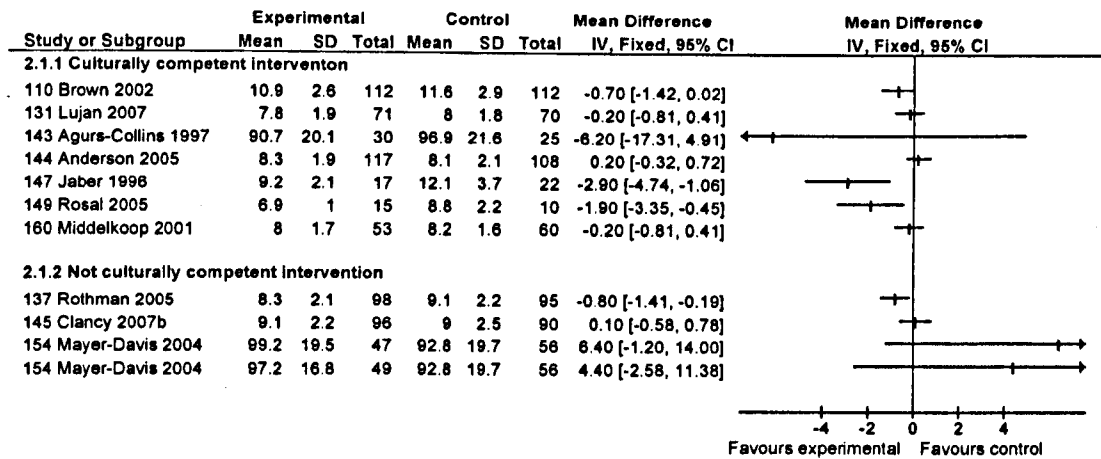
\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.6** Trials testing culturally competent and not culturally competent interventions, tabulated according to physiological outcome measures

#### Physiological measures ('usual care' control groups)

Two out of seven culturally competent interventions had an effect (16, 23) while one out of four of the non-culturally competent interventions showed a positive effect (24). The two culturally competent interventions that do report a positive effect are further away from the line of no effect than the non-culturally competent intervention that showed an effect. A conclusion, within the context of the small number of trials, may be that culturally competent interventions are more likely to show a positive effect than interventions that are not culturally competent.



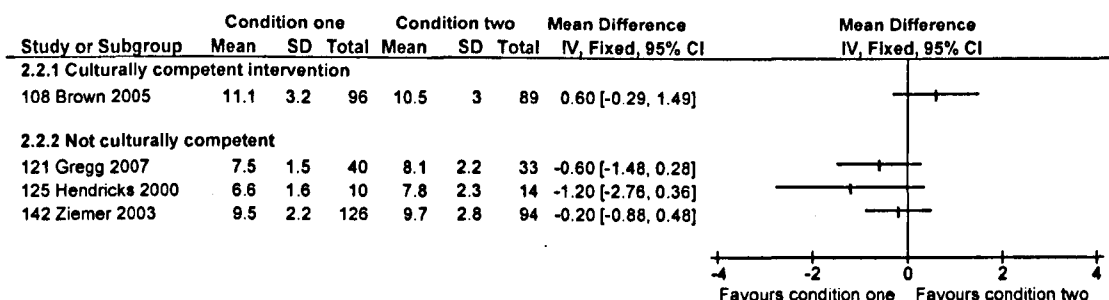
**Figure 4.3** The effects on physiological outcomes of culturally competent and not culturally competent interventions (with usual care control)

Trials 3, 11 and 25 were also culturally competent and reported effects on HbA1c as the primary outcome but did not provide the necessary information for inclusion in the graph. The intervention’s effectiveness was reported in the trials using p-values, limitations of which are discussed in section 4.2.6.4. As a result of their limitations, although p-values are reported here, their evidence was downgraded. Anderson-Loftin et al (2005) reported the findings of trial 3 as not significant; they had conducted a sample size calculation and had included 97 participants meeting the criteria showing their analyses to be sufficiently powered. Gary et al (2004) reported trial 11 as not-significant; although they had included 186 participants they did not report conducting a sample size calculation. Finally, Skelly et al (2005) of trial 25 reported significant findings; they had conducted a sample size calculation and by including the required 47 participants they achieved it. These findings do little to change the conclusion made earlier.

### Physiological measures (comparison groups)

The four trials in this category were neither directly comparable with one another nor with the trials that employed ‘usual care’ controls. They are on the same forest plot only for ease of presentation and commentary. This information will not be repeated in the remaining trial sub-sets, although it is true for all. Details about the characteristics of interventions tested in the trials can be found in Appendix 4.1. None of these four interventions showed a positive effect.





**Figure 4.4** The effects on physiological outcomes of culturally competent and not culturally competent interventions (with different comparison groups)

**Attitudinal measures**

	'Usual care' control	Comparison group
Culturally competent	27	8
Not culturally competent	9*	-

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.7** Trials testing culturally competent and not culturally competent interventions, tabulated according to attitudinal outcome measures

**Attitudinal measures ('usual care' control groups)**

There was only one trial (27) in this category that had the necessary information to calculate effect size. It delivered a culturally competent intervention and did not find a positive effect.

There was also only one trial (9) in this category that was not culturally competent but it lacked the necessary data to calculate effect size. This trial had 186 participants and while a sample size calculation was not undertaken, a significant p-value was reported.

**Attitudinal measures (comparison groups)**

There was only one trial (8) in this category, it tested a culturally competent intervention and showed there was no difference in the effects of culturally competent interventions and those that were not culturally competent. Trial 8 compared two versions of the same educational intervention, where one was compressed (condition one) and the other extended (condition two).

The findings for attitudinal measures were inconclusive because there were so few trials reporting on it as their primary outcome and moreover, none were directly comparable. This was true for all ten of the trial sub-sets.

**Behavioural measures**

	'Usual care' control	Comparison group
Culturally competent	17* 26*	13 21* 22
Not culturally competent	5*	-

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.8** Trials testing culturally competent and not culturally competent interventions, tabulated according to behavioural outcome measures

**Behavioural measures ('usual care' control groups)**

Both of the trials 5 and 17 had three arms with interventions. One of the interventions in trial 17 (the 'culturally competent intervention') showed a positive effect and one of the interventions in trial 5 (the 'not culturally competent intervention') showed a positive effect. While 17 was further from the line of no effect, 5 had a far smaller confidence interval. Confidence intervals are used to indicate the reliability of an estimate. Calculating confidence intervals requires making assumptions about the nature of the estimation process including whether the population of scores from which the sample came was normally distributed. Trial 26 tested a culturally competent intervention but authors did not provide the necessary information to calculate effect size. While trial 26 had a small sample (n=38 participants) and did not report a sample size calculation, it reported a significant p-value between the groups. Since the evidence from trial 26 was downgraded because of the previously detailed limitations of p-values, nothing conclusive can be said about the effect of an intervention's cultural competence on behavioural outcome measures.

**Behavioural measures (comparison groups)**

There were three trials in this category all of which tested culturally competent interventions. Trial 13 compared condition one (counselling in conjunction with group education) with condition two (type 2 diabetes education counselling only),

there was a positive effect for the first condition. Trial 22 compared two programmes presenting exercise and diet in a different sequence. Condition one received the diet component first while condition two received the exercise component first. There was no statistical difference between the two conditions. Trial 21 could not be used in secondary analyses because some data were missing but the authors reported the results to be statistically non-significant.

The findings for behavioural measures were inconclusive because again, there were so few studies that were directly comparable. As with attitudinal measures, this was true for all ten of the trial sub-sets.

### Knowledge measures

	'Usual care' control	Comparison group
Culturally competent	4 14*	-
Not culturally competent	-	-

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.9** Trials testing culturally competent and not culturally competent interventions, tabulated according to knowledge outcome measures

#### Knowledge measures ('usual care' control groups)

As there were only two trials in this category both of which tested culturally competent interventions, no reliable conclusions can be made. Trial 4 showed there to be no difference in the effects of culturally competent interventions and not culturally competent interventions. Trial 14 similarly reported no significant effect and it did not provide the necessary information to calculate effect size.

The findings for knowledge measures were inconclusive because again, there were so few studies. As with attitudinal and behavioural measures, this was true for all ten of the trial sub-sets.

#### 4.2.5.2 Intervention based on theoretical framework versus not

This sub-set refers to interventions where researchers made explicit mention of employing (or not) any theoretical framework in the developmental process. However, since there were so many different theories included in the review,

conclusive statements about any one theory were impossible to make. Theoretical frameworks were wide ranging and included: social cognitive theory; prece-de-proceed model; acceptance and commitment therapy; theory of planned behaviour; behaviour change theory; theory of community empowerment; self-efficacy; conceptual model of symptom focused management; long-term condition self-management model; motivational interviewing; social action theory; pharmaceutical care model; cognitive behavioural framework and social learning theory.

**Physiological measures**

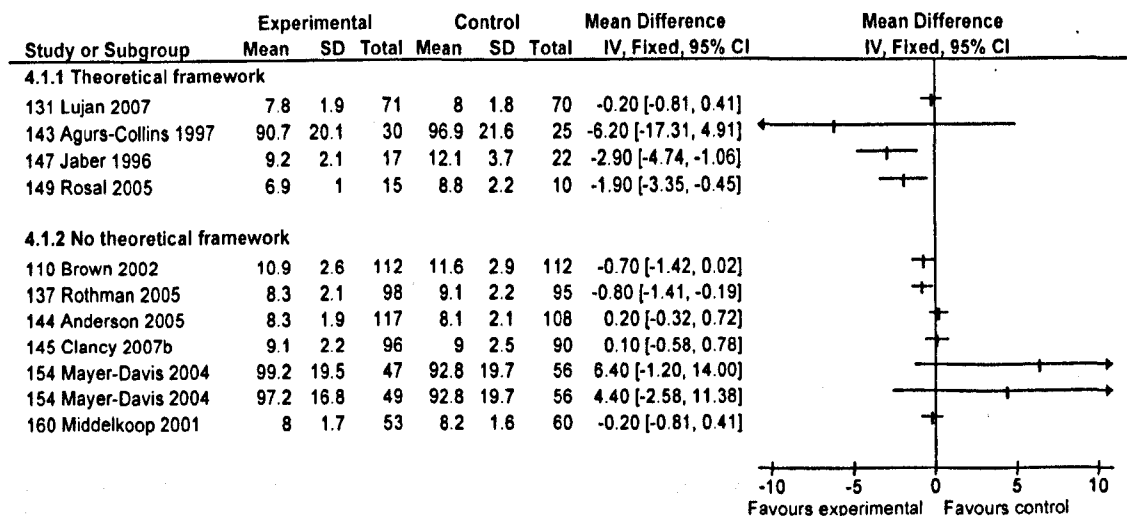
	'Usual care' control	Comparison group
Theoretical framework	1 11** 16 18 23 25*	12
No theoretical framework	2 3* 6 10 19* 20 24	7 15 28

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.10** Trials testing interventions with a theoretical framework and with no theoretical framework, tabulated according to physiological outcome measures

**Physiological measures ('usual care' control groups)**



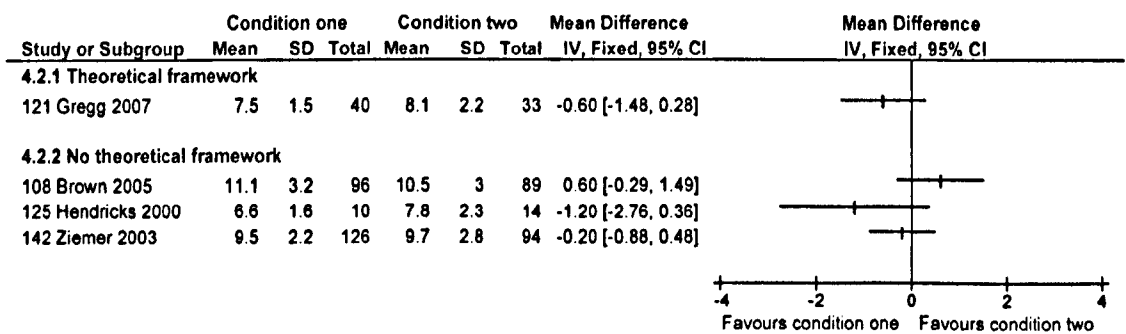
**Figure 4.5** The effects on physiological outcomes of interventions with a theoretical framework and without a theoretical framework (usual care control)

It appears that interventions that were developed using a theoretical framework were more likely to be effective than those that were not. Two of four interventions developed with a theoretical framework had an effect (16, 23). Whereas only one of

the six interventions developed without a theoretical framework had an effect (24). It can be concluded therefore that interventions based on a theoretical framework were more likely to show an effect than interventions that were developed without a theoretical framework.

Interventions tested in trials 11 and 25 were also developed using theoretical frameworks but did not provide the necessary information for the calculations of effect size. The effectiveness was reported in the trials using p-values. Gary et al (2004) reported trial 11 as not-significant; although they had included 186 participants they did not report conducting a sample size calculation. Finally, Skelly et al (2005) of trial 25 reported significant findings; they had conducted a sample size calculation and by including the 47 participants they achieved it. Trial 3 was developed without using any theoretical framework. It lacked the necessary information to undertake calculations of effect size. Anderson-Loftin et al (2005) reported the findings of trial 3 as not significant; they had conducted a sample size calculation and had included 97 participants meeting the criteria showing their analyses to be sufficiently powered. The findings of these three trials do little to change the earlier conclusion.

### Physiological measures (comparison groups)



**Figure 4.6** The effects on physiological outcomes of interventions with a theoretical framework and without a theoretical framework (different comparison groups)

None of the four trials in this category showed a positive effect.

**Attitudinal measures**

	'Usual care' control	Comparison group
Theoretical framework	27	-
No theoretical framework	9*	8

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.11** Trials testing interventions with a theoretical framework and with no theoretical framework, tabulated according to attitudinal outcome measures

**Attitudinal measures ('usual care' control groups)**

There was only one trial in this category (27) that had the necessary information to calculate effect size. Its intervention was based on a theoretical framework and it did not find a positive effect. The other trial (9) in this category had no theoretical framework and lacked the necessary data to calculate effect size. Trial 9 had 186 participants and while a sample size calculation was not undertaken, a significant effect had been reported.

**Attitudinal measures (comparison groups)**

There was only one trial in this category, its intervention was not based on a theoretical framework and it showed no positive effect.

**Behavioural measures**

	'Usual care' control	Comparison group
Theoretical framework	5* 17* 26*	13 22
No theoretical framework	-	21*

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.12** Trials testing interventions with a 'theoretical framework' and with 'no theoretical framework', tabulated according to behavioural outcome measures

**Behavioural measures ('usual care' control groups)**

The two three-arm trials (5, 17) were both developed with a theoretical framework. One of each trial's arms showed a positive effect. The figures required

for secondary analyses were unavailable for trial 26 which was also based on a theoretical framework. However despite a small sample (n=38 participants) and no reported sample size calculation undertaken, the trial did report a statistically significant effect. These findings go some way to suggesting that having a theoretical framework improves the likelihood of an intervention having a positive effect of behavioural outcome measures.

**Behavioural measures (comparison groups)**

There were three trials in this category. Two developed their interventions using a theoretical framework. While trial 13 reported a positive effect, trial 22 did not. Trial 21 was not developed with a theoretical framework, nor could it be used in secondary analyses because some data were missing. The study authors reported non-significant p-values. The findings for behavioural measures suggest support for the effectiveness of interventions based on theoretical frameworks. This was a tentative conclusion however, due to the small number of trials.

**Knowledge measures**

	'Usual care' control	Comparison group
Theoretical framework	-	-
No theoretical framework	4 14*	-

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.13** Trials testing interventions with a theoretical framework and with no theoretical framework, tabulated according to knowledge outcome measures

**Knowledge measures ('usual care' control groups)**

There were only two trials in this category. Both trials were testing interventions developed without a theoretical framework and neither showed a positive effect.

**4.2.5.3 Educational versus educational and practical**

All interventions reported in this section were educational, providing factual or technical information about diabetes self-management in a variety of ways. Some interventions delivered additional practical elements, for example a cooking

demonstration, or real life examples such as food label reading. Here especially, interventions with comparison groups serve to illuminate whether method of delivery; amount of follow-up and patient choice influence the effectiveness of educational interventions.

**Physiological measures**

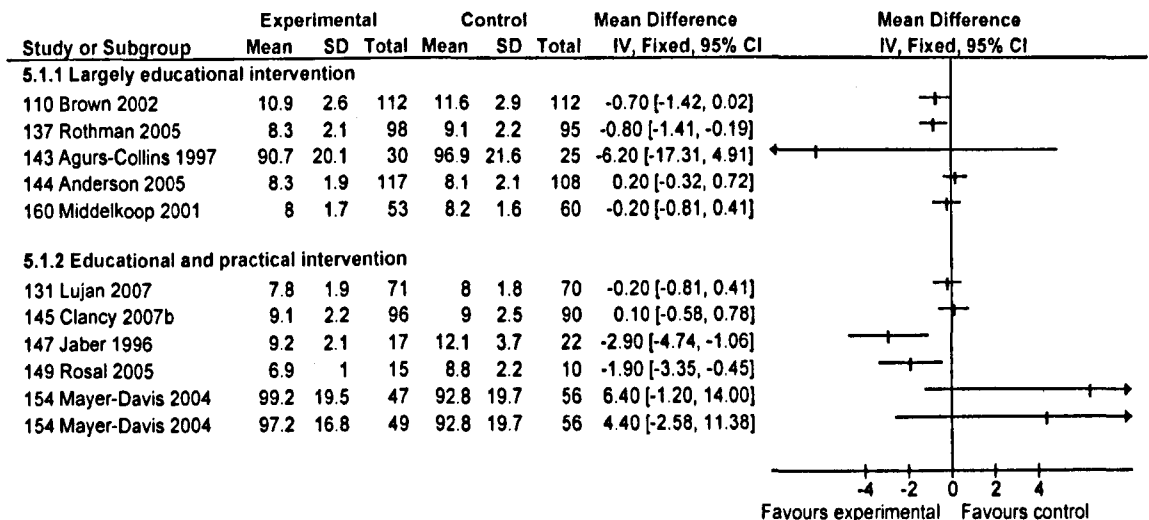
	'Usual care' control	Comparison group
Educational	1 2 6 11** 20 24	7 15
Educational and practical	3* 10 16 18 19* 23 25*	12 28

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.14** Trials testing educational and combined educational and practical interventions, tabulated according to physiological outcome measures

**Physiological measures ('usual care' control groups)**



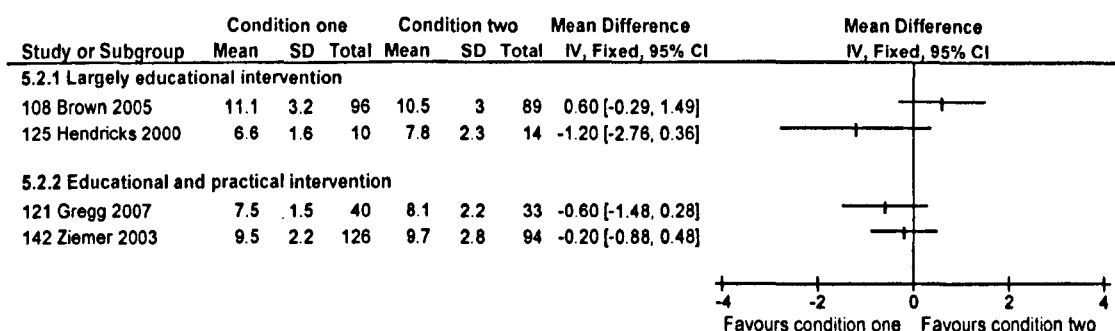
**Figure 4.7** The effects on physiological outcomes of educational and combined educational and practical interventions (usual care control)

One of the five trials (24) testing educational interventions had a positive effect as can be seen in Figure 4.7. Whereas, two of the five trials (16, 23) testing interventions with both educational and practical components had a positive effect. A conclusion, which must be tentative because of the small number of trials, was that trials with both educational and practical components were more likely to show an effect favouring the intervention than trials that were testing educational interventions alone.



Trials 11 tested an educational intervention alone but did not provide the necessary information for the calculations of effect size. The effectiveness was reported in the trials using p-values. Gary et al (2004) reported trial 11 as statistically not-significant; although they had included 186 participants they did not report conducting a sample size calculation. Trials 3 and 25 tested interventions with both an educational and practical component, they too did not provide the information required for secondary analyses. Anderson-Loftin et al (2005) reported the finding of trial 3 as not significant; they had conducted a sample size calculation and had included 97 participants meeting the criteria showing their analyses to be sufficiently powered. Skelly et al (2005) of trial 25 reported significant findings; they had conducted a sample size calculation and by including the 47 participants they achieved it. These findings support the tentative conclusion made earlier.

### Physiological measures (comparison groups)



**Figure 4.8** The effects on physiological outcomes of educational and; educational and practical interventions (different comparison groups)

None of the four trials in this category showed a positive effect.

### Attitudinal measures

	'Usual care' control	Comparison group
Educational	9*	8
Educational and practical	27	-

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.15** Trials testing educational and combined educational and practical interventions, tabulated according to attitudinal outcome measures

### **Attitudinal measures ('usual care' control groups)**

There was only one trial in this category (27) that had the necessary information to calculate effect size. Its intervention included educational and practical components and it did not find a positive effect. The trial 9 in this category tested an educational intervention. It lacked the necessary data to calculate effect size but a significant effect had been reported in the paper favouring the intervention. However, trial 9 did not report a sample size calculation.

### **Attitudinal measures (comparison groups)**

There was only one trial in this category, it tested an educational intervention and showed no positive effect.

### **Behavioural measures**

	'Usual care' control	Comparison group
Educational	-	13 21*
Educational and practical	5* 17* 26*	22

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.16** Trials testing educational and combined educational and practical interventions, tabulated according to behavioural outcome measures

### **Behavioural measures ('usual care' control groups)**

There were three trials in this category, all of which investigated educational and practical interventions. Two of these trials (5, 17) were three arm interventions. One of the arms for both trials showed a positive effect. Trial 26 did not have the necessary information to calculate effect size, while it had a small sample (n=38 participants) and did not report a sample size calculation it too reported a significant effect. Although the evidence from 26 was downgraded because of the previously detailed limitations of p-values, these findings suggested that an intervention with educational and practical components improved the likelihood of an intervention having a positive effect on behavioural outcome measures.

### **Behavioural measures (comparison groups)**

There were three trials in this category. Trial 13 tested an educational intervention by comparing condition one, which was counselling in conjunction with group education with condition two which was type 2 diabetes education counselling only. The first condition had a positive effect. Trial 21 also assessed an intervention that was educational but it could not be used in secondary analyses because some data were missing; the authors reported the differences between the groups to be non-significant.

Trial 22 assessed an intervention with educational and practical components. It compared two programmes presenting exercise and diet in a different sequence. Patients in group one received the diet component first while those in group two received the exercise component first. There was no statistical difference between the two groups.

The findings for behavioural measures were inconclusive because so few studies can be compared.

### **Knowledge measures**

	'Usual care' control	Comparison group
Educational	4 14*	-
Educational and practical	-	-

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.17** Trials testing educational and combined educational and practical interventions, tabulated according to knowledge outcome measures

### **Knowledge measures ('usual care' control groups)**

As there were only two trials in this category, both tested educational interventions and neither showed a positive effect, no conclusions can be made.

#### 4.2.5.4 Interventions delivered to individuals, groups or both

This sub-set refers to interventions that were delivered on a one-to-one basis or those that were intended for a wider audience or interventions that employed both components.

#### Physiological measures

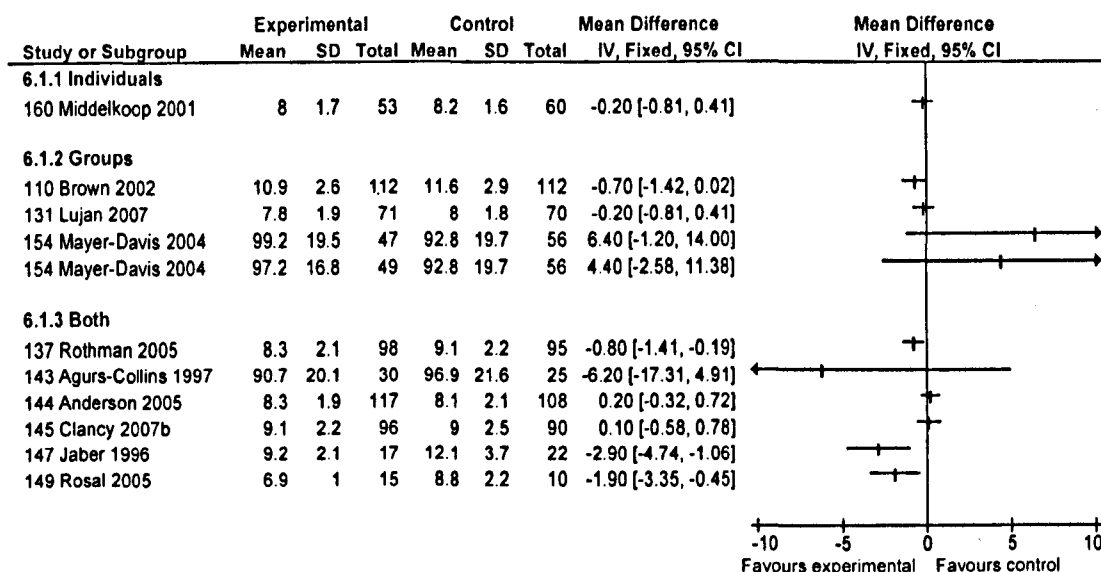
	'Usual care' control	Comparison group
Individuals	11** 20 25*	28
Groups	3* 6 18 19*	7 12 15
Both	1 2 10 16 23 24	-

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.18** Trials testing interventions delivered to individuals, groups and to both individuals and groups, tabulated according to physiological outcome measures.

#### Physiological measures ('usual care' control groups)



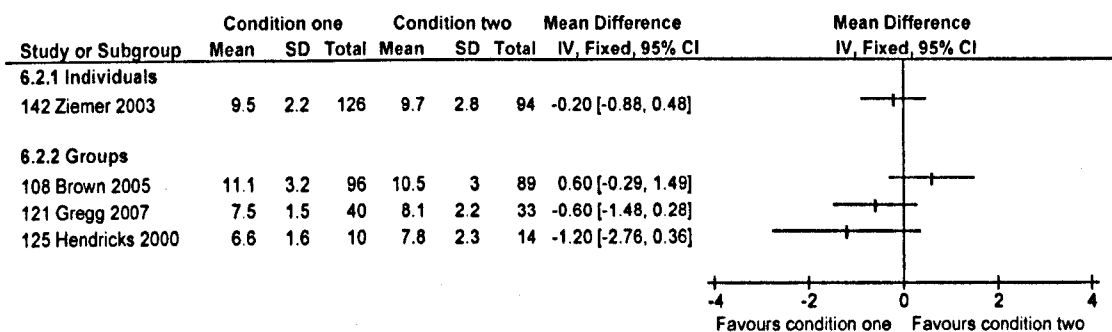
**Figure 4.9** The effects on physiological outcomes of interventions delivered to individuals and to groups and to both (with usual care control)

Figure 4.9 shows one intervention (20) was delivered to individuals and it showed no positive effect. Three interventions were delivered to groups (6, 18 19), none of which showed a positive effect. Six interventions were delivered to both individuals and groups and three of these were effective (16, 23, 24). A conclusion,

which must be tentative because of the small number of trials was that interventions delivered to both individuals and groups were more likely to show an effect than interventions delivered to groups alone. Since there was only one intervention in this category delivered to individuals however, this limited confidence in the conclusion.

Two more interventions were delivered to individuals but these did not provide the necessary information for the calculations of effect size (11, 25). The effectiveness of both interventions were reported within the trials using p-values. Gary et al (2004) reported trial 11 as not-significant; although they had included 186 participants they did not report conducting a sample size calculation. Skelly et al (2005) of trial 25 reported significant findings; they had conducted a sample size calculation and by recruiting the 47 participants they achieved it. Trials 3 did not provide the information required for secondary analyses and the trial's findings were reported as not statistically significant; they had conducted a sample size calculation and had included 97 participants meeting the criteria showing their analyses to be sufficiently powered. These findings do not affect the earlier tentative conclusion.

**Physiological measures (comparison groups)**



**Figure 4.10** The effects on physiological outcomes of interventions delivered to individuals and to both, individuals and groups (with different comparison groups)

None of the four trials in this category showed a positive effect.

### Attitudinal measures

	'Usual care' control	Comparison group
Individuals	-	-
Groups	27	8
Both	9*	-

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.19** Trials testing interventions delivered to individuals, groups and to both individuals and groups, tabulated according to attitudinal outcome measures

#### Attitudinal measures ('usual care' control groups)

There was only one intervention in this category (trial 27) that had the necessary information to calculate effect size and it showed no difference between the groups. The intervention in this category (trial 9) was delivered with both a group and an individual component. It lacked the necessary data to calculate effect size. Trial 9 had 186 participants and while a sample size calculation had not been undertaken, a statistically significant effect had been reported in the study.

#### Attitudinal measures (comparison groups)

There was only one intervention in this category (trial 8), it was delivered to groups and showed no positive effect.

### Behavioural measures

	'Usual care' control	Comparison group
Individuals	5*	-
Groups	26*	21* 22
Both	17*	13

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.20** Trials testing interventions delivered to individuals, groups and to both individuals and groups, tabulated according to behavioural outcome measures

### Behavioural measures ('usual care' control groups)

The intervention delivered to individuals (5) and the intervention delivered to both individuals and groups (17) had three arms. One of the arms from each intervention showed a positive effect. The intervention delivered only to groups (trial 26) did not have the necessary information to calculate effect size. Trial 26 had a small sample (n=38 participants) and while there was no reported sample size calculation it reported a significant effect. The evidence from trial 26 was downgraded because of the previously detailed limitations of reported p-values. As a result nothing conclusive can be said about a trial's effect on behavioural outcome measures depending on whether it was delivered to individuals, groups or both.

### Behavioural measures (comparison groups)

There were three trials in this category. Trial 22 compared two programmes presenting exercise and diet in a different sequence to groups, there was no statistical difference between the two groups. For one of the interventions that was delivered to groups (trial 21) missing data prevented there being any secondary analyses. The authors reported the results to be non-significant in the trial.

The intervention in trial 13 was delivered to both individuals and groups. It compared condition one (counselling in conjunction with group education) with condition two (type 2 diabetes education counselling only). Secondary analyses provided support for the first condition, which involved both individual and group elements. As with attitudinal measures, the findings for behavioural measures were inconclusive because there were so few studies that were directly comparable.

### Knowledge measures

	'Usual care' control	Comparison group
Individuals	14*	-
Groups	4	-
Both	-	-

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.21** Trials testing interventions delivered to individuals, groups and to both individuals and groups, tabulated according to knowledge outcome measures

### Knowledge measures ('usual care' control groups)

As there are only two trials reported here, no reliable conclusions can be drawn. Trial 4 tested an intervention delivered to groups and showed no positive effect. The intervention in trial 14 was delivered to individuals, the necessary information to calculate effect size was lacking. The study reported no statistically significant effect of the intervention, having recruited 201 participants, meeting their sample size calculation.

#### 4.2.5.5 Care setting

This sub-set refers to the context in which an intervention was delivered. They were distinguished in the following four categories: community; community and primary; primary and secondary.

### Physiological measures

	'Usual care' control	Comparison group
Community	2 6 18 23	7 15
Community and primary	25*	-
Primary	3* 10 11** 16 19* 20 24	12 28
Secondary	1	-

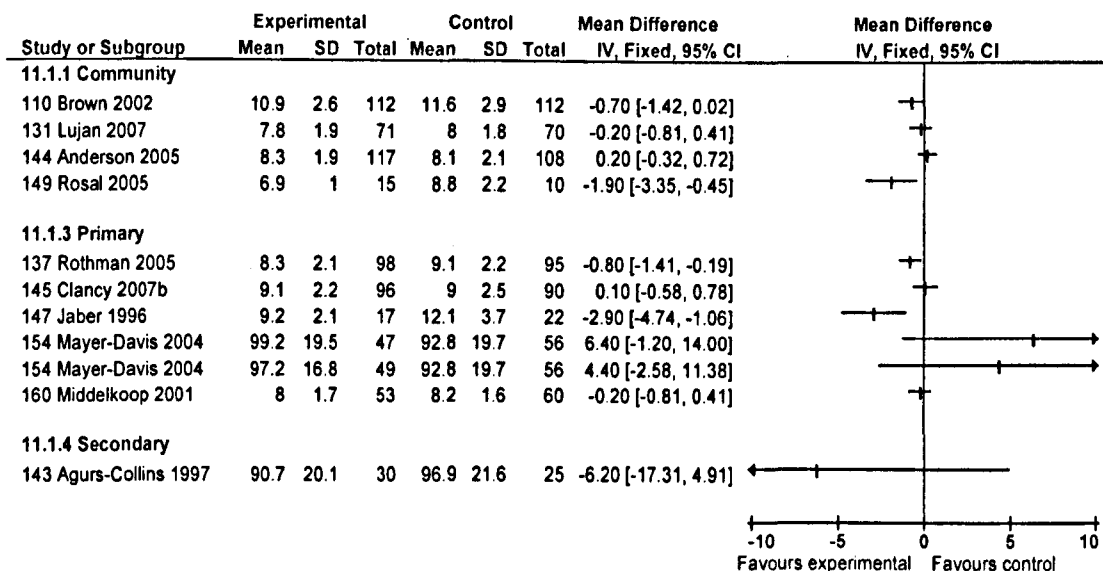
\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.22** Trials testing interventions delivered in community, primary and secondary healthcare settings, according to physiological outcome measures



**Physiological measures ('usual care' control groups)**

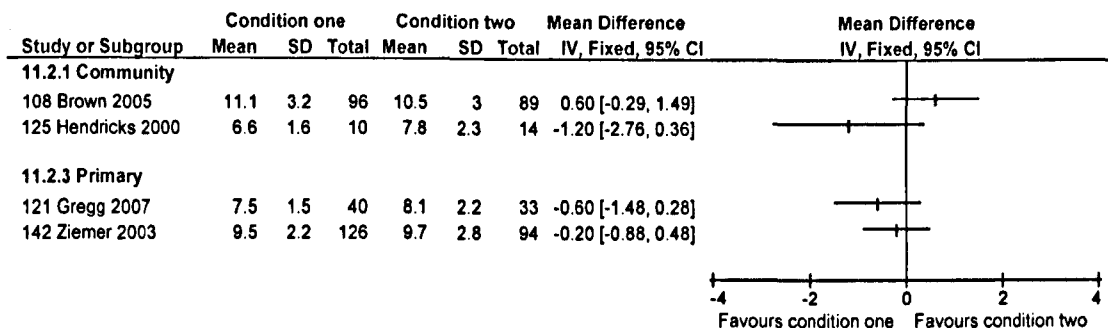


**Figure 4.11** The effects on physiological outcomes of interventions delivered in a community, primary and secondary health care setting (usual care control)

One of the four interventions was delivered in a community setting and had a positive effect (23). Two of the five interventions delivered in a primary health care setting had a positive effect (24, 16). Only one intervention was delivered in a secondary health care setting and this was not found to be effective (1). A tentative conclusion because of the small number of trials was that an intervention delivered in a primary health care setting was the most likely to be effective.

In addition to these were three trials (3, 11, 25) that did not provide the necessary information for the calculations of effect size. The effectiveness of these interventions was reported in the trials using p-values. The intervention in trial 25 was delivered in a community setting. Skelly et al (2005) of trial 25 reported significant findings; they had conducted a sample size calculation and by including the 47 participants they achieved it. The interventions in trials 3 and 11 were both delivered in primary healthcare settings. Anderson-Loftin et al (2005) reported the findings of trial 3 as not significant; they had conducted a sample size calculation and had included 97 participants meeting the criteria showing their analyses to be sufficiently powered. Trial 11 was also reported to be not-significant; although they had included 186 participants they did not report conducting a sample size calculation. Although these findings do not wholly support the tentative conclusion made earlier, they do little to change it.

**Physiological measures (comparison groups)**



**Figure 4.12** The effects on physiological outcomes of interventions delivered in a community and primary healthcare setting (different comparison groups)

None of the four trials in this category showed a positive effect.

**Attitudinal measures**

	'Usual care' control	Comparison group
Community	-	8
Community and primary	-	-
Primary	9* 27	-
Secondary	-	-

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.23** Trials testing interventions delivered in community, primary and secondary healthcare settings, tabulated according to attitudinal outcome measures

**Attitudinal measures ('usual care' control groups)**

There were only two interventions that were delivered in a primary care setting (9 and 27). Trial 9 lacked the necessary data to calculate effect size. Trial 9 had 186 participants and while a sample size calculation was not undertaken, a significant effect had been reported. Trial 27 did not find a positive effect.

**Attitudinal measures (comparison groups)**

There was only one trial (8) in this category, its intervention was delivered in a community setting and did not show an effect.

**Behavioural measures**

	'Usual care' control	Comparison group
Community	-	22
Community and primary	-	-
Primary	17* 26*	21*
Secondary	5*	13

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.24** Trials testing interventions delivered in community, primary and secondary healthcare settings, tabulated according to behavioural outcome measures

**Behavioural measures ('usual care' control groups)**

There were three trials in this category. Trial 26's intervention was delivered in a primary care setting and did not have the necessary information to calculate effect size, it had a small sample (n=38 participants) and did not report a sample size calculation but reported a significant effect. Trial 17 had three arms with interventions delivered in a primary health setting and showed a positive effect. Trial 5, another three arm trial, delivered its intervention in a secondary health setting and showed a positive effect. While trial 17 was further from the line of no effect, trial 5 had a far smaller confidence interval.

**Behavioural measures (comparison groups)**

There were also three trials in this category. The intervention in trial 22 was delivered in a community setting and compared two programmes presenting exercise and diet in a different sequence. Neither condition had a positive effect. The intervention in trial 21 was delivered in a primary care setting and an effect size could not be calculated because of missing data but the authors reported the results to be non-significant in the trial with a sample size of 596 and no reported sample size calculation. The intervention in trial 13 was delivered in a secondary health care setting and compared condition one, which was counselling in conjunction with group education with the condition two which was type 2 diabetes education counselling only. The first condition showed a positive effect. The findings for this category were inconclusive as result of too few comparable studies.

**Knowledge measures**

	'Usual care' control	Comparison group
Community	-	-
Community and primary	4	-
Primary	14*	-
Secondary	-	-

\* Did not have the necessary information to calculate effect size

\* 3+ arm intervention

**Table 4.25** Trials testing interventions delivered in community, primary and secondary healthcare settings, tabulated according to knowledge outcome measures

**Knowledge measures ('usual care' control groups)**

There were only two trials that reported effects on this category and in light of this limitation no reliable conclusions may be made. Trial 4 delivered its intervention in a community and primary setting, showing no positive effect. Trial 14 delivered its intervention in a primary setting and it also reported no significant effect of its intervention, the study did not provide the necessary information to calculate effect size.

**4.2.5.6 Length of intervention**

This sub-set refers to the length of an intervention. These data were distinguished in the following four categories: <1 month; 1-3 months; 4-6 months; >7 months. While some interventions were provided on a single occasion with no subsequent follow-up or opportunities for reinforcement, other interventions had more than one session allowing participants opportunity to absorb knowledge and enable clarification.

A very tentative finding due to the small number of trials was that the length of intervention had little influence on its effectiveness. However, the findings for this sub-set were inconclusive because so few studies were directly comparable.

	'Usual care' control	Comparison group
<1 month	5 14	12 15
1-3 months	1 4 20 23 25 27	13 21
4-6 months	3 16 18	22 28
>7 months	2 6 9 10 11 17 19 24 26	7 8

**Table 4.26** Trials testing interventions delivered in <1 month, 1-3 months, 4-6 months and >7 months, tabulated according to all outcome measures

#### 4.2.5.7 Delivered by health professional(s) versus other

This sub-set refers to the individual(s) delivering the intervention. Whether this was through the more traditional medium of health professionals or non-health professionals, for example peers who were successfully self-managing and had subsequently received training.

A finding which must be very tentative because of the small number of trials that were directly comparable was that the deliverer of an intervention had little influence on the effectiveness of interventions. However, these findings were inconclusive because so few studies that were directly comparable.

	'Usual care' control	Comparison group
1 health professional	3 4 14 16 19 25	21 22
2 health professionals	1 2 9 10 11 20 24	15
3+ health professionals	6 23 26	7 8 13 28
Non-health professional	5 17 18 27	12

**Table 4.27** Trials testing interventions delivered by 1 health professional, 2 health professionals, more than 3 health professionals and non-health professionals, tabulated according to all outcome measures

#### 4.2.5.8 Single self-management behaviour versus multiple self-management behaviours

This sub-set refers to interventions that focused on only one behaviour during the intervention (e.g. foot care) or more than one (either concurrently or consecutively). When trials were classified and analysed according to this sub-set

the findings were inconclusive since too few directly comparable studies made an interpretation tenuous.

	'Usual care' control	Comparison group
Single self-management behaviour	3 4 5 17 26	13 28
Multiple self-management behaviours	1 2 6 9 10 11 14 16 18 19 20 23 24 25 27	7 8 12 15 21 22

**Table 4.28** Trials testing single self-management behaviour and multiple self-management behaviour interventions, tabulated according to all outcome measures

#### 4.2.5.9 Didactic versus interactive versus both

This sub-set refers to the different delivery styles. A didactic intervention was designed to convey information, while an interactive intervention involved the user. The limited evidence in this category prevented any reliable conclusion to be drawn.

	'Usual care' control	Comparison group
Largely didactic	11 14 24	21
Largely interactive	2 5 9 10 18 19 23 25	22 28
Both	1 3 4 6 16 17 20 26 27	7 8 12 13 15

**Table 4.29** Trials testing interventions delivered in didactic, interactive and both didactic and interactive styles, tabulated according to all outcome measures

#### 4.2.5.10 Lifestyle versus general self-management versus health service use versus single self-management behaviour

This sub-set refers to the focus of the interventions. Since the inclusion criterion for outcomes had been broad (see section 3.2.4.1), this category attempted to differentiate effectiveness between type of intervention. For detail on the characteristics of the interventions tested in the included trials see Appendix 4.1. It was difficult to draw even a tentative conclusion because of the very small number of trials within the different categories of this sub-set.

	'Usual care' control	Comparison group
General self-management	2 4 6 10 11 14 20 23 24 27	7 8 12 15
Lifestyle	1 3 17 19 26	13 21 22 28
Health service use	9 18	-
Single self-management behaviour	5 16 25	-

**Table 4.30** Trials testing general self-management, lifestyle, health service use and single self-management behaviour interventions, tabulated according to all outcome measures

#### 4.2.5.11 BME group

This sub-set refers to the BME group that the intervention was delivered to. Trials 12 and 13 were not included in this analysis as they had been delivered to more than one BME group. When trials were classified and analysed according to this sub-set it was difficult to draw even a tentative conclusion since too few studies were directly comparable and this made an interpretation tenuous.

	'Usual care' control	Comparison group
African-American	1 2 3 9 10 11 16 17 19 24 25 28	15 22
Latino	5 6 23 26 27	7 8 18 21
South-Asian	4 14 20	-

**Table 4.31** Trials testing general self-management, lifestyle, health service use and single self-management behaviour interventions, tabulated according to all outcome measures

#### Summary of results from eleven sub-sets of trials

Within the limitations of the findings a summary of the results for trials reporting on physiological measures was:

\* Culturally competent interventions; interventions based on a theoretical framework and interventions with both an educational and practical component were more likely to demonstrate a positive effect.

\* More tentative findings were that interventions with both an individual and group component and interventions delivered in a primary healthcare setting were more likely to demonstrate a positive effect.

\* Very tentative findings, as result of the small number of trials in the different categories, were that intervention length and deliverer of intervention did not affect effectiveness.

\* Limited evidence for the remaining four subsets (Single versus multiple self-management behaviours; didactic versus interactive versus both; type of self-management behaviour and BME group) prevented a reliable conclusion.

\* All results regarding the attitudinal and knowledge measures had been inconclusive due to the small number of trials that had reported on these measures. This was also true for behavioural outcome measures apart from on two occasions when the six trials reporting on behavioural measures as their primary outcomes were distributed evenly across two categories. This enabled a tentative conclusion, strengthened however by the fact that in both cases findings supported what the physiological outcome measure had found. Interventions that were culturally competent and based on a theoretical framework were also more likely to have an effect on behavioural outcome measures.

#### **4.2.6 Methodological commentary on sources of heterogeneity amongst included trials**

In addition to the already detailed causes of trial heterogeneity, broad selection criteria and diversity in reported primary outcomes, there were other important sources of heterogeneity and these are detailed here.

##### **4.2.6.1 Control and comparison groups**

Twenty of the trials had a 'usual care' control group. The remaining eight trials employed comparison groups and examined different aspects of self-management interventions, see Table 4.5. This meant that the trials with 'usual care' controls were comparable with one another while the trials with comparison groups were neither directly comparable with one another nor with the 'usual care' control trials. For this reason, during presentation of results they were reported separately.



Nonetheless, as identified throughout the results, the trials employing comparison groups served a useful function of illuminating important contextual issues that cannot readily be addressed with the trials employing only a control group. Throughout the presentation of results for the eleven sub-sets of trials, details of these comparison groups were elaborated where appropriate.

**Table 4.32** Trials tabulated according to primary outcome measure and control

	<b>'Usual care' control group</b>	<b>Not a 'usual care' control group</b>	<b>Total</b>
<b>Physiological measures</b>	1 2 3 6 10 11 16 18 19 20 23 24 25	7 12 15 28	17
<b>Attitudinal measures</b>	9 27	8	3
<b>Behavioural measures</b>	5 17 26	13 21 22	6
<b>Knowledge measures</b>	4 14	-	2
<i>Total</i>	20	8	28

#### 4.2.6.2 Three and four arm trials

Another cause of heterogeneity was that four of the included trials had multiple arms while the remaining 24 included trials had two arms. Trial 5 had two levels of intervention (one was a five minute foot risk assessment using a monofilament and the other was a fifteen minute foot self-care intervention that used educational and behavioural strategies), and a 'usual care' control was used. Trial 11 tested a community based intervention to improve general type 2 diabetes control so as to prevent complications and had four parallel arms. One arm assessed the effectiveness of a nurse case manager, the second of a community health worker, the third of a nurse case manager and community health worker team and the final arm was the control arm of 'usual care'. Trial 17 tested a physical activity intervention and had three treatment conditions. The first was clinic and community, the second was clinic only while the third was a minimal intervention and participants were just provided with a relevant pamphlet. Finally, 19 was a clinical trial of weight management strategies. It compared an 'intensive lifestyle' intervention and a 'reimbursable lifestyle' intervention (condensed version) with a 'usual care' control.

### 4.2.6.3 Follow-up times

Table 4.33 presents the follow-up times. Six months was the most commonly reported time, in 12 studies. No single time point was common to all trials.

**Table 4.33** Trials tabulated according to reported follow-up time

ID No	1 mth	1.5 mths	3 mths	4 mths	6 mths	12 mths	24 mths
1			X		X		
2		X					
3					X		
4			X				
5	X						
7			X			X	
8			X			X	
6			X		X	X	
9						X	
10						X	
11							X
12			X				
13			X				
14					X		
15					X		
16				X			
17					X	X	
18			X		X		
19					X	X	
20					X		
21					X		
22				X		X	
23					X		
24						X	
25	X						
26			X				
27			X				
28					X		
Total	2	1	10	2	12	9	1

Enforcing one follow-up time for the analysis was considered however whilst it would produce homogeneity, some of the previously included trials would be excluded from the systematic review. Instead, since logically all trials had a final time point it was decided to adopt that in the analyses of the review.

It is interesting to note, that while there were eight longitudinal studies recording data at repeated intervals over a short period (7, 8, 6, 17, 18, 22, 1, 19), there was an absence of any research in the systematic review that took place over a span of time that extended beyond two years. The impact of this was that included interventions did not report on whether results were long-lasting. This is important for a long-term condition such as diabetes which requires sustained behaviour change.

#### **4.2.6.4 Missing data**

Another consideration was that thirteen trials had data missing from the article that prevented secondary analyses. For example the mean, standard deviation or sample sizes were not reported, for baseline or the last time point. This is accepted as an inevitable cause of variation between trials and an indicator of quality and not a source of heterogeneity in the method. However, just as with the sources of heterogeneity in the completeness of datasets it contributed to challenges in analysis. When the authors of the trials with incomplete data were contacted asking for clarifications or additional data, five provided the required details (5, 24, 23, 19, 20), two did not respond (3, 9) and five stated that they no longer had access to the requested data (11, 14, 21, 25, 26).

For the seven studies where limited information prevented secondary analyses, the p-values of effectiveness of the intervention as reported in the primary trial were considered in the narrative analysis. However, this evidence had less weighting because of the limitations of p-values. Limitations include that non-significant p-values (conventionally  $p > 0.05$ ) may be a reflection of the study being underpowered rather than a lack of effectiveness. In recognition of this, robustness of these data sets was reported, chiefly whether the primary investigators of these seven trials conducted a sample size calculation and moreover if they recruited a sufficiently large sample. Table 4.34 presents this information. Another limitation is generally accepted to say that differences are significant if the probability is less than 0.05,

Bland (2000) advises against using it as an absolute demarcation. He adds, that a difference may well be real and statistically significant but be of little clinical importance (or vice versa).

Overall, fifteen trials did not report whether or not the sample size had been calculated and thirteen trials reported calculating a required sample size. Of these thirteen trials, ten achieved the calculated sample size and three did not.

**Table 4.34** Trials tabulated according to issues regarding sample size

<b>ID No.</b>	<b>Sample size</b>	<b>Required sample size calculated</b>	<b>Sample size achieved</b>
1	64	Yes	No
2	239	No	Unclear
3	97	Yes	Yes
4	145	No	Unclear
5	167	Yes	Yes
6	256	No	Unclear
7	216	Yes	Yes
8	216	Yes	Yes
9	186	No	Unclear
10	186	Yes	Yes
11	186	No	Unclear
12	81	Yes	Yes
13	61	No	Unclear
14	201	Yes	Yes
15	30	No	Unclear
16	45	No	Unclear
17	200	Yes	No
18	150	Yes	Yes
19	26	Yes	No
20	113	No	Unclear
21	596	No	Unclear
22	22	No	Unclear

23	25	No	Unclear
24	217	Yes	Yes
25	41	Yes	Yes
26	38	No	Unclear
27	17	No	Unclear
28	648	No	Unclear

#### 4.2.6.5 Risk of bias in individual studies

An important feature of systematic reviews, as opposed to other literature reviews is their ability to detect and control for bias. This is through the assessment and consideration of the methodological quality of included studies. Lundh and Gotzsche (2008) examined the guidelines of the 50 Cochrane review groups, for their recommendations on methodological quality assessment of primary studies. They reported that forty-one of the review groups (82%) recommended quality assessment using a list of separate components for the different methodological areas and the remaining nine suggested the scale approach, which involves summarising the information in an overall quality score. The decision was made to use the component approach in the work in this thesis. The following five components were derived from the Cochrane Collaboration's tool for assessing risk of bias (The Cochrane Handbook, 2008):

- Adequate sequence generation
- Allocation concealment
- Blinding of participant
- Blinding of key study personnel
- Incomplete outcome data addressed

This data are presented in Table 4.35. Overall the studies tended to have a low risk of bias in relation to 'adequate sequence generation' and 'incomplete outcome data addressed.' 'Allocation concealment' was largely unclear and was the main item that was poorly reported. As a result of the style of the intervention within these trials, i.e. self-management, it is unavoidable that either 'blinding of participant' or 'blinding of key study personnel' will be subject to high risk of bias this meant that the 'overall risk of bias within study' was unclear or high in all cases. Thus, studies were not excluded or weighted on the basis of their risk of bias.

**Table 4.35** Trials tabulated according to risk of bias in individual studies

<b>ID No</b>	<b>Adequate sequence generation</b>	<b>Allocation concealment</b>	<b>Blinding of participant</b>	<b>Blinding of study personnel</b>	<b>Incomplete outcome data</b>	<b>Overall risk of bias</b>
1	Low	Unclear	High	Unclear	Low	High
2	Low	Unclear	High	Unclear	Low	High
3	Low	Low	High	Unclear	Low	Unclear
4	Low	Unclear	High	Low	High	High
5	Low	Unclear	High	Unclear	Low	High
6	Low	Unclear	Unclear	Low	Low	Unclear
7	Low	Unclear	Unclear	Unclear	Low	Unclear
8	Low	Unclear	Unclear	Unclear	Low	Unclear
9	Low	Low	Unclear	Low	Low	Unclear
10	Low	Unclear	High	Unclear	Low	High
11	Low	Low	Unclear	Low	Low	Unclear
12	Low	Low	Unclear	Low	Low	Unclear
13	Low	High	High	Low	High	High
14	Low	Low	High	Low	Low	High
15	Low	Unclear	Unclear	Unclear	Low	Unclear
16	Low	Unclear	High	Unclear	Low	High
17	Low	Unclear	Unclear	Unclear	Low	Unclear
18	Low	Unclear	High	Unclear	Low	High
19	Low	Unclear	Low	Unclear	Low	Unclear
20	Low	Unclear	High	Unclear	Unclear	High
21	Low	Low	Unclear	Low	Low	Unclear
22	Low	Unclear	Low	Low	Low	Unclear
23	Low	Unclear	High	Unclear	Low	High
24	Low	Low	High	Low	Low	High
25	Low	Unclear	High	Low	Low	High
26	Low	Unclear	High	Unclear	Low	High
27	Low	Unclear	High	Unclear	Low	High
28	High	High	Low	Unclear	High	High

#### **4.2.7 Summary of intervention strand's results**

These results suggest that an intervention was more likely to show a positive effect on physiological outcome measures if it was culturally competent, based on a theoretical framework, delivered in a primary health care setting and had both educational and practical components. An intervention's effectiveness was not shown to be influenced by its length or by whom it was delivered. All other sub-sets of trials produced inconclusive results. Results on all other outcomes were also inconclusive. The small number of trials that reported effects on attitudinal, behavioural and knowledge measures resulted in small sample sizes for secondary analyses and this meant that the findings could not be definitive.

### **4.3 'Views' strand results**

This section presents the results of the 'views' strand synthesis. It will begin with a description and quality assessment of included studies. Following this, the results of the thematic synthesis will be presented with information on descriptive and analytical themes.

#### **4.3.1 Description of studies**

Fifty-seven studies with a total of 1735 participants were included in this 'views' strand of the systematic review. One study was of a quantitative design, two studies were of a mixed-method design whilst the remainder were qualitative. The most popular methods of data collection were interviews (n=33) and focus groups (n=22). One study combined interviews and focus groups, while another employed a mixture of interviews, observations and case studies.

Thirty-eight of the 57 studies were undertaken in the USA and a further three in Canada. Fourteen studies were undertaken in Northern Europe, 11 of these in the UK and the other three in Scandinavian countries. The remaining two studies were Australian. Perhaps unsurprisingly, since the literature was dominated by North American research, most of the black or minority ethnic (BME) groups under study were of African (n=18) or Latino origin (n=17). The next largest numbers of studies included South Asian populations (n=11) and then Oriental groups (n=5). One study included Italian immigrants; the remaining five studies included participants from more than one BME group. Nine of the 57 included studies included a female only sample, while just one study had a male only sample.

As the outcome inclusion criteria of the systematic review was kept broad to include any outcome related to self-management, the studies included in the review addressed a diverse set of issues relating to type 2 diabetes self-management. The issues explored, ranked in order of frequency, included: general lived experience (n=9); lifestyle (n=8); general beliefs about diabetes (n=8); perceptions of health professionals' impact on self-management (n=5); factors influencing self-management specific to the individual (n=4); diabetes education (n=4); alternative treatments (n=3); explanatory models of type 2 diabetes (n=3); insulin therapy (n=2); family roles (n=2); depression (n=2); cultural issues (n=2); healthcare goals (n=1); health service use (n=1); medicines therapy (n=1); symptoms (n=1); social



support (n=1); fatalism (n=1); general self-management (n=1); problem solving (n=1) and empowerment (n=1). All but three of the included studies (62 73 49) investigated only one issue.

#### **4.3.2 Quality assessment**

As detailed in section 3.2.6, 26 quality assessment items were applied to the 'views' studies. One 'views' study was quantitative (50) and so for this only 24 of the quality assessment items were relevant. The two items 'Information collected with sufficient detail and depth' and 'Evidence of reflexivity' were not assessed. For the two studies of a mixed method design (73, 78) and the remaining 54 qualitative studies, all 26 of the quality assessment items were applied. Table 4.36 summarises the number of studies meeting these quality assessment criteria.

All of the included studies provided: 'Clear aims'; 'Clear articulation of rationale' and 'Clear description of data collection'. Most studies (>80%) also scored 'yes' on the following items: 'Clear description of setting'; 'Clear description of self-management behaviour'; 'Clear description of recruitment procedure'; 'Clear description of sampling procedure'; 'States inclusion and exclusion criteria'; 'Clear description of sample'; 'Appropriate sampling'; 'Information collected with sufficient detail and depth'; 'Interprets findings in context of other studies/theory'; 'State implications' and 'Conclusion justified'. Studies scored poorly (<30%) on the following items: 'Explicit theoretical framework'; 'Stated measure of self-management'; 'State participation rates'; 'Target sample achieved'; 'Provision of attrition data'; 'Evidence of reflexivity'; 'Explicit mention of health literacy' and 'Evidence of consumer involvement'.

Seven studies were judged to score poorly overall on quality assessment criteria, since they met only 50% or less of the criteria. Four of these studies (43, 57, 79, 31) were published over ten years ago, when published research was subject to fewer standardised criteria and this may be the reason for their meeting fewer quality criteria. The remaining three studies (51, 62, 68) were published more recently and in peer reviewed journals. Since these seven studies' findings did not contradict those of good quality studies it was decided to retain them in the analysis.

**Table 4.36** Number of studies scoring a 'yes' on quality assessment criteria by study design

	All		Qualitative	Mixed	Quantitative
	N	%	(n=54)	(n=2)	(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	42	74	40	1	1

analysis methods reported					
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
<hr/>					
Total (of possible 1486)	1021		962	39	20
% of maximum possible score	69		68	75	83

### 4.3.3 Thematic Synthesis

The findings of the 57 studies were integrated using thematic synthesis (Thomas and Harden, 2008) and in so doing, key themes were identified to answer the overall review question ‘What are the barriers to, and facilitators of the self-management of type 2 diabetes amongst ethnic minority groups?’ and the sub-question two ‘What are ethnic minority patient’s views of type 2 diabetes self management?’ There were four stages to the thematic synthesis process: the line-by-line coding of the key findings (Appendix 4.2); the organisation of the data set according to the three broad questions, developed *a priori* (see section 3.2.7.2); the development of ‘descriptive themes’ which remain proximate to the primary studies, and the generation of ‘analytical themes’ which require reviewers’ interpretation to produce more abstract and conceptual constructs (Thomas and Harden, 2008).

The descriptive themes and analytical themes are presented overleaf. The identity numbers of the relevant ‘views’ studies will be presented in brackets throughout the descriptive themes. For detail on the study author, date and title of publication see Table 4.2.

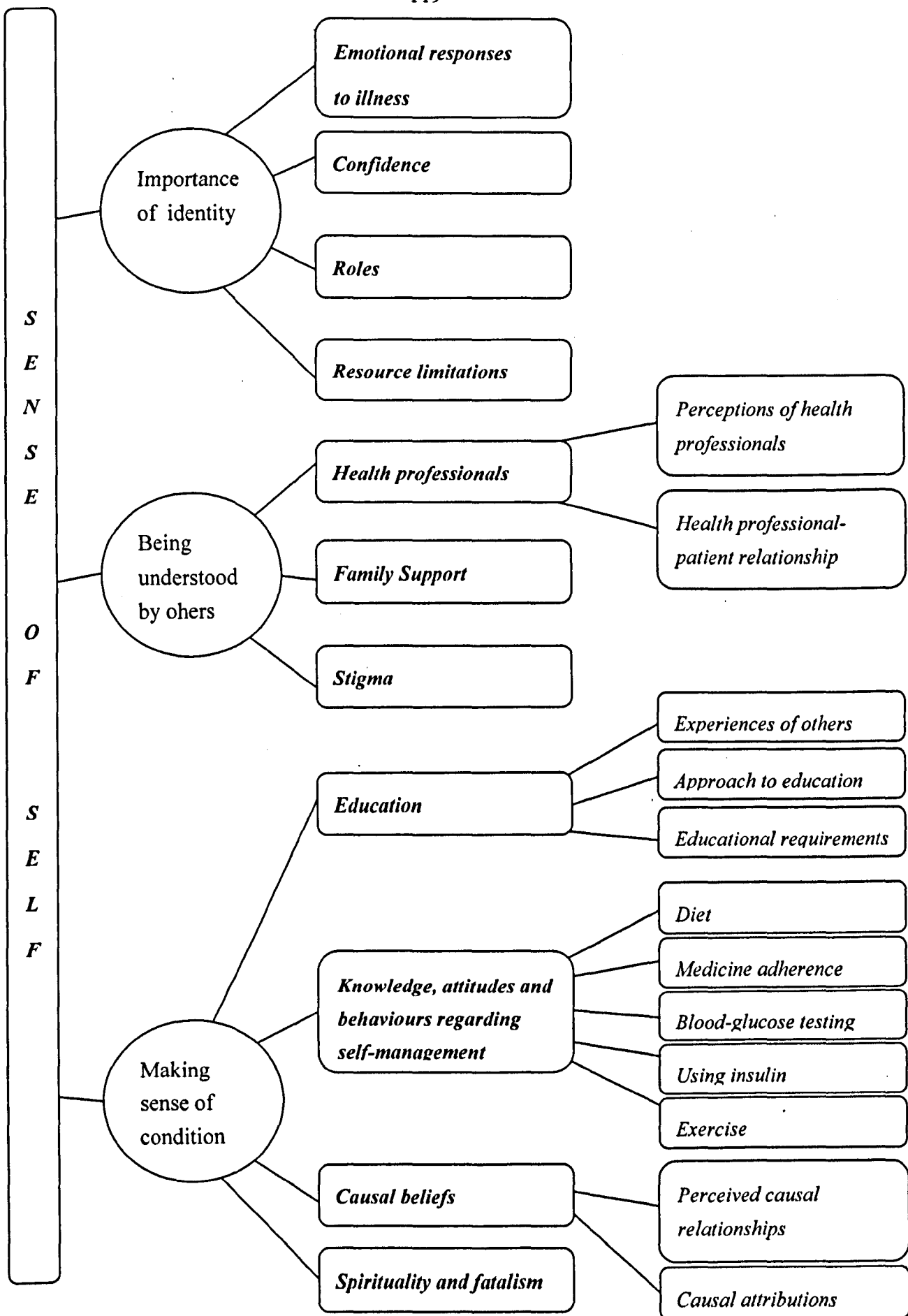


Figure 4.13 Identified descriptive and analytical themes

#### **4.3.3.1 Descriptive themes**

The earlier stage of line-by-line coding had developed a bank of codes and by looking across them a 'translation' of concepts between studies was enabled (Britten, 2002). Then the codes were grouped into a hierarchical structure which enabled the meaning of groups of codes to be captured as a descriptive theme (Thomas, 2008). This was an iterative process.

The synthesis resulted in 11 descriptive themes with 11 sub-themes and three analytical themes, these are presented in Figure 4.13. The 11 descriptive themes and their related sub-themes will now be discussed in turn. As is illustrated in Figure 4.13 the themes were not entirely independent and any overlap is discussed. Wherever views were specific to a BME group this is stated, otherwise it can be assumed to be a general finding across different BME groups.

#### **Emotional responses to illness**

Participants from 22 studies recalled their emotional response when first learning of their diagnosis; although varied, these were overwhelmingly negative. Depression was cited in several studies (36, 38, 51, 52, 83) as was denial (31, 35, 36, 44, 49, 52, 63, 67) and anxiety (62, 65, 76, 80). Others talked of feelings of resignation (30, 38, 44, 66, 67, 74, 80, 82) which may be in part a result of the high rates of type 2 diabetes incidence in these groups. Many reported helplessness and pessimistic health views (66, 84) focusing on the negative outlook of a future without a cure (29, 30, 36, 42, 44) and considering poor outcomes as inevitable (29, 30, 42, 52, 65).

Emotional responses to self-management (as opposed to diagnosis) were mentioned by participants in 16 studies. Participants talked about feelings of self-blame at not being able to meet diet demands (34). Related to this, they mentioned experiencing guilt due to being dishonest with their health professionals when failing to follow medical advice (46). Other participants' reported being frustrated (52, 66, 70, 83) and angry with the complexity of the type 2 diabetes regimen (36, 52, 83). In one sample this complexity was also reported to cause stress (67). Furthermore, the fear of diabetes (67) and of its long-term complications (36, 37, 51, 60, 61, 65, 74, 80, 84) was perceived to add to the difficulties associated with good self-management.

Interestingly, a popular strategy to facilitate self-management demonstrated by participants in 19 different studies, was consciously seeking to improve one's own emotional well-being. This perhaps suggested participants' recognition on some level of their negative responses to diabetes. Participants approached this in a variety of ways, some became involved in activities that made them feel happier and healthier (42, 56, 82) whether that be by prayer (59, 78) or through employing positive coping styles such as focusing on those less fortunate (82), wishful thinking (60) and trying not to worry about the disease (85).

Avoidance was another strategy used to improve emotional well being. Participants spoke of avoiding irritating situations after discovering that anger raised their blood sugar (84). Avoiding 'bad news' regarding disease progression was also mentioned and this was achieved through fewer visits to the health professional (62) or cessation of self-monitoring because blood glucose readings were always high (50). Similar avoidance strategies were to eat "normal" foods until a crisis in glucose levels was encountered and then eat more carefully until control was regained (56). Other participants spoke of more extreme strategies where they did 'not claim their diabetes', this concept was related by the participants to 'religiosity' and involved not showing signs of sickness, not undertaking any self-management or accepting treatment (37; 44).

For others, doing the opposite and accepting their diabetes was a way to improve emotional well-being (32, 37, 52, 58, 67). By accepting diabetes, participants were better able to accept support from friends and families (82) and even led some to join support groups (42, 62, 74, 75, 77). Furthermore, participants who reported accepting that they had diabetes employed a range of practical self-management strategies focusing on diet (36, 37, 52, 58, 74, 75, 82, 84).

It would be interesting to know whether the range of emotional responses identified was mediated by time. However, since the review included so many participants at different stages of their condition, details of which were infrequently reported, it was not possible to draw any firm conclusions about this.

### **Confidence**

Wide ranging views across 21 studies observed the influence of participants' sense of confidence on effective self-management. Participants in seven studies

recognised what built their confidence and this included: an empowered perspective on one's own ability to self-manage (67); success at symptom management (32); volunteering in religious institutions (77) and obtaining spiritual care from a health professional (72). Participants also noted how their confidence positively affected their future (33, 42) with one sample specifying that it aided coping with culturally insensitive health advice (47).

Views from seven studies however suggested that developing type 2 diabetes had resulted in a perceived loss of confidence (29; 33, 70). One group of participants felt themselves to have inadequate 'tools' to implement behavioural changes and control the disease (62) while another seemed resigned to a view that the rigorous lifestyle changes required to manage diabetes meant it was unlikely that an individual would stay in control for long (44). Participants from a different study shared a similar perception of having a limited capacity to break familiar habits (38) whilst other participants demonstrated feelings of disempowerment due to a lack of knowledge (30).

Furthermore, people often expressed the view that diabetes had changed them (29, 63) and this in turn was likely to affect their sense of confidence. Participants saw the unpredictable nature of diabetes as a betrayal by their own body (85), while others noted how glucometer readings bore little relation to how they felt (71). On the other hand, there were groups of participants who demonstrated high confidence. These participants emphasised the personal experience of living with diabetes, maintaining they were in the best position to self-manage as their own knowledge of their bodies could not be surpassed and as such they sometimes chose to not conform with medical advice (29, 30, 32, 33, 35, 37, 42, 52, 57, 63, 67, 84).

### **Roles**

Gender roles were discussed in 23 studies (29, 31, 34, 37, 38, 39, 40, 45, 48, 49, 56, 62, 66, 67, 68, 69, 70, 73, 76, 77, 80, 84, 85). Men tended to focus on how diabetes effected on their physical performance (56, 84, 85), including their sexual ability; (67); ability to provide financially for their family (40, 70) and the ability to retain social eating and drinking activities (66). Whereas women expressed an array of general concerns about the effects of a reduced level of health (29, 40, 84, 85).

Cultural norms were more evident in women's discourse, particularly South Asian women. They spoke of a cultural norm to stay indoors (66); not being socialised to participate in sports (66); feelings of vulnerability because of low literacy (66, 69) which were perhaps reflected in hesitations to participate in type 2 diabetes education programmes (77); and a preference for gender specific education sessions (80). The findings of a mixed-methods study included in this review found that a group of South Asian women evidenced poorer glycaemic control and poorer knowledge than their South Asian male counterparts (50). This finding did not appear to be cross-cultural since African-American women in another study showed more interest in receiving accurate information from health professionals' instructions than men in the same study (85).

Gender was also found to influence the support received from family, with men reporting significant family support (34, 40, 49, 56, 67, 85) and women feeling unsupported (40, 49, 66, 76, 84). This may offer some explanation for the gender difference in attitudes towards discussing their condition after initial diagnosis. Men reported freely sharing their diagnosis with people in their social networks (67), while women reported selective discussion of their diabetes and said this was in order to maintain their valued caregiver role (37).

It emerged from many women that their gender roles competed with diabetes self-management. Some women explained that their role as the family cook made accessible "normal" foods hard to resist (56). Other women talked about how their role of caregiver made it difficult physically and emotionally to maintain effective self-management of their diabetes (29, 31, 34, 37, 38, 39, 45, 56, 62, 66, 68, 70, 73, 76, 77). Some women noted how their diagnosis did not translate into reduction of accustomed expectations from family members (66, 76). Others took the position that the role of caregiver made it important to adhere to self-care so as to remain fit and continue their responsibilities (62) with an emphasis on family finances (37, 66, 77).

A clear assertion within this descriptive theme were the participants' motivations to maintain their pre-diagnosis roles (37, 54, 62, 84). Health goals were commonly described in functional rather than biomedical terms, i.e. being able to continue with aspects of their daily routine (54, 56, 58, 71, 84). Similarly, symptoms were defined in terms of their impact on social, familial and working



roles (37, 45, 51, 58, 60, 66, 67, 71) with some participants reporting that they ignored symptoms so as to accomplish roles (37, 71).

Alongside this desire to maintain their current roles, participants frequently reported an unease about being dependent on others due to their diabetes (37, 42, 49, 64, 65, 67, 71, 74, 84). Some perceived a loss of identity because they felt that other people focused on their condition and not on them as an individual (29); others believed the diagnosis had reduced their social standing (29, 32, 36, 39). Participants were motivated to maintain their roles in order to uphold identity with their own social, religious and familial groups (43); some feared that giving up habits because of diabetes would lead to isolation (84).

### **Resource limitations**

Participants from 29 studies expressed views on their financial limitations and how these impacted on their diabetes self-management. Economic costs were mentioned in general terms since appropriate diabetic management imposed additional financial burdens (31, 33, 34, 36, 37, 38, 40, 45, 56, 58, 74, 77, 84). Economic costs were also mentioned more specifically in relation to inadequate or unaffordable health insurance (29, 37, 40, 85) as well as the high cost of required medical supplies (29, 34, 37, 40, 49, 56, 82). Unsurprisingly the vast majority of references to monetary resource limitations were made in studies from the USA, which has a private or insurance-based health care system.

Participants in only four studies directly specified a lack of transport as having a negative effect on their use of diabetic services (31, 69, 77, 80), whereas access limitations more broadly, were the most frequently reported resource issue. These limitations ranged from a poor knowledge of services (50, 77) to the inconvenience of locations (65, 77, 80, 82), to a lack of diabetes resources for example too little information regarding their condition (36, 38, 40, 49, 50, 75, 77, 83, Mex-Am) and the availability of health care providers (48, 82, 83).

Furthermore, medical adherence was more frequently reported when educational resources were readily accessible (29, 31, 47, 49, 80, 82) or treatment was readily available (33, 82). Similarly, culturally sensitive facilities (66) improved access to health services, as did the provision of culturally appropriate information, such as leaflets and videos in minority languages (48, 80).

In a similar vein, two studies suggested that participants who were 'accultured' that is to say adapted aspects of the host culture as result of sustained contact, were better able to access available medical resources (30), since they 'knew' how to behave as patients (46). Some participants talked directly of the systemic stressors they experienced due to their immigrant status and how this led to competing considerations that interfered with self-management (34, 40, 47, 56, 76, 84). Time limitations (29) is an example with some participants attributing their work-schedules to not having adequate or regular enough opportunities to eat properly (38, 47), as is required for well controlled type 2 diabetes.

### **Health professionals**

There are two subthemes within this descriptive theme, 'Perceptions of health professionals' and 'Health professional-patient relationship.' These will now be presented in turn.

#### *Perceptions of health professionals*

This was a strong descriptive sub-theme to emerge, with 31 studies reporting on perceptions of health professionals. However, its context varied, ranging from expressions of respect and gratitude for health professionals, to criticism and disregard of their recommendations.

Participants frequently reported that they sought guidance from their health professional (29, 32, 34, 36, 37, 38, 40, 46, 52, 63, 72, 85). Evidence of respect for the physician included showing a high regard for their educated status (80) that translated into faith in their competence (77; 62). For some respondents this respect meant taking care to never overtly criticise health care professionals (34, 46) despite conflicts at times between the physician's recommendations and their own inclination (85). Other participants indicated that their respect for the health professional was conditional on the professional's attitudes and behaviours, specifically on whether they provided quality care. Participants appeared to show high regard for health professionals who exhibited good communication skills, i.e. explaining to them in a meaningful way and ensuring understanding (29, 72, 75) and also for health professionals who offered genuine patient centred care (29, 32, 35, 85).

Despite or possibly as a result of the respect and gratitude for health professionals, some participants talked about withholding information from them. For some this was about the integration of a dietary regimen into their lives (34) emphasising “good” behaviours and playing down “bad” behaviours (85), whilst some intermittently ceased to see the family doctor if they had not adhered to advice consistently (63). There was also a suggestion of other motivations for withholding information from health professionals including wanting to avoid treatment changes (62, 69) and not feeling understood (74).

A range of participants from different BME groups reported being mindful of the health professional’s lack of time (50, 77). This led some participants to be critical of the quality and amount of information that they received (62), whereas others indicated an acceptance, stating that they felt health providers were busy and did not have the time to sit and talk with them or teach them about diabetes (36, 82, 83). Participants in another study stated that they experienced difficulties in establishing a relationship with their family doctor because of limited consultation time. In particular there was no opportunity to discuss issues related to the social and personal impact of diabetes (63). The importance of this issue was alluded to in another study, when participants said they sought a caring health worker who took time to listen to their story and give advice (46).

Some participants stated that they do not always choose to follow the health professional’s recommendations (38, 75) and provided practical reasons for doing this, which included facing the challenges of daily life with a complex regimen (34, 71, 82, 83, 85) further complicated by restricting co-morbidities (32, 34, 40, 47, 51, 66, 80, 82). Other participants said that they did not always choose to follow health professionals’ recommendations because they were critical of their style of advice. Examples include it being unrealistic (29, 32), inappropriate for BME groups (47, 83), insincere ‘scare tactics’ (29, 32, 53, 62, 63), or in the form of an injunction (62). Two studies including South Asian participants criticised the health professional for the opposite, in giving non-directive advice which was a different approach to what they were used to on the sub-continent (46, 47).

Elsewhere, there were views more directly expressing criticism of the health professionals (62) and this was largely reported as being due to feelings of distrust (33, 35, 44, 46, 70) and in one case because they felt the health professional lacked

basic knowledge about African-American people (70). Some South Asian participants felt that they had not received proper treatment if they were not physically examined (65) and in a similar vein other South Asian participants talked about being unwilling to leave the house for education alone, if they were not also going to see the doctor (50). Non-medical health professionals in India are accorded less respect than in the West (77). Some participants reported difficulties distinguishing between nutritionists, nurses, and health educators (75).

#### *Health professional-patient relationship*

In 19 studies participants expressed how the cultural and linguistic appropriateness of the healthcare exchange shaped their perceptions of the health professional.

Participants spoke of health professionals' inability to relate with their life-story (46) as poor people (32, 36, 47, 85), as black people (70), or as people subscribing to a holistic view of health and not the biomedical model (74, 77). Health professionals' dietary recommendations were commonly perceived as expecting the patient to reject their own food traditions and as such participants frequently ignored this advice. The range of reasons for doing this included feeling devalued (47) and insecure about what they could still eat of their traditional foods (84). It was also felt by some that health professionals lacked sufficient knowledge of their dietary preferences when dispensing advice (35, 46, 47, 49). Moreover another group found the recommended diet to be wholly unrelated to Latino lifestyle and culture (74).

Equally, the linguistic appropriateness of the exchange with the health professional was mentioned by participants of recent immigrant groups when they spoke and understood none or little of the host country language (40, 80). Participants generally spoke positively of consultations with health professionals with whom they shared a common language and culture (29, 43, 77) since it made communication easier (69), more direct and culturally sensitive (29, 65) and so this gave the health professional more credence (74). However, this is not to say that matching the health professional and patient with a common language alone is sufficient. A Vietnamese participant in one study halved her medicine dose due to

dizziness but did not mention it to her Vietnamese-speaking USA educated physician, because she felt he would not understand her reasons (69).

Some of the participants who had consultations with health professionals with whom they did not share a common language, highlighted the inadequacy of working through interpreters as compared to direct communication with bilingual staff (49, 65). Participants commented on how the limited availability of interpreters affected the service they received (46, 47). Some participants suggested feelings of discrimination if they were not seen or if they experienced long waits for an interpreter (49). Others felt pressurised to limit the exchange because of the perceived lack of time for an interpretation process (65) and a few suspected that information was edited or lost when communicated through a relative (53, 65, 77).

### **Family support**

This was a commonly reported descriptive theme, with 31 of the 57 studies reporting familial emotional or practical support at least once, but its context ranged on a broad spectrum from participants resisting support to expecting support.

Interestingly, all explicit statements that family support was 'valued' came from North American studies of African-Americans or Latinos (31, 37, 39, 61, 70, 76, 82, 83, 85). In contrast, two studies of Chinese participants' reported resisting family support by concealing their disease. One study revealed how participants concealed their disease since they did not want their family to feel compelled to meet cultural expectations for assistance (41) while in the other study concealment was used as a mechanism to protect family members from worry (62). Some Chinese-American participants' expectations of support were considered to be a completion of reciprocal role responsibility, with participants acknowledging that their families called on them to maintain their function of managing their diabetes (41).

Sometimes women resisted their family's attempts to supervise their self-management as they sought to maintain a sense of control (39) or where the women perceived their families 'uninformed' advice as intrusive and overwhelming (62). Elsewhere participants were reluctant to ask their children for help whom they perceived as already busy (37, 65).

Some participants reported that their families lacked understanding of the need for a strict diet (46, 84) at times tempting them with "treats" (83); meaning the risk of causing offence by declining had to be balanced with the risk of less than ideal management of their condition (29, 68, 80). Similarly, it was frequently reported by participants that feeling supported by one's family depended on the family's understanding of the disease since this decreased the perception that the participant was handling a complex regimen alone (31, 32, 33, 37, 38, 40, 83).

Elsewhere it was noted that disclosure elicited practical and emotional support from the family (61, 62, 80, 83). Families were reported as trying to motivate the participant in practical ways, including: focusing on the importance of self-management because of the danger of complications and the absence of a cure (62); reminding the participant what they should eat (36); making the participant renew self-management efforts by showing an interest in their health (62); and co-operating with the participant's diet thereby making it much easier to maintain (39, 43, 45, 48, 61, 82).

Although identified less often, there were also views suggesting a lack of familial support (84). Sometimes this was the result of a lack of understanding (31, 37) or circumstance, such as not living nearby (75). One study with an elderly diabetic population had the most views advocating a real lack of emotional and practical support from families who did not discharge them of home responsibilities (77). This lack of support included no provision of transport for participation in education, no provision of items required for self-management and no accompaniment to programmes where English is spoken. Similarly, views identified in another study demonstrated a lack of empathy from family members with no change in expectations of the woman's care giving role after diagnosis of diabetes (76).

### **Stigma**

Views presented in nine studies mentioned stigma as a concern (29, 37, 53, 60, 61, 66, 67, 82, 77) which at times led to participants' impaired ability to successfully self-manage.

Some participants explicitly stated that they did not disclose their disease to co-workers or employers in case they had reservations about a diabetic person's

ability to perform their job competently (37, 60). Another set of participants also spoke of keeping their condition a secret from wider social groups, especially when it was well controlled and would not arouse suspicion (77). Views in two other studies related how a social stigma to needle use acted as a barrier to insulin treatment (53, 66). Selective disclosure, as detailed here, appeared to affect the participants' ability to self-manage as well as impinge on their access to professional and social support. What was perhaps most surprising, were the views of one study where a participant reported feeling stigmatised by his own family since they considered diabetes to be a serious infectious disease and this resulted in the participant having limited physical contact even with their own children (60).

Elsewhere however there were views relating to diabetes as a common condition and as such participants felt comfortable telling people they had the condition (61, 67). The descriptive sub theme 'Experiences of others' has more details on the results of sharing information. It might be inferred here that the high prevalence of diabetes in these BME communities, Mexican-American and African-American, and their host country reduced the stigma held about diabetes. Alternatively or additionally, it may suggest an effectiveness of already developed and available interventions in the USA. For example, one USA study with an African-American population (82) mentioned that local church sponsored programmes helped provide a supportive atmosphere and to overcome the stigma of diabetes. However, this was not a consistent finding, participants in another USA study with a Latino population made an explicit plea for the community to have a greater appreciation of the difficulty of managing diabetes (29).

## **Education**

There are three subthemes within this descriptive theme, 'Experiences of others,' 'Approach to education' and 'Educational requirements.' These will now be presented in turn.

### *Experiences of others*

The experiences of others acted as an informal education and this was mentioned in 24 studies. Peers' and family members' experiences diagnosed with type 2 diabetes were often considered to be a useful information source (30, 32, 35,

36, 42, 48, 52, 60, 70, 75, 80, 82) and some participants specified story-telling as a useful method for learning about type 2 diabetes (29, 42, 48).

The experiences of peers and family members heavily influenced participants' healthcare goals. Social comparison was maladaptive for some respondents since there were views illustrating how it led participants to consider poor outcomes as inevitable (29, 30, 38, 44, 51, 52, 66, 67, 74, 80, 82) and also to understate the severity of their own problems (54). Participants from one study described a 'sugar' condition they had heard of in the Caribbean, where older people took little action to treat it and therefore it was assumed that it was a condition without much consequence (35).

For others however, exposure to morbidity and mortality amongst their kin and community was adaptive since it facilitated acceptance of their diagnosis (63) and for some observing friends or relatives suffering from complications was a realisation of the possible outcomes and as such was a motivator to self-manage well (35, 40, 52). Several studies reported views detailing the benefits of having good role models since they inspired hope for a normal life (32) and provided the opportunity for discourse with someone who was successful at self-management and understood the challenges (83) putting them in a good position to endorse successful approaches (74). An important consideration here is the potentially negative effects of sharing experiences in the absence of good understanding. Participants in one study stated that they viewed information deduced from their own observations of and conversations with friends and family more sceptically than information that is received from health professionals (37).

#### *Approach to education*

The diversity of the BME groups under study in this review is reflected well within this sub theme since conflicting views from 21 studies on participants' preferred approaches to education were clearly evident. Some participants sought a non-didactic approach to education (36, 54, 59, 63, 70, 82) with a preference for programmes that were taught using props which facilitated group discussion and encouraged participants to initiate actions (75, 81, 83). Meanwhile, other participants sought a more didactic approach to education where formal learning techniques were employed (29, 32, 77) and the health professionals were considered



the authority since they held medical expertise (34, 44, 46, 50, 54, 60, 63, 65, 68, 75, 80, 83, 85).

It was interesting to note that the majority of the nine studies reporting participants seeking a non-didactic approach to education were American (n=7). Whereas, the majority of the 16 studies that reported participants seeking a didactic approach to education had a South Asian sample (n=7). This represented more than half of the studies with a South Asian sample included in this review.

Participants in five studies talked favourably of having attended educational classes (38, 36, 61, 74, 82). Group education was positively received by participants within the review. This seemed to be related to its supportive (48, 62, 66, 74, 80, 82) and motivational atmosphere (75). Participants, mostly from Latino groups, appeared to seek the inclusion in the group education of their family members, partly for their supportive qualities but also as a chance for them to receive the appropriate education alongside the individual (31, 46, 74, 75, 83).

#### *Educational requirements*

Participants in 15 studies commented on their educational requirements. They were all seeking practical and culturally relevant education to aid their understanding of self-management lifestyle behaviours. Interestingly it appeared that, practical educational requirements tended to centre on diet, whereas cultural educational requirements were typically focused on physical activity.

Practical suggestions for learning about eating behaviours included: cooking demonstrations with serving size and group discussion of popular meals (48), food label reading (48, 57), focusing on foods which have negative consequences for diabetes (75), nutrition classes and food preparation classes (45) for healthy adaptations of traditional meals (74, 81, 82, 83), non-generic and culturally specific information (36, 73, 82, 83).

In terms of physical activity, culturally relevant suggestions for education included the supply and use of exercise videos (48) or indoor equipment, since they may constitute a viable solution to cold climates and gendered roles (66, 75). Salsa dancing was suggested by one BME group as a form of exercise that should be

recommended by health professionals as it is more familiar, appealing and culturally appropriate than the 'generic' suggestions of exercises such as walking (83).

While participants frequently noted their own educational shortcomings they did not present these to be an area of educational requirement. The use of health jargon in the healthcare context was identified as an educational barrier (47, 50, 63) as were participants' own limited literacy skills (75, 81, 83). One Hmong participant asserted that he did not check glucometers since he could not read numbers (42); another Somalian participant with poor literacy acknowledged struggling to be independent with prescribed self-care since he tried to learn all the advice from the health professionals by heart but admitted sometimes misunderstanding it (84). This limited literacy led some to perceive interactive education sessions as threatening (50).

### **Knowledge, attitudes and behaviours regarding self-management**

There was a broad range of knowledge, attitudes and behaviours regarding diabetes self-management from 48 studies. From the quantity of references throughout, it can be inferred that there are more primary studies referencing a lack of knowledge, negative attitudes and behaviours than those referencing good knowledge, positive attitudes and behaviours about living with and managing type 2 diabetes.

Evidence of limited general understanding included participants' views showing they perceived their diabetes control as adequate although it was not (77). Elsewhere a description of type 2 diabetes as the 'silent condition' was a pertinent reflection of confusion (30), as was the preoccupation with and 'hunt for a cure' (42, 60, 69). Other participants explicitly commented on the complexity of knowing what to do to manage diabetes (82). These views suggest a limited knowledge about self-management in general. However it was recognised by participants elsewhere that deficient knowledge meant that self-management was lacking (36, 37, 82). Meanwhile, although participants in another two studies showed evidence of knowledge, it was alongside an overt unwillingness to make lifestyle changes despite having seen family and friends suffering complications or death due to diabetes (44, 52).

Participants' knowledge and attitudes towards specific self-management behaviours are now presented in the five following subthemes. These are presented in order of frequency of mention in primary studies: diet (n=33); medicine adherence (n=29); blood-glucose testing (n=18); using insulin (n=15) and exercise (n=14). These views were associated with socio-economic and cultural factors. Participants' knowledge, attitudes and behaviours relate to traditional health beliefs and although these have been referred to intermittently in most of the descriptive themes they are brought together and reflected on here.

### *Diet*

Some participants spoke of the importance of diet (42, 61, 74, 76, 83) and illustrated an understanding of the relationship between food and blood sugar (48, 84). However, there was considerable evidence to emerge across numerous studies to show that many participants had limited knowledge about what constitutes a healthy diabetic diet (29, 45, 47, 61, 71, 74, 77, 75, 83, 84). Participants views affirmed that their lack of formal education was the main barrier in adhering to a healthy diet (29, 67, 71, 73, 80, 84).

Cultural barriers to eating a diabetic diet included the management of big appetites and cravings for traditional foods recognised as problematic to diabetes (29, 36, 60, 74, 82, 84). Traditional beliefs about food indicated the importance placed upon it across the different BME groups. Many studies suggested that people were attached to their cultural perception of healthy food practices (31, 40, 42, 49, 50, 56, 60, 61, 64, 70) despite recognition in some cases that certain methods of cooking and some types of food in traditional diets may be problematic (61, 80, 83). This led some participants to augment medical advice by incorporating professional advice with their own cultural perception of a healthy diet (49, 61).

This was coupled with negative perceptions of the diabetic diet, including its taste (31, 45, 56, 74, 84) and expense (36, 45, 56, 74) especially when participants reported it necessary to prepare two separate meals (34, 45, 56) suggesting the diabetic diet was considered inappropriate for the rest of their family. For many participants from different BME groups protecting the eating experience for their family was a clear concern (29, 34, 41, 35, 45, 49, 56) reiterating their view that diabetic food was inferior. Furthermore, participants own dietary needs were

frequently subordinated for the sake of family, reflecting the importance of food and family dynamics for example, with communal eating (29, 34, 37, 42, 47, 56, 68, 74). Similarly, many studies reported that it was particularly difficult to adhere to a diabetic diet during special occasions such as family get-togethers (36, 45, 50, 52M 60, 68, 80, 81).

#### *Medicine adherence*

Participants had strong attitudes about the importance of medication as part of the management of diabetes (42, 61, 64) and the importance of taking it as prescribed (54, 56, 61, 71, 80, 82, 84). Attitudes that had a negative influence on participants' adherence included an inconsistent motivation to take medicines (33, 57, 62) and a reluctance to change to medication when the participant perceived this as indicating a deterioration in their general health (37, 62). Some participants were uncertain about the effectiveness of medicines (74) and prioritised short-term goals such as avoiding moving onto insulin (47, 56) and relief from the symptoms of poorly managed diabetes (66) by taking their medicine irregularly. These types of attitudes towards medication led to a loss of commitment to adherence if the participant saw no change in their condition (57, 62). Similarly participants related that they reduced medicine intake if they felt well (42, 64, 67, 69) or that they took medication as a substitute for changes in other self-management behaviours (56). As with all of the self-management behaviours reported, participants' discourse disclosed behaviours that suggested a lack of knowledge about how the self-management behaviours brought about a physiological effect.

Traditional beliefs about medicine also featured strongly. Some BME populations tended to distrust Western medications (35, 42) and this was due to a range of concerns including, the side effects of prescription medicines (53, 64) as opposed to traditional remedies (69, 74, 77), the long-term health implications of taking oral hypoglycaemic agents alongside prescription medicines for co-morbidities (64) or alongside complementary treatments (69, 82), and the relative recency of Western medications when compared to Chinese medicines (53). Meanwhile, another group of participants perceived British medicines as more effective and of better quality than those that could be obtained in the Indian subcontinent and, as a result, thought it acceptable to take fewer of them (64).

Traditional remedies were referred to frequently by participants across different BME groups (30, 31, 35, 42, 53, 59, 60, 61, 62, 64, 69, 70, 74, 77, 78, 81, 82, 83) and it was apparent that these were used to varying degrees. Some participants mentioned traditional remedies but remained sceptical about their effectiveness (59, 78), or were concerned about their financial costs (77, 78). Participants from another study had a preference for traditional remedies because of familiarity and ease of access (53). Elsewhere, participants claimed to have witnessed the positive effects of traditional remedies (53) and consequently used only herbal medications (42, 62, 69). Location was also important, with some participants using traditional remedies when in their home country (35), while other participants talked about prioritising biomedical regimens in their host country (59, 78, 82) and even not seeking herbal remedies (64). Other participants preferred to integrate biomedical and traditional treatments (59, 60, 61, 82) whilst others abandoned traditional medicines if they proved ineffective (69). Participants in one study stated that they were seeking to cure their diabetes with traditional medicines and not just treat it (69).

#### *Blood glucose testing*

Some participants demonstrated an understanding that blood sugar should be tested daily (50) and that this helped successful management (60). Others noted that blood glucose testing was useful to evaluate how diet or exercise was affecting them (42) and also helped them evaluate symptoms (71). Some participants demonstrated that they knew what to do when blood glucose was too high or low (82), although they remarked at not always having the time and energy to respond (37).

It is noteworthy that participants from within one study displayed contrasting responses after finding that they had failed to achieve and maintain the desired blood glucose levels, some became more vigilant, experimenting and closely monitoring themselves, whereas other participants in the same group became defeated and abandoned self-management efforts (58). Since both sets of participants were observing and processing information to seek appropriate strategies, it is unclear why some participants continued to monitor their glucose levels while others did not. Participants in other studies also referred to abandoning self-monitoring because results were 'always high', indicating poor management (50, 58). As with the other self-management behaviours, there was also confusion regarding the

relationship between blood sugar readings and long-term health outcomes (75, 77, 83). Some participants were discouraged from using glucose meters because they disliked the pain of finger pricks (75) and in one study participants spoke of how their everyday life was filled with worries regarding high blood sugar levels because of their low levels of literacy (84). This demonstrates the breadth of barriers to testing blood-glucose.

Hypoglycaemia was clearly described by participants in several studies (61), quite frequently alongside a demonstration of fear (36, 42, 56, 67). Rapidly falling blood glucose is a frequent side effect of diabetes medication which, even at mild levels, can produce symptoms such as dizziness, sweating, disorientation, and palpitations, but it is of clinical concern only when it reaches severe levels. It may be to avoid this that participants reported maintaining a higher than recommended level of blood glucose (34, 42, 67, 74). In contrast to descriptions of hypoglycaemia, the single view of hyperglycaemia reported in these studies was rather vague and incorrect (61) as were details on the treatment for hyperglycaemia (77). Some participants however understood that stress elevated their blood sugar and reported using prayer, meditation and yoga for means of control (78).

#### *Using insulin*

There was evidence of negative perceptions of using insulin especially among Oriental participants. One group of participants deemed oral medications as more acceptable (42) whilst others displayed a reluctance to start insulin even when recommended by health professionals (53, 60, 69). There was also a stigma concerning insulin use that surfaced in the review, with people believing that regular use leads to addiction (61) or dependency (37, 53) or a desire for higher doses (B-69, Vietnamese). This was in part due to insulin's association with needle use (53, 66). It was also thought to indicate past failure to care for oneself (37, 53) and was held responsible by some for the unpleasant symptoms of low blood glucose levels (37).

Possibly related to this belief, participants reported adopting dangerous strategies in an effort to limit or avoid insulin use including relying on traditional remedies until blood glucose levels were very high (69) and reducing doses until

glucose levels were high (37). The most frequently mentioned barrier to insulin use was the dislike of injections (37, 53, 61, 66, 69, 76).

Only two studies reported views favouring the use of insulin. There were three main sets of views. First, that it was understood to help avoid complications and maintain energetic feelings (37); second, that it was faster acting than oral hypoglycaemic agents (63) and third that it helped control symptoms and prolonged life (37). On the other hand, there was also a lot of apprehension around insulin use, particularly on one's health outlook in terms of the progress and likely outcome of diabetes (37) as well as the possibility of administration errors causing further health problems (37).

Quite frequently insulin was understood to indicate the severity of diabetes (35, 37, 53, 60, 68, 69) and was thought to be directly related to severe complications, such as blindness and amputations (37, 61, 69, 74). This view was perhaps unsurprising since participants spoke of health professionals holding insulin as a threat or bargaining tool, suggesting insulin to be an outcome of failure to comply with earlier treatment (37, 53). Participants' experiences suggest this strategy is 'maladaptive' in the long-term as it can lead to a sense of personal failure and confusion, whilst reinforcing a 'dislike' of insulin.

Some regarded insulin to be unbeneficial (74) while others believed that there was no serious harm to health unless their diabetic regimen required insulin therapy (35).

### *Exercise*

Fewer participants remarked on the importance of exercise (42, 61, 66, 74, 75) than any of the other self-management behaviours. Socio-economic factors were identified as barriers to pursuing an active lifestyle, including prohibitive health club costs (31, 83), fear of walking in high-crime neighbourhoods (42, 43, 56, 74) and the difficulty of incorporating activities into already busy lives with long working hours (31, 42, 66). Cultural barriers included a lack of culturally relevant information on physical activity (74, 83) and a lack of culturally sensitive facilities. This was especially true for South Asian women who talked of staying indoors and not participating in sports (66) and the African-American elderly who talked of leading sedentary lifestyle as the norm (81). Physical barriers were also cited in

participants' views of exercise and these included the cold climate of the host country for a range of migrant BME groups (31, 42, 66, 73, 84). Co-morbidities and pain (31, 42, 56, 66, 73, 74) were other barriers to exercise.

There was a difference of opinion on what constituted sufficient level of exercise. For example participants in one study referred to how activity from their job or house work was enough (61). Others considered 'being active' to include deliberate exercise, for example walking (82), as part of their daily routine (48, 84). There was also some evidence of culturally ambivalent attitudes about obesity; for example in one study respondents suggested how a heavy person was seen as healthy and strong, while thin people were often viewed as ill (61). However, views also reflected the knowledge that exercise could control blood sugar levels (48, 61, 66, 84). Only one study reported a traditional health belief surrounding exercise. Participants perceived sweating, increased heart rate and breathlessness during and after exercise not as by-products of activity but rather as condition states to be avoided (66). It is interesting to note that there is no Hmong word for exercise because Hmong people traditionally have an active lifestyle; meaning it was a new concept to comprehend in the context of self-management for this population (42).

### **Causal beliefs**

There are two subthemes within this descriptive theme, 'Perceived causal relationships' and 'Causal attributions.' These will now be presented in turn.

#### *Perceived causal relationships*

Participants' understanding of causal relationships were evident in 19 studies. However, more views were incorrectly identifying causal relationships between symptoms and complications according to the biomedical framework than were correctly identifying them.

Symptoms of high blood glucose were correctly identified by participants in five studies, who also suggested that symptom meanings can be interpreted and used to adjust lifestyle and treatments accordingly (61, 71) and that the aim of a person with diabetes is to avoid the symptoms that indicate condition progression (42, 56, 60, 71). Other participants however, linked the definition of diabetes to the symptoms of poor self-management suggesting that they are perceived as inevitable



(30). Others still, incorrectly identified symptoms, for example rather than seeing sweating, increased heart rate and breathlessness as effects of physical activity, they were perceived as diabetes states to be avoided (66). Tiredness was viewed as a general symptom, rather than as a sign of poor diabetes control (51, 76) and some participants thought it was normal to experience feelings of tingling and numbness in the hands and feet (70) and so delayed seeking medical attention (32, 70, 82). This behaviour was especially evident in participants with multiple health conditions (71). Elsewhere, if the most severe symptoms did not recur, then participants believed themselves to be well (71).

The causal relationships between complications and prolonged periods of high blood-glucose were correctly identified by respondents in two studies (38, 42) with a further two studies identifying a goal to prevent complications through good self-management (52, 54). This is not to say that complications were always understood well (77). As with symptoms, some participants believed the severity of diabetes was related to the presence of complications (60) or that complications were inevitable (29, 30, 42, 52, 65). Another study reported the view that self-monitoring of blood glucose levels was an unimportant behaviour in regards to complications (74). Although other participants referred to using glucose monitors, exercising and dieting, they did not identify these as methods of delaying or preventing complications (30).

### *Causal attributions*

The views from 21 studies within this descriptive theme reflect the complexity of this review, since self-management practices are influenced by a host of health beliefs that are related to type 2 diabetes.

The causes of type 2 diabetes were ascribed to a range of lifestyle factors including diet (51, 57, 60, 67) specifically a perceived lack of fresh foods in UK (35), as well as a lack of exercise and weight gain (60, 61). Some participants ascribed the cause of type 2 diabetes to genetics and they evidenced an attitude of expectancy (30, 44, 80). Hereditary factors were identified as having a role (29, 44, 51, 57, 60, 61, 66, 67), whereas participants in one study despite having multiple family members diagnosed with type 2 diabetes, denied heredity any role (61).

Interestingly, a largely Latino sample attributed the onset of their type 2 diabetes to an emotional life event such as the death of a family member (29, 40, 49, 51, 57, 61, 68, 75). General sadness and stress were also identified as causes (35, 38, 42, 60, 69) as was intense anger (51, 61). Similarly, some participants made a link with the distress of the migration experience (35, 40) or the move to a new environment (35, 42, 43, 49, 60, 66, 68).

Attributional beliefs including eating too many sweets (30, 68, 70), taking medicines prescribed for other conditions (64), or perspiring less in the new climate (69), were considered by one or more groups of participants to be causes of type 2 diabetes. Similarly, spiritual factors such as God's will (66, 80), the devil (44) or a generational curse (44) were provided as other reasons. Participants from two other studies stated they did not know the cause of their type 2 diabetes (51, 60).

### **Spirituality and fatalism**

Spirituality is equated with the inclination to find meaning through an organized body of thought or faith and it has been characterised as playing a role in enhancing coping abilities, positive health beliefs, positive health behaviours, and positive health outcomes (Powe, 1997). In contrast, fatalism is philosophically opposed to this embodiment of spirituality. Fatalism is characterised by perceptions of powerlessness and despair, representing a dependency of health outcomes on external forces, powerful others or chance (Egede, 2003). This demonstrates how spirituality, for example a belief in God's divine plan for one's life, cannot automatically be considered to mean fatalism.

Powe and Finnie (2003) addressed the philosophical underpinnings of fatalism in a review and concluded that the perceptions of fatalism and spirituality are not mutually exclusive. In fact they noted that components of spirituality aided coping and helped modify fatalistic perceptions. They suggested that incorporating spirituality into interventions was an effective way to negate the feelings of hopelessness that are associated with fatalism.

Spirituality and fatalism were seen to both support and hinder coping in 21 studies. Related to the previous descriptive theme is the notion of fatalism which was seen both to support and hinder coping. Participants articulated positive fatalistic attitudes about how being able to accept that their fate has helped improve

their mental health (42). Negative fatalistic attitudes included participants believing that their present actions would not change their future (42) and reporting helpless and pessimistic feelings about their future health (29, 30, 42, 52, 65, 66, 84) particularly being without a cure (29, 30, 36, 42, 44).

Several groups of participants identified the important role of spirituality as an emotional support, enabling them to adopt an optimistic outlook (35, 36, 38, 62, 76, 80). Participants in one study noted spirituality's more practical role in supporting coping with type 2 diabetes, noting that including prayer in one's lifestyle helped control elevated blood glucose by reducing levels of stress (78). Religious communities were also felt by some, to provide psychosocial support (37, 82). Other participants stated that, although they had faith that God had direct influence on the outcome of their disease, this did not excuse them from self-management (35, 59). The religious practices themselves were also reported as an essential component of coping (76, 82). Participants in one study felt prayer helped reduce stress and anxiety (59). Furthermore, the conclusion drawn from three studies suggested that individuals with strong religious faith had less fatalistic attitudes (44, 76, 77). One study aimed to investigate the role of the health provider as giving spiritual care and found a range of views including that it meant participants felt less discouraged by diabetes and more confident to receive God's healing (72).

Like fatalism, spiritual beliefs were, as well as a help, interpreted as a hindrance to coping for some respondents. There were extreme examples of participants 'not claiming the diabetes' which were related to religiosity, and this involved not showing sickness, not undertaking any self-management or rejecting treatment (37, 44). There was also mention from two groups of participants of letting their religious considerations prevail over dietary ones, since women continued to observe the custom of sharing foods offered to the gods (43) and another group of participants did not want to give up their religious observation of fasting in Ramadan (84). There were no participants who saw faith alone as being adequate in dealing with their condition so much so that they channelled all their energies into devotion rather than education, although participants from two studies spoke of knowing someone who was like this (77, 82).

### **Summary of descriptive themes**

The findings of the original 57 'views' studies were synthesised and resulted in 11 descriptive themes: Emotional responses to illness; Confidence; Roles; Resource limitations; Health professionals; Family Support; Stigma; Education; Attitudes, behaviours and knowledge regarding self-management; Causal beliefs and Spirituality and fatalism. These descriptive themes deliberately remained 'close' to the key findings of the original primary studies. This stage of analysis had sought only to combine the findings of the primary studies into a list of themes which described BME participants' views on their diabetes self-management. Additional understanding of the concept under study was to be generated by 'going beyond' the findings of the primary studies in the next stage of analysis.

#### **4.3.3.2 Analytical themes**

Up until the analytical themes stage the synthesis product had not directly addressed the review question '*What is known about the barriers and facilitators of type 2 diabetes self-management amongst BME groups?*' As such, the synthesis product had not 'gone beyond' the findings of the primary studies. Findings had not yet contributed to extending understanding to a more conceptual level.

To achieve this next step, the descriptive themes were considered in the context of how they applied to and answered the systematic review's question. Barriers and facilitators to self-management were surmised from the views that BME participants expressed about their diabetes self-management. Furthermore, the implications of the findings for intervention development were considered and through this process more abstract and analytical themes were developed.

At this stage of the process the relationship between different levels of themes were carefully considered until the significance of over-arching themes became clear. Refinement of these resulted in three analytical themes, all of which addressed the systematic review question. It was crucial to consider the validity of the data set by establishing whether the analytical themes had referred to the review's entire data set. Figure 4.13 acts as a thematic map and demonstrates the relationship of the analytical themes to the descriptive themes. This doubled as a check ensuring that the analytical themes were a reflection of all of the 'views' data set.

Three analytical themes were identified: Importance of identity; Being understood by others; and Making sense of condition. Detail on each of these will now be presented, followed by detail on how all three analytical themes link to each other under the over-arching theme; Sense of self.

### **Importance of identity**

Identity was seen to be important for effective self-management in four different ways matching the four relating descriptive themes (see Figure 4.13). The importance of identity was seen to act either as a barrier or a facilitator of self-management depending on the outlook adopted by the participant.

Firstly, it was clear from participants' views, that inherent to diabetes management is a focus on and an adaptation of the self. People, and perhaps migrants especially, are attached to their identities and they seek to maintain them. These attachments to their identity can sometimes be in conflict with managing the long-term condition of diabetes for which adjusting lifestyle behaviours is a key requirement. Participants' overwhelmingly negative emotional responses to their condition, especially at the time of diagnosis, give an insight into how they viewed diabetes as an 'assault' on their identity and way of life. Similarly, participants' reactions to the complexity of the diabetes regimen were equally negative resulting in a failure to meet demands for diabetes self-management.

Secondly, the important role of confidence on self-management reiterated the importance of identity. Some participants, who had demonstrated an empowered perspective to self-management, suggested an ability to embrace their new and evolving identity. By the same token, other participants' views suggested that behavioural changes required by type 2 diabetes were not possible due to loss of confidence. These had their origins in feelings of disoriented identity or outright rejections of their new identity.

Thirdly, there is the importance of participants' self-identified family, social and work roles. Again, participants provided conflicting responses. For some participants these roles acted as a facilitator to self-management as they felt it was important for them to effectively self-manage and maintain their health, so as to retain their identity, independence and sense of normality. Meanwhile other participants reported considering their work, social and familial roles to be a barrier

to successful self-management, since the roles monopolised their time and energy making it physically and emotionally difficult to self-manage effectively.

Fourthly, many participants evidenced a strong attachment to spiritual and fatalistic attitudes as well as to traditional and cultural health beliefs about the different self-management behaviours but particularly those of diet and medicine taking. This seemed to be, in part at least, related to a connection with their cultural or religious identity.

### **Being understood by others**

Participants' views suggested that they felt positively towards those that supported them in their circumstances and there was a particular emphasis on being understood by others. Participants emphasised the relevance of their family and community showing an understanding of their condition and its self-management requirements. Meanwhile, views also showed that participants seek health professionals who show an understanding of their cultures and traditions. These three groups of 'others' match the three relating descriptive themes (see Figure 4.13).

Favourable talk of the practical and emotional support provided by family members was the most commonly presented view within the review. The level of familial support participants' felt they received depended on the level of understanding they perceived their family to have. Likewise, criticisms of family responses were mostly concerned with participants' feeling that their condition was misunderstood.

Despite the high prevalence of type 2 diabetes in many of these BME communities some participants did voice concerns about feelings of stigma. This lack of understanding of living with type 2 diabetes in society at large prevented some participants from disclosing their diagnosis whereas the perception of diabetes as a normal and common condition facilitated open discussion which in turn gave opportunity for information sharing. The experiences of others with type 2 diabetes were commonly considered as useful information sources by participants, who typically came from communities with high incidence and prevalence of type 2 diabetes. Again, this may be a result of being able to relate to others in the community. A favourable view of the opportunity for discourse with someone who

understands the challenges of diabetes self-management, goes some way to explaining participants' support for group education classes.

Participants' perceptions of the support that health professionals provided was another important theme. Participants considered constructive attributes to include health professionals providing quality care by taking the time to communicate in a meaningful way. Participants criticised health professionals who they felt did not provide appropriate treatment or who dispensed medical advice that they felt devalued cultures and traditions to which they were strongly attached. There was also a definite focus on the cultural and linguistic appropriateness of the health professionals' communication. Again as with perceptions of family support, favourable views regarding the abilities of health professionals can be seen to be a reflection of the level of understanding the participants perceived the health professional to have.

Furthermore, in regards to education classes participants articulated a clear preference for practical diet education and culturally appropriate physical activity education. In connection with this, participants spoke elsewhere about how their socio-economic stressors and cultural factors influenced self-management efforts. This is unsurprising to some degree since it is well documented that BME groups have a higher risk of ill health as result of a plethora of factors including social deprivation (see section 2.2.2.1). In this way, a desire to be understood was demonstrated once again in participants' views.

### **Making sense of own condition**

As with both other analytical themes, this analytical theme covers its four relating descriptive themes (see Figure 4.13).

Participants evidenced an array of notions surrounding attitudes and knowledge of various diabetes self-management behaviours. These biomedical and cultural health beliefs were primarily regarding food and medicines. It could be interpreted from participants' views that these health beliefs were core to both their understanding of their condition and the meanings they attributed to it.

While participants evidenced a broad range of views regarding various self-management behaviours, a clear majority demonstrated a lack of knowledge and

negative attitudes towards having to make changes in their lifestyle so as to accommodate for self-management behaviours. Similarly, most participants incorrectly noted the perceived causal relationships between symptoms and complications. These views reflected misunderstanding of type 2 diabetes and consequently its self-management. Furthermore, traditional beliefs regarding spirituality and fatalism appeared to further impact on the participants' understanding of diabetes.

#### **4.3.3.3 Over-arching theme 'Sense of self'**

The three analytical themes are all inter-related. They all fit together since each can be seen to influence the others. An individual's perception of their condition is in part influenced by how they identify themselves. Furthermore, it is clear from participants' views that it is important that others understand the participant's (perception of their) condition.

As such the over-arching theme identified was 'sense of self' as this conveys the story of the three analytical themes and how they relate to one another. This seems entirely reasonable in the broader context since self management is essentially the mediation between one's personal resources and one's environment.

#### **4.3.4 Summary of 'views' strands results**

Thematic synthesis identified eleven descriptive themes, three analytical themes and one over-arching theme. The analytical theme 'Importance of identity' related to four of the descriptive themes: 'Emotional responses to illness'; 'Confidence'; 'Roles' and 'Resource limitations'. The analytical theme 'Being understood by others' related to three descriptive themes: 'Health professional'; 'Family support' and 'Stigma'. Finally, the analytical theme 'Making sense of condition' related to the remaining four descriptive themes: 'Education'; 'Knowledge, attitudes and behaviours regarding self-management'; 'Causal beliefs' and 'Spirituality and fatalism'. These three analytical themes were conceptually linked with one another under the over-arching theme 'Sense of self'.



#### 4.4 Cross-synthesis results

The previous two sections of this chapter have presented the results of the interventions strand and the 'views' strand of the systematic review. The end-product of the narrative synthesis on the intervention strand was secondary analyses on eleven sub-sets of trials. The end-product of the thematic synthesis on the 'views' strand was three analytical themes. This next section provides the results of the cross-synthesis of these two end products.

There were two steps to the cross-synthesis. In the first step, the three analytical themes (Importance of identity, Being understood by others and Making sense of own condition) identified from the thematic synthesis of the 'views' strand data were considered in the context of the barriers and facilitators they posed to achieving effective type 2 diabetes self-management. From this, nine potential implications on intervention development were proposed (labelled A-I). This information is provided in Table 4.52. In the second step, these nine potential interventions were considered alongside the eleven sub-sets of trials (from the interventions strand). The aim was to establish whether the nine potential interventions addressed any of the sub-sets of trials (match or gap); and if so, whether secondary analyses had demonstrated these to be harmful, beneficial or neither to good self-management of type 2 diabetes.

The results of this step are presented in Table 4.51. There were gaps for two of the implications identified from patients' views (B, F). Meaning two of the potential implications for intervention development as identified in the 'views' strand were entirely unaddressed by the secondary analyses of the intervention strand. For five of the implications there were matches (C, E, G, H, I). Meaning these potential implications for intervention development had been addressed by the effectiveness synthesis. For the other two implications (A, D), there was insufficient evidence to draw a conclusion. This meant that, while the potential implication for interventions as identified by participants' views were addressed by a trial, there was insufficient evidence for secondary analyses.

Each of the potential implications for intervention development will now be discussed in turn. Detail will be provided as to why the potential implication is considered to represent a gap, match or insufficient evidence.

**Table 4.37** Effectiveness synthesis addressing implications for interventions identified from ‘views’ studies synthesis

	<b>Potential implication for intervention development</b>	<b>Content/Delivery of intervention</b>	<b>Effectiveness synthesis addressing implication</b>
<b>A</b>	Gender specific intervention	Content/Delivery	Insufficient evidence
<b>B</b>	Support positive outlook towards spirituality and fatalism	Content	Gap
<b>C</b>	Address patient confidence	Content	Match
<b>D</b>	Include family in intervention	Delivery	Insufficient evidence
<b>E</b>	Individual versus group education	Delivery	Match
<b>F</b>	Support information sharing with peers but regulate it for accuracy	Content	Gap
<b>G</b>	Practically, culturally and linguistically relevant communication	Content /Delivery	Match
<b>H</b>	Support positive outlook towards type 2 diabetes	Content	Match
<b>I</b>	Improve knowledge of type 2 diabetes behaviours	Content	Match

#### **4.4.1 Matching patients views to evaluated interventions: Implications for potential interventions**

##### **4.4.1.1 Gender specific intervention (A)**

The implication here was for a potential intervention that had a gender specific component. Participants’ views suggested that culturally social, familial and work roles are different for men and women and if this was recognised by a component of the intervention and tailored then its effectiveness may be optimised. Participants’ views also suggested that gender influenced the level of support they received from their families. Women related how they could feel unsupported while also reporting that familial expectations of their caregiver role remained the same. Meanwhile men reported receiving helpful familial support. ‘Views’ suggested gender specific interventions could be particularly advantageous for females since they share the same challenges and are experienced in providing support to others and so could do so for each other.

When this potential implication for interventions was reviewed alongside the outcome of the effectiveness synthesis there was insufficient evidence to say whether there was a gap or match between participants' views and the effectiveness of interventions. Due to the small number of interventions delivered specifically to one gender group (17, 22, 25, 15) gender was not a sub-set that was explored in the effectiveness synthesis. These results suggest that gender specific interventions could usefully be explored in subsequent research.

#### **4.4.1.2 Support positive outlook towards spirituality and fatalism (B)**

The implication here was for a potential intervention that supported a positive outlook towards spirituality and fatalism. Related to a connection with their cultural or religious identity, participants evidenced strong attachment to spiritual and fatalistic attitudes and this suggested evidence of both hindering and supporting coping depending on the participant's outlook (see Figure 4.13). When this potential implication for interventions was reviewed alongside the outcome of the effectiveness synthesis a gap was identified.

Only one trial (18) considered participants religious beliefs and this was only as part of its follow-up. Moreover, this trial did not show a positive effect on self-management outcomes. A potential implication for cross-synthesis suggests interventions could be used to promote or enhance a positive outlook towards spirituality and fatalism but there was not any evidence from the interventions strand to support or oppose this.

#### **4.4.1.3 Address patient confidence (C)**

'Views' studies indicated that participants with strong feelings of confidence demonstrated an empowered perspective towards diabetes self-management and this enabled them to embrace their new and evolving identity. On the other hand, lost confidence prevented participants from making behavioural changes which made the managing of type 2 diabetes more difficult. When this potential implication for interventions was reviewed alongside the outcome of the effectiveness synthesis a match was identified.

While none of the eleven sub-sets of trials (see section 4.2.5) considered this implication of targeting confidence directly, it was found that trials were more likely to be effective when based on a theoretical framework than when not. Furthermore,

many of these theoretical frameworks focused on confidence. This finding in itself was not conclusive although it was useful in that it indicated this to be an important area for further research. Not all of the theoretical frameworks had considered patient confidence, equally there were trials that had considered confidence in their design and delivery but had not labelled them in this way. The cross-synthesis suggested interventions should continue to address patient confidence.

#### **4.4.1.4 Include family in intervention (D)**

The implication here was that including family members in an intervention could serve to better utilise existing or potential support frameworks. Participants had noted how a lack of understanding from their families about diabetes meant they felt unsupported and alone in handling a complex condition. Participants with families who understood type 2 diabetes were able to elicit emotional and practical familial support.

When this potential implication for interventions was reviewed alongside the outcome of the effectiveness synthesis a gap was identified. That said, while this was not one of the eleven sub-sets of trials investigated by the effectiveness studies synthesis, five of the reviewed trials did include family in the intervention (7, 8, 6, 3, 11) however there was insufficient evidence to report an effect. This suggests that the inclusion of family in interventions should be directly assessed for effectiveness.

#### **4.4.1.5 Individual versus group education (E)**

The implication here was for a potential intervention to consider the impact of delivering education individually or to a group. Participants talked about the understanding their community had for them and their condition. There was a range of experiences reported some of which acted as barriers to self-management while others were facilitators for self-management. Some patients said that social stigma around type 2 diabetes led them to conceal their condition and this impinged on their ability to self-manage successfully. Others spoke about how because diabetes was common in their social groups they felt able to freely disclose their condition to others. This gave an opportunity for open discussion and information sharing. When this potential implication for interventions was reviewed alongside the outcome of the effectiveness synthesis a match was identified.

One of the trial sub-sets was directly related to this implication, analysing the effectiveness of trials, individuals versus groups versus combined education (see section 4.2.5.5). A tentative conclusion of the narrative synthesis was that interventions delivered to both individuals and groups were more likely to show an effect than those delivered to groups or individuals alone. Cross-synthesis suggest interventions should continue to address both components.

#### **4.4.1.6 Support information sharing with peers but regulate it for accuracy (F)**

The implication here was for a potential intervention to support already existing information sharing but to also regulate it for accuracy. A number of the views of participants indicated that they valued the experiences of their peers and family members with whom they shared a cultural background as useful information sources. Depending on the peers' and family members' level of understanding of diabetes, this could be a barrier or facilitator to self-management. If the information source was sharing experience in the absence of good understanding, this could be harmful to self-management. Whereas, if first hand experiences of the challenges of diabetes and how to overcome them were being shared then this could be beneficial to self-management.

When this potential implication for interventions was reviewed alongside the outcome of the effectiveness synthesis a gap was identified. Although there were trials that had built in components of group discussion that were based on similar principles of information sharing, they differed in that the groups in the trials were composed of strangers, albeit from the same community. The 'views' strand emphasised participants valued learning of experiences from their own family and friends. There were no trials included in the interventions strand that directly considered this. The cross-synthesis results suggest this to be a missed opportunity.

#### **4.4.1.7 Practically, culturally and linguistically relevant communication (G)**

The implication here was for health professional's to consider participants' identity and as a result deliver care in a practically, culturally and linguistically appropriate way. Participants' views emphasised the importance of an appropriate healthcare exchange. Patients spoke of positive consultations with health professionals with whom they shared a common language or culture. Patients also

showed a high regard for health professionals who provided high quality care in terms of time taken to communicate in a meaningful way. Difficulties were noted when the patient spoke and understood little or none of the host country's language. Participants also exhibited a low regard for health professionals whom they felt provided inappropriate treatment or dispensed impractical or unrealistic medical advice that devalued the cultures and traditions to which participants were strongly attached.

When this potential implication for interventions was reviewed alongside the outcome of the effectiveness synthesis a match was identified. One of the eleven sub-sets of trials directly considered this implication by analysing the relative effectiveness of culturally competent trials versus trials that do not consider cultural competence in their development or delivery (see section 4.2.5.1). A tentative conclusion was that culturally competent interventions are more likely to show an effect than those that have not considered cultural competence. The cross-synthesis suggests this provides support for this move towards culturally and socially appropriate group education and suggests it should be continued.

#### **4.4.1.8 Support positive outlook towards type 2 diabetes (H)**

The implication here was that interventions needed to maintain or develop a patients' positive outlook towards their condition, for example by lowering expectations of a cure or immediate effects. Participants' suggested that negative emotional responses to diagnosis and failing self-management prevented them from making behavioural changes, whereas participants who emphasised the personal experience of diabetes were more successful at making behavioural changes.

While none of the eleven sub-sets of trials (see section 4.2.5) considered this implication directly, the effectiveness synthesis had considered outcomes according to attitudinal, behavioural, knowledge and physiological measures. However, since only three trials reported effects on attitudinal measures as their primary outcome (8, 9, 27) and none of these were directly comparable (see section 4.2.3), findings were inconclusive. This means that cross-synthesis suggests an intervention needs to be developed and delivered so as to consider its potential effectiveness.

**Table 4.38** Barriers, facilitators and potential implications for interventions to promote self-management amongst BME patients

<b>Analytical Theme</b>	<b>Barriers</b>	<b>Facilitators</b>	<b>Potential implications for intervention development</b>
<i>Importance of identity</i>	Social, familial or work roles made it difficult physically and emotionally to self-manage.	Social, familial or work roles made it important to self-manage so as to maintain identity, independence and a sense of normality.	<b>A</b> Culturally the caregiver role was the norm for females suggesting that gender specific interventions should be considered.
	Related to a connection with their cultural or religious identity, participants evidenced strong attachment to spiritual and fatalistic attitudes, which suggested evidence of hindering coping.	Related to a connection with their cultural or religious identity, participants evidenced strong attachment to spiritual and fatalistic attitudes which suggested evidence of supporting coping.	<b>B</b> Range of attitudes towards spirituality and fatalism suggest evidence of it both supporting and hindering coping. An intervention could support a positive outlook.
	Poor confidence prevented behavioural changes due to lost confidence because of a disoriented identity or rejections of new identity.	Participants with strong confidence demonstrated an empowered perspective to self-management and embraced their new and evolving identity.	<b>C</b> A component of the intervention needs to address patient confidence by making the patient more receptive to education.

<b>Being understood by others</b>	Lack of understanding from families about diabetes meant the participants felt unsupported and alone in handling a complex regimen.	Understanding from families about diabetes meant participants were able to elicit emotional and practical familial support.	<b>D</b> Include family in intervention so as to better inform and thereby utilise an existing (or potential) support framework.
	Gender was found to influence support received from family. Women felt unsupported. Expectations of their caregiver role remained.	Gender was found to influence support received from family. Men reported significant support.	<b>A</b> Gender-specific intervention. Female-only support group as they share the same challenges, are experienced in providing support and can do so for each other.
	Social stigma around diabetes led patients to conceal their condition and this impinged on their ability to self-manage successfully.	When diabetes was considered a normative disorder patients disclosed their condition and this gave opportunity for open discussion and information sharing.	<b>E</b> Individual education. <b>E</b> Group education.
	Participants commonly considered the explanations of peers and family members as information sources but it can be dangerous in the absence of good understanding.	Participants commonly considered the explanations of peers and family members as information sources because they had first hand experience of the challenges.	<b>F</b> Intervention can support information sharing with peers but regulate it for accuracy.



	Culturally and linguistically inappropriate healthcare exchange can be an obstacle to good understanding.	Culturally and linguistically appropriate healthcare exchange can enable good understanding.	<b>G</b> Consider participants' identity and communicate in a practically, culturally and linguistically appropriate way.
<b><i>Making sense of own condition</i></b>	Attitudes towards spirituality and fatalism hindered coping.	Attitudes towards spirituality and fatalism supported coping.	<b>B</b> Range of attitudes towards spirituality and fatalism suggest evidence of it both supporting and hindering coping. An intervention could support a positive outlook.
	Negative attitudes towards diabetes.	Positive attitudes towards diabetes.	<b>H</b> Support positive outlook towards diabetes.
	Lack of knowledge about diabetes.	Abundant knowledge about diabetes.	<b>I</b> Improve knowledge of self-management behaviours.

*Note*= Letters in bold in 'potential implications for intervention development' column relate to Table 4.37 and to cross-synthesis headings.

#### **4.4.1.9 Improve knowledge of type 2 diabetes self-management behaviours (I)**

The implication here was to provide health education that serves to improve knowledge of self-management behaviours in type 2 diabetes. Unsurprisingly, the 'views' review showed that a lack of knowledge about type 2 diabetes was a barrier to self management while a good knowledge was a facilitator. One way to do this could be by emphasising appropriate behavioural responses to avoid the symptoms and complications of poorly managed diabetes in health messages. The 'views' strand demonstrated these areas as being particularly misunderstood and in need of an educational intervention.

When this potential implication for interventions was reviewed alongside the outcome of the effectiveness synthesis a match was identified. While none of the eleven sub-sets of trials (see section 4.2.5) considered this implication directly, as noted earlier the effectiveness synthesis had considered outcomes according to attitudinal, behavioural, knowledge and physiological measures. However, since only two trials reported effects on knowledge measures as their primary outcome (4, 14) and neither of these was directly comparable (see section 4.2.3) findings were inconclusive. Nonetheless, cross-synthesis gives support to this type of intervention as being valued and well-received by BME patients.

#### **4.4.2 Summary of cross-synthesis results**

In summary, the key messages from this cross-synthesis of the effectiveness and views strands were:

\* Of the nine potential implications for interventions there were five matches i.e. when the effectiveness synthesis had already addressed the implication.

-Of these, there were two instances when the effectiveness synthesis had demonstrated there to have been a positive effect. Participants' views favoured education that was culturally competent and they also noted the benefits of individual education as well as the benefits of group education. The trials also showed interventions to be most effective when they were delivered in a culturally competent way and when they had both a group and individual component.

-It was unclear in the other three instances whether the effectiveness of the following interventions matched participants' views and so these required further evaluation. These were: addressing patient confidence; supporting a positive outlook towards diabetes and improving knowledge of diabetes.

\* Of the nine potential implications for interventions there were two instances where there was insufficient evidence to draw a conclusion and so these too require further evaluation. These were including family members in self-management and providing gender specific interventions.

\* Of the nine potential implications for interventions the remaining two were gaps. These were supporting information sharing amongst peers and supporting a positive outlook towards spirituality and fatalism. In these instances the 'views' data identified gaps which provides guidance on opportunities for developing and evaluating innovative interventions.

## **Chapter 5**

### **Discussion**

#### **5.1 Introduction**

This systematic review had two strands, one reviewing intervention studies of self-management interventions for type 2 diabetes delivered to BME populations, and the other reviewing BME patients' 'views' studies on type 2 diabetes self-management. The synthesis of the intervention studies strand aimed to answer the question 'How effective are existing interventions to support self management of type 2 diabetes in BME patients?' The thematic synthesis of the 'views' strand aimed to answer the question 'What are BME patients' views surrounding self management of type 2 diabetes?' Following this, there was a cross-synthesis, where the findings of both the 'views' and interventions strand were integrated to answer the question 'Do existing interventions address the identified views of ethnic minority patients?'

A key strength of this systematic review was that by employing EPPI's methodological approach the inclusion of studies of multiple research designs was enabled. This approach was entirely novel in this area of research. Each of the two search strands had its own synthesis process and each could essentially be regarded as a systematic review in its own right. The cross-synthesis of these two strands was an additional dimension.

These intervention and 'views' strands are now discussed in turn. First the interventions strand is discussed, focusing on confidence in the findings and then discussing the key findings in light of other systematic reviews. Second the 'views' strand is discussed, focusing again on the confidence in the findings and discussing the key findings with suggestions for future research. After this a brief commentary is provided on the cross-synthesis. Finally some limitations of the systematic review are presented concluding with a reflection on methodological issues in conducting systematic reviews.

## **5.2 Interventions strand**

### **5.2.1 Confidence in secondary analyses**

This was an effectiveness review of 28 trials testing interventions for self-management of type 2 diabetes. Amongst these trials there was heterogeneity on seven different issues, these were: trials reported effects on different primary outcome measures including physiological, attitudinal, behavioural and knowledge measures; for each of the primary outcomes there were multiple different measures reported for example for physiological measures trials reported effects on HbA1c and weight change; while 20 of the trials had used a 'usual care' control group eight trials employed comparison groups; four trials had multiple arms; follow-up times differed between trials and finally, risk of bias varied between studies. The various sources of heterogeneity among trials prevented a meta-analysis and made synthesis of the interventions strand somewhat challenging.

### **5.2.2 Methodological issues in conducting the interventions strand**

A challenge was that the review was broad, complex and inclusive. For the reasons already detailed in the previous section, the decision was made not to employ a meta-analysis. To undertake secondary analyses, the sources of heterogeneity amongst trials had to be overcome. There were five limitations in the undertaking of these secondary analyses and these will now be presented. Some are specific to this review while others are more general.

Firstly, since a meta-analysis was not appropriate, for the purpose of analysing the review's findings the interventions were classified into ten suitable categories according to the intervention's focus and method of delivery. This meant the issue of small sample sizes was exacerbated, especially when number of categories within the sub-set increased. Four of the sub-sets had four categories (length of intervention; care setting; delivered by health professional(s) versus other; lifestyle versus general self-management versus health service use versus single self-management behaviour).

Secondly, absolute scores were used instead of relative scores e.g. weight (rather than weight change). This issue of absolute versus relative scores is complex. On one hand change scores can help account for allocation by primary investigators and while variation in reporting was one challenge to doing this it can

be considered a role of secondary researchers to approach primary authors for these data. However, on the other hand, when a sample size had not been calculated, change scores might be misleading as the study may be underpowered. Furthermore, while with physiological measures it is straightforward to calculate data before and after an intervention, with attitude, behaviour and knowledge measures it can be harder as responses may be influenced by the repeated completion of a psychometric measure and so in that regard, outcome scores can be more reliable than change scores. Poor sample allocation in trials (especially where there were small sample sizes) meant that baseline scores were not comparable and the reliability of the results was limited. The employment of confidence intervals however reduced this problem. As can be seen from the 'risk of bias' table (Table 4.35) all but one study had a low risk of bias due to adequate sequence generation (i.e. investigators described a random component in the sequence generation process). However, Table 4.34 shows that only 13 studies reported their required sample size and of these ten achieved it.

Thirdly, the problem of multiple testing in trials meant there was danger of Type I error, i.e. when the null hypothesis is incorrectly rejected. Secondary analyses tried to overcome this issue by basing analysis on the primary outcome as identified (rather than all of the outcomes) within each trial. However this limits comparability of included trials since they are all subject to different biases and levels of accuracy. There was also the potential issue of selective reporting of outcomes based on the direction of results (Chan et al, 2004). Related to this was the issue of publication bias being a possible source of error. Since only published articles were included in the systematic review, it is possible that more trials producing a small or no result were not included in the interventions strand, suggesting the review overestimates the benefits of the interventions tested (Dickersin et al, 1992; Easterbrook et al, 1991). That said, the results of included trials did not all present positive findings, this shows that with some trials there was clearly not a publication bias.

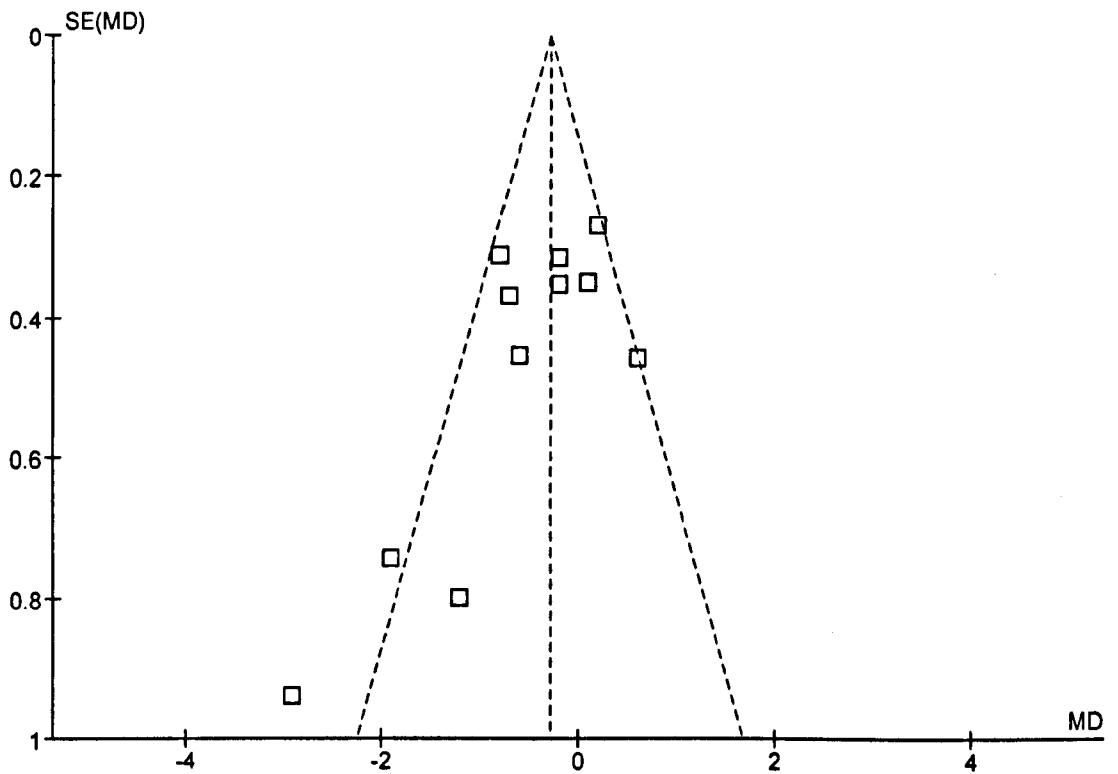
The funnel plot is a simple graphic technique that is commonly used for detecting publication bias (Light and Pellimer, 1984). The funnel plot is a scatter plot of the component studies in a review with the treatment effect plotted on the horizontal axis, and a weight, such as the inverse standard error, or sample size,

plotted on the vertical axis. Larger weights correspond to more precise estimates of treatment effect. Smaller weights produce effect sizes that spread across the horizontal axis. The funnel shape is produced since larger, more precise studies tend to be closer to the true effect, whereas the smaller studies are more variable. A symmetric, inverted funnel shape is commonly interpreted as implying there to be no publication bias. However, if the funnel is missing points from the lower corner of the plot which is associated with ineffectiveness of treatment, there is potential bias.

Terrin et al (2005) recommend caution when employing and interpreting funnel plots noting there to be causes for funnel plot asymmetry other than publication bias. They suggest that heterogeneity in studies is an overlooked aspect of asymmetry. Heterogeneity can be due to variation between study protocol, study quality and patient characteristics. A funnel shape cannot be expected when multiple treatment effects are estimated. Furthermore, an implication of their research was that a funnel plot should not be employed when there are ten or fewer primary studies since there would be a lack of power and the symmetric or asymmetric funnel shape may simply be due to chance.

In light of these caveats it was clear the only outcome variable in the review with enough studies to benefit from the application of a funnel plot was the physiological measures outcome. All but two of these trials reported the interventions effect on HbA1c levels. To increase homogeneity the two trials reporting on weight change (1, 19) were excluded from the funnel plot.

The plot overleaf appears to be symmetrical and is of an inverted funnel shape. However, the funnel has missing points from the right hand corner of the plot which is associated with the ineffectiveness of an intervention, suggesting there to be a publication bias present in trials reporting on HbA1c.



**Figure 5.1** An inverted funnel plot of trials measuring HbA1c to detect publication bias *Note:* MD=mean difference SE(MD)=standard error(mean difference)

The fourth limitation in the undertaking of secondary analyses was that the primary outcome measures differed and were not comparable in terms of clinical significance. Behaviour is arguably the outcome where it is most difficult to show an effect whereas knowledge is perhaps easier to change but this does not mean behaviour change can be assumed. It was therefore decided to not compare across different groups of primary outcome measures. Related to this, a difference may be statistically significant and real but not necessarily clinically important; on the other hand (and what was more likely to have been true with this review) was the issue that while a difference may not be statistically different due to a small sample size it may still be a real and important difference (Bland, 2000). Related to this was the general criticism that self-management programmes tend to have their effectiveness measured by clinical outcomes although the focus of the self-management programmes is often on improving the patients' skill and improving quality of life and so other outcomes may be more relevant (Osborne et al, 2008). Osborne et al (2008) also criticised self-management programmes that focus on confidence as their primary outcome measure of improved self-management since this can be criticised as overlooking the social environment of the individual with the long-term condition who often poor functional capacity and live in socially deprived areas.



Lastly, differentiating the effects of ethnicity from the effects of socio-economic status was prevented because socio-economic status was generally reported as low across all samples. This was disappointing since this systematic review was unable to add to the understanding of when ethnicity is a genuine variable and when it is masking underlying causal factors.

These limitations made generalisations problematic about which interventions were effective and which were not.

### **5.2.3 Key findings as compared with other systematic reviews**

The findings of the interventions strand showed that a self-management intervention was more likely to show a positive effect if it was culturally competent, based on a theoretical framework, delivered in a primary health care setting and had both educational and practical components. An intervention's effectiveness was not shown to be influenced by its length or by whom it was delivered. The remaining four sub-sets of trials produced inconclusive results, these were regarding whether the intervention: focused on a single self-management behaviour versus multiple self-management behaviours; was delivered to individuals, groups or both; was delivered in a didactic or interactive style and what type of self-management behaviour the intervention focused on. Limitations of these findings have already been discussed.

Although this review found an intervention's effectiveness not to be influenced by its length, Warsi et al (2004) noted that while short self-management programmes did improve knowledge, behavioural and attitudinal outcomes these effects were not necessarily long-lasting since none of the included interventions lasted longer than 72 weeks. This point is related to the fact that while there were eight longitudinal studies that were recording data at repeated intervals over a short period in this systematic review (see Table 4.33), the median follow-up period was only six months. This meant that included interventions did not report on whether results were long-lasting. Coulter and Ellins (2007) had collated existing evidence from 67 well conducted systematic reviews and they found that interventions that were providing information alone were unsuccessful whereas education supplemented with clinician support was shown to improve health outcomes in a range of long-term conditions including diabetes. This supported the findings of this systematic review. Deakin et al (2005) found group based educational programmes

to improve a range of physiological, knowledge and quality of life measures in type 2 diabetes patients. While a sub-set of trials in this review did test interventions delivered to individuals versus interventions delivered to groups versus interventions with both individual and group components, results were inconclusive.

Four published systematic reviews have been identified that evaluated different styles of type 2 diabetes self-management intervention with BME populations. Their key findings and included studies are now discussed in the light of the findings of this systematic review.

Sarkisian et al (2003) undertook a systematic review of diabetes self-care interventions designed to improve glycaemic control or quality of life of older African American or Latino Adults. Twelve studies were included, eight were of a trial design. Of these four studies were included in the interventions strand of Study One (1, 6, 16, 21). The other four were excluded on the basis of population criteria. This was because the primary studies had samples partially comprising people without type 2 diabetes, or not of BME groups. Results were descriptive and in these terms the theoretical basis and cultural competence of the included interventions were noted.

The findings of Sarkisian et al (2003) can be seen to have similarities with the interventions strand of Study One. Sarkisian noted that successful interventions were those that were tailored to culture and age. Study One's intervention strand had also provided support for interventions that were culturally competent. Sarkisian noted that successful interventions used a group support component. In Study One, while evidence had been more limited for this subset, the tentative conclusion had been interventions containing both an individual and group component were most likely to be effective. Sarkisian also noted the success of interventions to depend partly on poor HbA1c at baseline and involvement of the participant's spouse or children. These components had not been addressed in the secondary analyses of Study One's intervention strand.

Whittemore (2007) conducted a systematic review which focused on culturally competent interventions for Hispanic adults with type 2 diabetes. Eleven empirical studies were included. Of these seven were of a trial design. Three of the seven were excluded from this review based on population criteria and the other four were

included (6, 7, 21, 23). Since Whitemore's review only included culturally competent trials it was not able to comment on the effectiveness of culturally competent trials versus not culturally competent trials. The author did not report on theoretical frameworks. While it was commented that the majority of interventions were delivered in a community setting, they did not explore whether setting influenced the effectiveness. Since Whitemore (2007) found that heterogeneity of outcomes precluded meta-analysis statistical techniques they provided only a narrative analysis.

Whitemore found significant but modest improvements in physiological, behavioural and knowledge measures. In Study One there had been insufficient data to comment on the effect of interventions on attitudinal, behavioural or knowledge measures so in this way comparisons were limited. While Whitemore had only included culturally competent trials they recommended addressing linguistic and cultural barriers to care as a starting point for the improvement of diabetes self-management in Hispanic adults. The findings of Study One which favoured culturally competent interventions was in keeping with this finding from Whitemore.

Khunti et al (2008a) conducted a systematic review that focused on educational interventions for migrant South Asians living with type 2 diabetes in the West. Nine studies were included, of which only five were of a trial design. Three of these were included in this systematic review (4, 14, 20), two were excluded because their focus was on delivery of care not self-management. Khunti et al (2008a) did not consider the intervention setting in their review. Theoretical frameworks and cultural competence were also not considered in their review. Their review focused on educational interventions, but unlike this review, did not provide any sub-group analyses such as primarily educational interventions versus educational interventions with practical components. The review reported some of the included studies to have limited quality of reporting and omissions of important information. They attributed this, the low number and heterogeneity of studies as making the identification of factors linked to effectiveness difficult and meta-analysis inappropriate.

One of the findings of the systematic review undertaken by Khunti et al (2008a) was that improvements on knowledge measures were easier to achieve

than improvements on physiological outcome measures. The interventions strand of Study One had only included two trials that had considered knowledge measures to be their primary outcome preventing a useful comparison with Khunti.

Hawthorne et al (2008) undertook a Cochrane systematic review of clinical effectiveness on culturally appropriate type 2 diabetes health education interventions in BME groups. Eleven randomised controlled trials were included, ten of these were included in this systematic review (1, 2, 4, 6, 13, 14, 17, 20, 23, 25). The excluded trial was concerned with perceptions of care rather than self-management. Since the review only included culturally competent and educational interventions, comparisons could not be made with the findings of this systematic review which reported effects on the efficacy of culturally competent trials versus not and primarily educational interventions versus educational and practical interventions. Hawthorne et al noted the same issue of heterogeneity. Unlike the other systematic reviews however secondary analyses were conducted here. Unlike the analysis in this review which looks at the outcome measures at the last time point, Hawthorne et al looked at change scores over multiple time points. Furthermore, they ran multiple meta-analyses on a range of clinical and patient centred outcomes that they identified as primary or secondary outcomes.

This style of analysis enabled Hawthorne to demonstrate that HbA1c was improved at 3 and 6 months following culturally appropriate health education. Knowledge was also improved at 3, 6 and 12 months following an intervention. Various attitudinal measures and physiological measures other than HbA1c showed no effect as compared to control. As noted previously, because secondary analysis in the interventions strand of Study One had only included primary outcome measures at the last time point reported, comparisons have been limited with outcomes outside physiological measures, specifically HbA1c.

Finally, a systematic review conducted by Saxena et al (2007) was in some ways close in style to the one presented in this thesis. Firstly, Saxena et al (2007) did not focus on a specific ethnic minority group as Whitemore (2007), Khunti (2008a) and Sarkisian (2003) had done. Secondly, Saxena et al (2007) did not focus on particular outcome measure as Sarkisian (2003) had done. The trials strand of Study One had not excluded studies on the basis of BME group or outcome data either.

However, while there were these similarities, Saxena et al (2003) focused not on self-management intervention but on primary healthcare, identifying case management and link workers as the main models of care to improve diabetes outcomes in BME groups. They found 'case management' with diabetes specialist nurses and community health workers to have a greater effect on HbA1c than the use of 'link workers' matched to the patients ethnic group. Comparisons between these findings of Saxena et al (2003) and those of the intervention strand from Study One are impossible to draw since such trials had been excluded from Study One as they were not considered to meet the inclusion criteria of assessing 'self-management' interventions, but rather they were testing healthcare interventions.

As most of the available systematic reviews focused on BME populations from one host country and specific outcomes, their generalisability was limited. A strength of the review presented in this thesis is its broad scope. Any outcome measures relating to self-management and any BME population living in any country were included. This provided opportunity for useful comparisons and enabled comment on what components of the intervention contribute to its effectiveness. Despite heterogeneity amongst the 28 included trials the review has produced some interesting conclusions. Even with such broad inclusion criteria and limitations to secondary analyses culturally competent interventions showed a positive effect as did interventions based on a theoretical framework.

## **5.3 'Views' strand**

### **5.3.1 Confidence in 'views' analyses**

As discussed in section 3.1.3, systematic reviews of qualitative studies are a more recent development as compared to effectiveness reviews. While there were examples of qualitative research regarding the diabetes experience being synthesised (Paterson et al, 1998; Campbell et al, 2003) there was an absence of any qualitative systematic reviews focusing on BME group's views of diabetes self-management. A clear strength of this systematic review is that this 'views' strand was, the first of its kind. There is extensive primary research in this area making secondary analysis timely.

The synthesis of BME participants' own views on their experiences of type 2 diabetes self-management provided an insight into what issues BME participants themselves regarded as the barriers and facilitators of type 2 diabetes self-management, instead of what is assumed by health professionals, policymakers and trial researchers. As with the intervention strand, being inclusive in terms of outcome measures and population groups gave opportunity for interesting comparisons.

A real strength of 'views' synthesis is that it enabled the drawing together of data from similar populations in similar settings so as to examine commonalities and differences. This enables statements about theoretical generalisability to be made in a way that would be impossible for individual qualitative studies which prevents replications in research. As expected, the findings from the accumulative studies enabled a clear statement of what was already known from past research and what is now required from future research.

### **5.3.2 Methodological issues in conducting the 'views' strand**

A challenge was that the review was broad, complex and inclusive. For the reasons already detailed in section 3.1.7.1, the decision was made to employ thematic synthesis.

Thomas and Harden's (2008) publication on methods of thematic synthesis of qualitative research in systematic reviews went a long way to aid the synthesis of the 'views' strand although Thomas and Harden had used a specific and small review in

their worked example. The systematic review by Garcia et al (2002) included 74 primary studies and was a useful article for methodological reference. According to Dixon-Woods (2005), Garcia et al (2002) employed thematic synthesis and although Garcia et al did not explicitly articulate this as their method, one can infer it as such.

Garcia et al used a series of questions that emerged as part of the exploratory analysis to help organise the large data set, it was conceded in the paper that altered methods may have lead to different findings since descriptive themes were clearly orientated around sub-questions. While the advantage of having sub-questions with which to interrogate data was recognised and duly employed in the thematic synthesis of this review, care was taken to avoid the same pitfalls as Garcia.

The three questions with which to interrogate the 'views' data were kept broad and were developed a priori (see section 3.2.7.2) so as not to influence findings. These three broad questions provided a useful way to organise the data since they focused on different dimensions of the barriers and facilitators of self-management. The framework of barriers and facilitators itself helped understand the large amount of data under the descriptive themes.

Moreover, using the three questions to interrogate the 'views' data was a key factor in making the process of 'going beyond' the key findings of the primary data explicit and transparent. Although it had not been predetermined at which point of synthesis they would be employed it seemed to be the natural choice to apply them after the first step of line-by-line coding, to help organise the data into descriptive themes.

Another limitation of the Garcia (2002) paper and more broadly, of thematic synthesis as a method (Dixon-Woods et al, 2004) was that the description of the process of moving from descriptive to analytical themes lacked detail. This systematic review aimed to overcome this obstacle. Having the three broad questions to organise the data helped some of the process of arriving at the analytical themes from the descriptive themes. It was further enabled by writing discursively thereby providing a detailed and clear presentation of how the analysis was taken. Writing up the process of analysis further enabled interrogation and consolidation of the research question so as to develop conceptual codes at the analytical level. Since

this systematic review composed part of a thesis, word limits that bear heavily on articles and reports were less of a concern here.

### **5.3.3 Key findings with suggestions for future research**

The synthesis of 57 studies examining BME group's views on self-management of type 2 diabetes resulted in 11 descriptive themes with 11 sub-themes, three analytical themes and one over-arching theme. The analytical themes 'Importance of identity,' 'Being understood by others' and 'Making sense of own condition' will now be considered in turn, finally the over-arching theme 'Sense of self,' which captures all three analytical themes will be discussed. Although there were no existing systematic reviews of 'views' studies on type 2 diabetes self-management with which to draw comparisons, findings of the review do resonate with wider literature. This will be highlighted as the results for the over-arching theme 'sense of self' are discussed.

#### **'Importance of identity'**

Identity was seen to be important for effective self-management in four different ways (see Figure 4.2.3). Identity was seen to act either as a barrier or a facilitator of self-management depending on the outlook adopted by the participant. It seems key to improving self-management to understand what aspects of identity make participants feel and behave in different ways in regards to their diabetes. Unfortunately the synthesis did not tackle this but perhaps it would be an avenue for future research.

One of the ways in which identity was important for effective self-management was regarding the role of confidence. While some empowered participants were able to embrace their identity as a person with diabetes other participants' reflected being unable to make behavioural changes and this seemed to be due to a loss of confidence. The systematic review's findings reinforce the observations and recommendations of Gans et al (2009) that even the simplest diabetes education interventions can be intimidating for patients with poor management meaning there is a requirement to enhance these patients self-efficacy as well as their competency. It is proposed that this be done by individualising education based on diagnostic tests to the patients' skill level and learning style.



### **'Being understood by others'**

Participants' views towards support from family, based on feeling understood, were largely positive. There were however, some differences in responses to familial support based on participants' ethnicity. All explicit statements that family support was 'valued' came from North American studies of African-Americans or Latinos. In contrast, two studies of Chinese participants' reported resisting family support by concealing their disease. These are interesting findings and suggest that some differences in self-management are due to differences in how an ethnic group behaves or operates and this gives some support to tailoring interventions by ethnic group. Naturally, these issues would require further research since the thematic synthesis produced many more generic findings than specific ones.

### **'Making sense of own condition'**

Participants' included in the systematic review evidenced an array of biomedical and cultural health beliefs that were core to the meaning they attributed to their condition. Although it is feasible that participants' responses to the condition were not attributable to their ethnic and social status there is good reason for the relationship between ethnicity and self-management to be considered. As already detailed in the literature review (see section 2.2.2.1), ethnic minority populations suffer disproportionately from diabetes related ill health and interventions must seek to improve this. The high prevalence rates of type 2 diabetes in participants' communities came across in views. Participants' talked about learning through information sharing with their friends and family. These results suggest a rationale for cultivating these informal information exchanges while regulating them for accuracy. This finding endorses initiatives that employ these notions e.g. expert patient programme (DH, 2001).

### **'Sense of self'**

An interesting concept of this over-arching theme, sense of self, is that it suggests participant's perception of learning was not necessarily in keeping with older Western assumptions of how this may be achieved, for example through formal education classes. Rather 'views' suggested that learning was acquired through living with type 2 diabetes that is to say, through actually experiencing and overcoming situations. This suggests support for the participant-centred experiential

learning and interactive health education interventions that are becoming more common.

Another key issue from participants' views was their relating how their living with the condition influenced their identities. The findings of this systematic review's conceptual analysis particularly the over-arching theme 'Sense of self' resonates with the wider literature on long-term conditions. For example, the medical sociologist Bury (1982) conceptualised long-term conditions as the kind of experiences that acted as a biographical disruption. It was noted that the diagnosis of a long-term condition made pain, suffering and death a less distant possibility as was previously true for the individual. Expectations of the future were re-examined as were relationships with families and social networks which would potentially change from a reciprocal role to a dependent one. Morley (2008) paid particular attention to pain and a person's sense of identity. It was suggested that while acute clinical pain is interruptive, chronic pain that is persistent may have a profound consequence on a person's identity. This poses the interesting question regarding how much the findings are specifically true to the condition of type 2 diabetes (and an immigrant, socially and educationally disadvantaged population) and how much of the findings are true to anyone living with a long-term condition more generally? Sense of identity is explored further in Study Two.

#### **5.4 Cross-synthesis**

The final stage of the review was a cross-synthesis of the key findings from the intervention strand and the 'views' strand. This additional dimension is novel and makes the systematic review different from any review previously undertaken in this area. While the method was operationally simple, it was conceptually strong.

The fundamental motivation for doing a cross-synthesis in this systematic review was that the context and design of existing interventions could be critically analysed from the views of the patients they sought to target. This was achieved by considering the eleven sub-sets of trials (end product of the intervention strand) alongside the nine potential implications for the content and delivery of interventions (end product of the 'views' strand). The identification of gaps and matches in this way was a valuable component of the synthesis across review strands.

Of the nine potential interventions, cross-synthesis identified five matches with the intervention strand. It was unclear in three of these instances (addressing patient confidence; supporting a positive outlook towards diabetes and improving knowledge of diabetes) whether the effectiveness of interventions matched participants' views and so demonstrated that these required further evaluation. In the other two instances (education that was culturally competent and individual versus group education) the intervention strand demonstrated a positive effect and so cross-synthesis endorsed the existing interventions.

The recently revised and updated Medical Research Council guidance for the evaluation of complex interventions supports the potential implication regarding providing culturally competent interventions by stating that interventions may work best when tailored to local circumstances rather than being entirely standardised (Craig et al, 2008). Osborne et al (2008) also noted that it was important to develop programmes that are specific to particular conditions and communities, they emphasised that method of implementation and integration into the patients broader environment were of great importance.

There were two instances (including family members in self-management and providing gender specific interventions) where there was insufficient evidence to draw a conclusion and so these too required further evaluation. A surprising finding was regarding the implication 'gender specific intervention.' Only four interventions were developed and delivered according to gender and the 'views' results suggested this may be an oversight since culturally social, familial and work roles were different for men and women. Participants' views also suggested that gender influenced the level of support they received from their families. If these points were recognised by a component of the intervention then its effectiveness may be optimised.

Cross-synthesis identified two gaps in the last two potential interventions (supporting information sharing amongst peers and supporting a positive outlook towards spirituality and fatalism) that suggested avenues for the future development and evaluation of promising interventions.

## **5.5 Limitations of the systematic review**

Despite the advantages of this systematic review, one must also remain mindful of its limitations and these will now be discussed. Four limitations that applied to both strands of the review, focusing on search strategy and inclusion criteria, will be presented.

The first limitation was related to the decision to include international research in the review and not place restrictions on the country in which the research was undertaken. As a result of this, some comparisons could be challenged because of the different contextual factors affecting the different populations. For example the issue of language difficulties as a barrier to self-management is perhaps very different for first generation immigrants than for African-Americans whose history in the USA started in the 17<sup>th</sup> century. Nonetheless, since all populations belonged to a BME group they also shared some context and so it is was felt that the rationale for such inclusive criteria stood. Context of healthcare system was less often an issue, since the majority of research had been conducted in the USA.

Related to this, a further limitation of not making the systematic review specific to one country of interest i.e. the UK as EPPI does, is that findings can not be as directly applied to policy and practice, and any implications for interventions are not always transferable across cultures or universally applicable. This was especially true because the studies retrieved by the review had mostly been conducted on North American BME populations. For these reasons implications for policy and practice have not been presented, although many avenues for further research have been highlighted. The EPPI-Centre conducts systematic reviews for various funders across a range of topics including health promotion. Partly as a result their review questions tend to be precise and on a smaller scale as compared to this one.

The second limitation was regarding the decision to exclude studies focusing on indigenous populations. This was on the basis that while they are minority ethnic groups they are not immigrant groups and it was anticipated that as a result of this, the groups would experience different barriers and facilitators to diabetes self-management. Over the course of the review however thinking changed. Perhaps the likeness between Native Americans, an indigenous group and African-Americans, a

minority group that has lived in America for many generations, was greater than the likeness between African-Americans and first generation immigrants. While, the rationale and grounds for exclusion still stand in retrospect, this could be an interesting avenue to pursue in future work.

A third limitation was that a reason for excluding studies was because they did not explicitly refer to 'type 2 diabetes' but instead just mentioned 'diabetes'. While this was considered in some cases to be due to poor reporting, in the interests of being consistent all such studies were excluded. This approach meant some key papers such as Greenhalgh et al (1998) were excluded although they were likely to be investigating type 2 diabetes judging by the reference lists. This demonstrates that in spite of the extensive search strategies, some relevant literature was missed. Furthermore, given the resource limitations for a PhD searches of grey literature were not undertaken nor were studies listed in the reference lists of included studies followed up. Therefore, it is possible that some relevant studies were missed.

In a similar vein, the fourth limitation was that on reflection, the search strategy which was in excess of 240 terms (Appendix 3.1) and searched eight bibliographical databases and one specialist register, was perhaps over cautious. Originally it was considered that by being systematic in the search no relevant papers would be missed. However, in practice reviewing an initial 15,725 titles increased the likelihood of human error and a relevant paper could have been missed this way. Since both strands of the review were extensive, concerns regarding thoroughness of the search strategy are perhaps ill founded. Literature on this subject demonstrates the various considerations that can effect these decisions.

Harden et al (1999) studied different strategies for identifying relevant primary research in systematic reviews and concluded that searches that aimed to find all relevant research tended to be extremely complex and time consuming. Similar to the discussion here, they concluded that the simpler search strategy were useful to reduce effort but that there was an inevitable trade-off in regards to the number of potential studies that may be missed. When Flemming and Briggs (2006) evaluated three different search strategies for qualitative literature however they found the complex search strategy to be no more effective than the simple search strategy. Both research groups recommended selecting the most relevant databases as opposed to many database to be a useful strategy. Harden et al (1999) concede that

while it allows for better specificity, sensitivity is compromised. Flemming and Briggs however advise that when a research question has a clear nursing focus and is locating qualitative research only then it may be adequate to search CINAHL alone.

## **5.6 Summary of discussion**

This chapter has provided a summary of the results on the systematic review's interventions strand and 'views' strands; and also of the cross-synthesis of the intervention and 'views' strands. As well as comparing the findings with one another in the cross-synthesis section, key findings from both strand were compared with the wider literature.

This chapter has provided a critique of Study One. There has been a particular focus on the methodological challenges that were experienced and overcome in the undertaking of this mixed-method systematic review. Strengths and limitations of this fairly novel methodological approach were presented in this chapter.

Implications from this work on practice has also been suggested. Particularly additional work to fit in with the body of current literature. Implications on theory are reserved for the next chapter. Chapter 6 focuses on the subsidiary aim of Study One which related to Nutbeam's (2000) conceptual framework of health literacy.

## Chapter 6

### An exploratory study to refine Nutbeam's health literacy framework in the context of type 2 diabetes

#### 6.1 Introduction

The concept of health literacy was introduced in Chapter 2 which began by considering the various definitions that have been developed for health literacy (see section 2.3.1.), how well accepted they are and how much they have evolved since the introduction of the concept. The literature review went on to present several frameworks that have come to exist for health literacy (see section 2.3.3). Particular attention was paid to Nutbeam's framework, including a discussion of the rationale for its selection as the underpinning conceptual framework in this thesis. Related to the issue of definitions and frameworks is the measurement of the health literacy concept. Measures for 'Functional health literacy' and 'Wider health literacy' as defined according to Nutbeam's framework were presented (see section 2.3.4). Finally, the usefulness of health literacy in relation to type 2 diabetes self-management was outlined in sections 2.3.5. and 2.3.6.

A brief reminder of Nutbeam's health literacy framework is provided here. Nutbeam (2000) proposed a hierarchical framework with three levels of health literacy. *Functional health literacy*, which is having sufficient basic skills in reading and writing to be able to function effectively in everyday situations; *interactive health literacy*, entailing more advanced cognitive and social skills which can be used to participate in everyday activities, to extract information and derive meaning from different forms of communication and to apply new information to changing circumstances; and *critical health literacy*, which includes more advanced cognitive skills which, together with social skills, can be applied to critically analyse information and to use this information to exert greater control over life events and situations. The hierarchical nature of the framework proposes that health literacy levels progressively allow for greater autonomy in decision-making and personal empowerment, consistent with health promotion principles (Nutbeam, 2000).

The focus of this research was on understanding the self management of type 2 diabetes in BME groups using health literacy as the conceptual framework. Equally,

type 2 diabetes serves as an exemplar condition for the analysis of Nutbeam's health literacy framework. The health literacy framework was a rational choice to investigate diabetes self-management which is composed of various behaviours that require patient motivation and a complex set of skills. It is plausible that the health literacy framework may help further understanding of the reasons for health inequality. By developing an individual's health literacy, self-management should also be improved. For health literacy to be developed it needs to be better defined and better measured.

## 6.2 Aim

A subsidiary aim of the systematic review (presented in Chapters 3 to 5) was "*To refine Nutbeam's conceptual framework of health literacy (2000) in the context of type 2 diabetes.*" In pursuit of this aim there were three objectives:

1. To operationalise each of the three levels of health literacy (functional, interactive and critical) as defined by Nutbeam (2000). To identify knowledge, attitudes and behaviours considered indicative of each health literacy level from a selection of the studies included in the 'views' strand of the review.
2. To test the operational definitions of the three levels of health literacy (as developed in objective one) by applying them to the trials included in the 'effectiveness' strand of the review. This was anticipated to also provide insights as to which level of health literacy existing self-management interventions for type 2 diabetes were targeting.
3. To further test the operational definitions of the three levels of health literacy (as developed in objective one) by applying them to the product of the cross-synthesis of the systematic review, namely the potential implications for intervention development. It was anticipated that this would provide further insight into the relevance of health literacy to self-management interventions for type 2 diabetes. Furthermore, this would enable interesting comparisons to be made between existing and potential interventions, in terms of the way they map onto the health literacy framework.

The outcome of this component of the review was to produce clear operational definitions for Nutbeam's functional, interactive and critical levels of health literacy.



By more precisely identifying from this work which skills indicate each of Nutbeam's three levels of health literacy in the context of type 2 diabetes self-management, it was anticipated that future work on developing measures may be illuminated.

### **6.3 Methods**

The methods used to achieve each of the three objectives will now be presented individually.

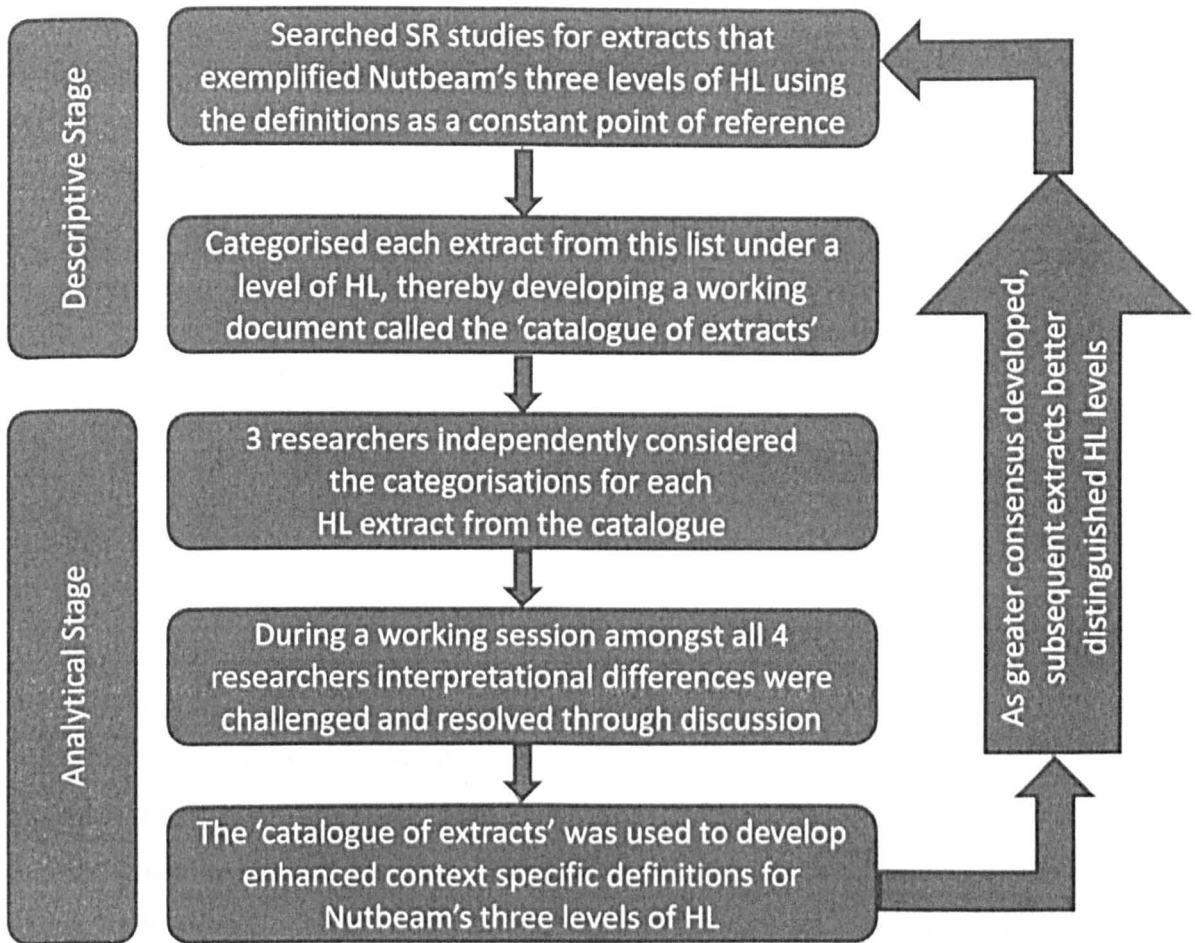
#### **6.3.1 Operationalising Nutbeam's level of health literacy in the context of type 2 diabetes self-management (*objective 1*)**

##### **Selection of 'view' studies**

The data from the first 27 'views' studies when put in an alphabetical order by study author, were re-examined. This number of papers was not selected *a priori* although the decision was taken at the outset to not include all 57 studies. Since the objective was to operationalise Nutbeam's three levels of health literacy, an exhaustive list of 'extracts' relating to health literacy from the entire 'views' strand was not deemed to be necessary. An 'extract' was a relevant section of text that was seen to be illustrative of a level of health literacy. Indeed, following the re-examination of the 27 studies data saturation was considered to have been achieved, that is, when the findings reflected consistently similar concepts and no new issues were being identified within the data set (Glaser and Strauss, 1967).

##### **Applying the Nutbeam framework to the 'views' data**

The process of operationalising functional, interactive and critical levels of health literacy comprised two stages, descriptive and analytical. This process is presented in Figure 6.1.



**Figure 6.1** Methods of applying the framework to 'views' data

*Note:* SR=systematic review. HL=health literacy.

### **Descriptive stage**

The first step consisted of careful re-reading of the results and discussion sections of the primary papers' and identifying extracts considered to exemplify one of the three levels of health literacy. Nutbeam's definitions of the health literacy levels were used as a constant point of reference when searching for extracts. These extracts were derived either from direct quotes of participants or from study authors' interpretation of the data, within the article's main text. The extracts reflected a list of attitudes, knowledge and behaviours specific to the context of type 2 diabetes self-management that were considered indicative of each health literacy level.

From compiling these, a 'catalogue of extracts' for each level of health literacy was developed (Figures 6.2 to 6.4). These were so termed because each of the extracts was categorised as functional, interactive or critical health literacy depending on how the attitude, knowledge or behaviour was considered to relate to

Nutbeam's definitions. Illustrative examples from the catalogue are referred to throughout the results section.

The process of identifying extracts from the 'views' studies had the advantage of judgements being data driven. This means that since the extracts were embedded in the actual results of an empirical study, reflection on the wider context of the extract was enabled. This allowed assumptions to be tested within the context of 'data' from the primary study included in this exercise. However, in some cases when the article had provided insufficient additional information, this was not possible. Nevertheless, even inconclusive statements raised important questions, as is detailed in the 'analytical stage' section. In this way the 'descriptive stage' was the first step of a preliminary analysis.

### **Analytical stage**

The key purpose of the 'descriptive stage' was to find extracts that were considered to exemplify a level of health literacy. Subsequently, these extracts were discussed within working sessions in the analytical stage. In practice the descriptive and analytical phases were cyclical and largely ran in parallel as is graphically presented in Figure 6.1. The 'analytical stage' comprised two key steps, which will now be detailed.

In the first step, three other reviewers (the PhD supervisors) independently considered the health literacy categorisations in the 'catalogue of extracts', enabling ideas to be tested out. All four researchers then met for a series of seven working sessions (held between August 2008 and February 2009). At each session the inclusion and categorisation of extracts from an average of four articles were challenged and debated until consensus was reached. Extracts were only retained in the catalogue if the level of health literacy was unanimously agreed upon. Any discrepancies that occurred between reviewer's interpretations were resolved through discussion. Through the process of revising what was and was not considered as functional, interactive and critical health literacy the reviewers' common understanding of the three levels of health literacy improved.

As previously mentioned the descriptive and analytical stages were run in parallel. The developing consensus as a result of each working session (in the analytical stage), influenced which extracts from subsequent 'views' studies (in the

descriptive stage) were recognised as health literacy. During the process, with each round of new extracts the reviewers were better able to distinguish between the different levels of health literacy and map the extract more clearly onto one of the health literacy levels.

Through this process some extracts no longer came to be seen to lie within the health literacy framework. These extracts exemplify how thinking had changed as part of this process. Examples are identified in the 'Results' section due to their vital role in helping arrive at the current understandings. Eventually, the analytical phase led to congruence between extracts for each level of Nutbeam's framework. In this way the development of the 'catalogue of extracts' was an iterative process.

From this, the second step followed. The refined 'catalogue of extracts' was used to develop enhanced operational definitions for each level of Nutbeam's health literacy framework specific to the context of type 2 diabetes self-management. These operational definitions along with the 'catalogue of extracts' are presented with the results (see section 6.4).

### **6.3.2 Mapping the operational definitions on existing interventions** *(objective 2)*

#### **Selection of intervention studies**

The operational definitions developed using the 'views' data were further scrutinised by applying them to all 28 trials included in the systematic review. This also demonstrated what level of health literacy existing diabetes interventions for BME patients pertained to.

The first step when mapping interventions onto a level of health literacy consisted of careful re-reading of the primary papers, whilst constantly referring to the operational definitions for each of the health literacy levels. Key consideration was given to the trial's aim, outcome and mode of delivery. From this interventions were considered to exemplify one of the three levels of health literacy. Illustrative examples are referred to throughout the results (see section 6.4).

Once all 28 trials were categorised as mapping onto one of, functional, interactive or critical health literacy, in a process similar to the application of the health literacy framework to the 'views' data, the other three reviewers (PhD

supervisors) independently considered these categorisations. Subsequently, all four reviewers met for a series of two working sessions (held in May and June 2010). At both sessions, interpretational differences regarding the categorisation of trials were discussed until a consensus was reached.

### **6.3.3 Applying the operational definitions to potential interventions** *(objective 3)*

#### **Selection of potential implications for interventions**

The outcome of the cross-synthesis was nine potential implications for intervention development (see section 4.4.1). For this exercise, each of these potential diabetes interventions for BME patients was examined to determine what level of health literacy it mapped onto. This enabled interesting comparisons between what level of health literacy existing (objective two) and potential interventions (objective three) pertained to.

The operational definitions for each of the health literacy levels were referred to alongside the available information on the nine potential interventions and from this classifications were made. There was limited information as compared to objective one and two, when making the decision about the level of health literacy potential interventions mapped onto. However, familiarity with application of Nutbeam's definitions in objective one, and application of the context-specific operational definitions in objective two, facilitated the undertaking of objective three.

## **6.4 Results**

### **6.4.1 Operationalising Nutbeam's levels of health literacy in the context of type 2 diabetes self-management** *(objective 1)*

In this section, functional, interactive and critical health literacy will be presented in turn. At the start of each section, Nutbeam's definition is provided. Then key issues that emerged for each level are presented, illustrated by the 'catalogue of extracts' (Figure 6.2 to 6.4). Following this, the proposed operational definition for that health literacy level in the context of type 2 diabetes is presented. Finally, more general reflections on all three levels will be presented in the final section where the theoretical application of Nutbeam's framework is considered.

Initially, it was anticipated that the majority of the debate would lie with identifying the self-management behaviours indicative of the levels of interactive and critical health literacy. This was for two reasons. First, at the time the work was undertaken, interactive and critical health literacy had not been operationalised in any of the available health literacy tools. For example, the specific skills for these two levels of health literacy had not been identified in the same way as for the functional health literacy level (see the TOFHLA and REALM measures as detailed in section 2.3.4). Second, Nutbeam's definitions for two of the levels of health literacy (interactive and critical) were considered to be overlapping. Both definitions referred to 'more advanced' 'literacy' 'cognitive' and 'social skills' albeit they were qualified differently. Interactive health literacy was qualified as being a continuum of functional health literacy 'everyday situations' with 'everyday activities' while critical health literacy was qualified as being composed of more exceptional circumstances as suggested by 'life events and situations' in the definition. In contrast, health literacy at the functional level focused on 'reading and writing skills' and was considered at the outset of this exercise as relatively uncomplicated to operationalise. In reality, when the work commenced, the reverse occurred with most discussion focusing on operationalising functional health literacy. The issues that emerged for each level of health literacy are presented and discussed below.

#### **6.4.1.1 Functional health literacy**

Nutbeam (2000) defines functional health literacy as 'Sufficient basic skills in reading and writing to be able to function effectively in everyday situations.' When this definition was considered within the specific context of type 2 diabetes self-management it was recognised that while literacy skills are important with type 2 diabetes on a daily basis the individual requires more to be able to function effectively. With a long-term condition like type 2 diabetes there are condition-specific skills that also need to be understood and used by the individual.

For functional health literacy there were two issues that arose during the development of the 'catalogue of extracts' and these were, 'adherence' and 'literacy'. Each of these will now be presented, referring across to illustrative extracts from Figure 6.2.

	Reference	Extract
1	Adams, 2003	Health care providers could exert either a positive or a negative influence on adherence depending on their approach.
2	Adams, 2003	Symptoms associated with high or low blood sugar levels, required patients to monitor blood sugar levels with periodic finger sticks. A problem for participants was their low level of formal education.
3	Duthie-Nurse, 1998	If people had access to a dietician from their own linguistic and cultural background who understood their difficulties, then they appeared to comprehend how important appropriate diet and exercise were.
4	Fagerli, 2005	Access to written information in Urdu could supplement the advice given directly by the health-worker.
5	Two Feathers, 2007	Many participants described how they had increased daily exercise through incorporating physical activity into everyday activities.
6	Two Feathers, 2007	Helpful activities included demonstrations of serving sizes and food label reading.
7	Hawthorne, 1999	Literate patients more likely to know how to handle persistently raised glucose levels.
8	Huang, 2005	Medical professionals were a major external influence on determining patients' healthcare goals and helped develop a daily care plan.
9	Jayne, 2001	Forty-three percent of participants mentioned their physicians as being key to their treatment e.g. reducing rice in diet on their advice.
10	Lawton, 2005	Most of those prescribed oral hypoglycaemic agents perceived them as an essential part of their diabetic regimen.
11	Lawton, 2006b	Respondents described how they undertook physical activity in conjunction with self-monitoring blood glucose and health literacy highlighted the sense of gratification and achievement from seeing readings reduce.
12	Mull, 2001	Patients said that in response to dietary advice, they had reduced their rice intake from 2 bowls to 1 at each meal.
13	Rosal, 2004	Reported use of a pill box to remember to take their medication.
14	Stone, 2006	Sources of knowledge were leaflets offered by the general practice in an appropriate South Asian language.
15	Vincent, 2006	Access to visual aids such as bilingual reading materials and videotapes to improve information access.

**Figure 6.2** Functional health literacy – ‘Catalogue of extracts’

## **Adherence**

As is illustrated by the extracts presented in Figure 1 the position of adherence emerged strongly when seeking to define functional health literacy behaviours. Adherence to health advice was articulated in two respects: either specifically from health professionals' advice (extracts 1, 8, 9, 12) or more generally, when referring to behaviours required for daily functioning, specifically type 2 diabetes self-management (extracts 2, 5, 6, 7, 10, 11, 13).

Extracts 1, 8, 9 and 12 prompted a discussion around whether an individual could be functionally health literate if they followed advice prescribed by a health professional without understanding why they were doing this. For example, in extracts 9 and 12, could a participant be considered to be only functionally health literate if they reduced their rice intake because they understood that carbohydrates increased blood glucose rather than simply complying with professional advice to do so? Similarly, a discussion surrounding a 'pill box' (multi-compartment compliance aid) was raised as a result of extract 13. It was argued that using pill boxes is not an illustration of functional health literacy, as they are primarily memory aides and do not indicate understanding.

It was difficult to reach a firm conclusion on whether adherence can be accepted as a skill within functional health literacy. On one hand, having a long-term condition like type 2 diabetes means it is important that a patient understands the basics of the condition and why they must engage in prescribed behaviours. However, adherence alone might simply be habit or routine, whereas for it to be considered as functional health literacy the behaviour may need to be conducted with an element of comprehension and conscious effort. On the other hand, practically managing type 2 diabetes requires a complex set of behaviours across a lifetime, so it is perhaps the patient's prerogative to decide where and to what extent to engage their energies in terms of what they seek to understand.

Eventually it was agreed that in order to be considered functionally health literate, an individual needs to acknowledge that the behaviour is necessary for good self management. This is perhaps demonstrated through the act of adherence alone. Arguably, a higher level of understanding is placed at a higher level of health literacy.



## Literacy

Literacy was the other main issue that arose when attempting to operationalise the functional level of health literacy (extracts 2, 3, 4, 6, 11, 13, 14, 15). This was perhaps unsurprising since Nutbeam's definition focuses on reading and writing skills. Much discussion was triggered around two aspects of literacy and these are presented here. First, is the level of application of Nutbeam's definition and second, is its cross-cultural relevance.

A discussion centred around whether Nutbeam's definition meant that a person who was not literate in absolute terms could not demonstrate functional health literacy (or any other level of health literacy). This is because the concept of health literacy is largely based on literacy in a health context (Nielsen-Bohlman et al, 2004). However it was also noted that adequate literacy does not necessarily translate into adequate health literacy (Ishikawa and Yano, 2008c). By the same logic then, it could be argued that inadequate literacy does not always translate into inadequate health literacy.

It was also questioned whether reading in the host language was sufficient for functional health literacy, while writing was indicative of interactive health literacy. While there is evidence to show that low levels of literacy tend to be associated with poorer health (Von Wagner et al, 2009) there are also data to support the notion that people with poor levels of literacy can successfully manage lifelong conditions (Aikins, 2003; Sarkar, 2006). Extract 13 demonstrated that there are ways to manage other than possessing the 'basic skills in reading and writing to be able to function effectively in everyday situations'. Indeed, engaging in the behaviour may be interpreted as demonstrating a basic understanding of an association between the behaviour itself and good health.

It was concluded that in moving through the health literacy continuum an individual ultimately strives towards achieving a knowledge of good health which requires access to written documents. If a person is unable to read and write they cannot be considered to be functionally health literate. Health literacy is about the ability to use and exchange written information to contribute to one's own health and this was considered to be at the heart of Nutbeam's definition of functional health literacy, 'reading and writing'.

The second literacy issue was regarding the relationship between literacy and health literacy being further complicated when an individual's indigenous language is different from the host language where they live. The question raised was whether a patient unable to speak the host language of the country in which they live can be seen to be health literate if information is communicated in the patient's indigenous language. This could be via a bilingual health professional (as illustrated in extract 3) or through written information (as in extracts 4, 14 and 15). Furthermore, how does the health literacy framework apply to languages with traditions other than reading and writing for information transfer? Related to this was the issue of whether a patient unable to speak the host language of the country in which they live could be perceived as health literate if they had existing skills in their native country that they brought with them to the UK? In this context of diabetes self-management in BME populations where English may not have been the patient's first language, it was considered crucial to define what health literacy meant.

It was concluded that while these points were important to consider, the purpose of this research was to investigate how to better support health literacy for self-management of type 2 diabetes amongst BME groups in Britain. In Britain people from BME groups with low literacy may find that their ability to self-manage a health condition is compromised in an environment where they have to read in English, for example, the process of making a hospital appointment or knowing how to 'navigate' the health system or purchasing health products. A key point that emerged from this work was that it suggested people immigrating can change from having critical health literacy and feeling empowered in the home country, to not having functional health literacy in the host country where they are not literate in the host language. This links to the notion that health literacy is context-specific.

The context-specific nature of health literacy is suggested in Nutbeam's definition for functional health literacy as relating to 'everyday situations'. This encompasses multiple factors including the nature of the patient's disease/condition, the country the patient lives in and the type and availability of the healthcare delivery system. An individual living with type 2 diabetes would be expected to have a level of knowledge about *their* condition and its management (living with

diabetes is their 'every day' experience) that would not be expected of a member of the general public without the condition.

While this literacy section has until now placed emphasis on prose literacy Nutbeam's definition can be interpreted to also include numerical skills. This is particularly appropriate in the context of diabetes self-management where patients are required to understand their blood glucose readings and know how to respond to these, a behaviour which clearly necessitates numeracy. Extracts 2 and 11 relate directly to this, while extracts 6 and 12 illustrate the importance of numeracy in other aspects of type 2 diabetes self-management.

As a result of this work the operational definition '*Adherence which enables daily functioning*' was proposed for functional health literacy.

#### **6.4.1.2 Interactive health literacy**

Nutbeam's (2000) definition of interactive health literacy is 'More advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances.'

The context of Nutbeam's definition at the interactive level is 'everyday activities,' this is a clear continuation of 'everyday situations' as defined at the functional level. The employment of the term 'everyday' in this way indicates how Nutbeam's framework is able to adapt well to different conditions. The definition at this level is extended to include 'changing circumstances'. As at the functional level, the definition for interactive health literacy made mention of 'more advanced literacy skills' while 'social and cognitive skills' were mentioned additionally. Nutbeam's definition for interactive health literacy also moves away from the more reactive notions suggested by 'basic skills to function effectively in everyday situations' to a more active patient role 'to actively participate, to extract... and to apply new information.' For interactive health literacy there were two main issues that arose during the development of the 'catalogue of extracts' and these were 'soliciting information' and to a lesser extent 'experiential learning'. Both these issues will now be discussed in turn.

### **Soliciting information**

The majority of extracts that were identified as reflecting interactive health literacy made reference to soliciting additional information. The sources of this information were other people with type 2 diabetes, friends and family (extracts 1, 2, 3a, 4, 6a, 7, 8, 10, 12a, 14a, 15a, 17a) and, less frequently, health professionals (extracts 12b, 15b, 17b). Health professionals featured far more in extracts describing the functional level within the context of adherence and a 'reactive' patient role than in the context of interactive health literacy when the patient's role emerged as 'more active'. A few participants mentioned actively seeking information from different literary sources including printed materials (extracts 9 11) and the media (extracts 9 16).

It is important to note that, at the level of interactive health literacy, while information was sought from different sources, the impetus remained on the individual with type 2 diabetes to use their own initiative to do this. This reflects the first half of Nutbeam's definition 'advanced cognitive and social skills which can be used to actively participate in everyday activities'. The majority of the 'soliciting information' extracts focus clearly reflect 'social skills' (extracts 1 2 3 4 6a 7 8 9 12a 14a 15a 17a).

### **Experiential Learning**

In addition to 'soliciting information', the extracts focused upon experiential learning (extracts 3b 5 6b 12c 13 14b 15c 18 19). Participants appeared to cope by making self adjustments to deal with their continually shifting situation within the context of their long-term condition. This supports and reflects the second half of Nutbeam's definition 'extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances'. These extracts indicate the participants' cognitive skills of problem solving where they develop ways to overcome gaps in their knowledge.

The operational definition arrived at for interactive health literacy is '*Patient uses their initiative to solicit additional information from different sources so as to implement more control over their health from day to day*'.

	Reference	Extract
1	Adams, 2003	Several Latinas noted that they solicited information from a variety of resources to learn more about self-management.
2	Adams, 2003	Storytelling is evidenced as a useful method to explain concepts about self-management.
3a	Anderson-Loftin, 2000	Frequently offered or asked for advice or information. Spoke of key learning experience and others asked how the story applied to their own situation.
3b	Anderson-Loftin, 2000	Frequently spoke of key learning experiences about self-management.
4	Alcozer, 2000	Women relied not only on what healthcare professionals said but also on what they learned from their family and community experiences.
5	Chesla, 2005	Accommodated family by eating prepared meals but by selecting foods that were suitable for people with diabetes.
6a	Two Feathers, 2007	Activities reported as helpful included role-playing and group discussion about typical diabetes self-management situations.
6b	Two Feathers, 2007	Activities reported as helpful included problem solving about typical diabetes self-management situations.
7	Kokanovic, 2006	Women sought and gained support from other people who had diabetes. They encouraged each other, shared concerns and stories.
8	Rosal, 2004	Small interactive talks appeared to be the preferred medium to obtain information about diabetes. Participants stated that group meetings help keep them motivated and are a great way to learn about diabetes:
9	Stone, 2006	Some interviewees had gained additional information from libraries, the internet, newspapers or television.
10	Vincent, 2006	Desired access to a role model, someone with diabetes who was successful at self-management and would understand the challenges.
11	Burns, 2005	Using a soul-food cook book, purchasing and cooking and using food pyramid were all helpful self-care strategies.
12a	Culhane-Pera, 2007	People have many ways to make themselves feel happier, and healthier including attending group sessions.

12b	Culhane-Pera, 2007	People have many ways to make themselves feel happier, and healthier including seeing a psychologist.
12c	Culhane-Pera, 2007	People have many ways to make themselves feel happier and healthier. They travel, work in their garden, create harmony at home, get out of the house, visit family and friends and get spiritual treatments.
13	Hill-Briggs, 2003	Positive problem-solving reflected adjusting to having to live with diabetes, gaining confidence in ones ability to manage diabetes and the challenges that arise.
14a	Hill-Briggs, 2003	Good control participants learnt from the good and bad experiences of family and friends with diabetes.
14b	Hill-Briggs, 2003	Good control participants learnt from their own good and bad experiences.
15a	Carbone, 2007	Managed by joining type 2 diabetes self-management group classes.
15b	Carbone, 2007	Managed by receiving guidance from individuals at health centre.
15c	Carbone, 2007	Managed by self-imposed changes in eating behaviour.
16	Huang, 2005	Information from the mass media on medical matters was another mentioned influence on healthcare goals. For example, reports on side effects motivated some patients to discontinue their medications.
17a	Anderson-Loftin, 2000	Common strategies included storytelling, vicarious experience, observation of role models and reflection of pattern by other people with diabetes
17b	Anderson-Loftin, 2000	Common strategy included help seeking from trusted advisors.
18	Wallin, 2007	Several of the participants perceived when blood sugar levels were too high. They had learned from experience that physical exercise managed the situation by regulating a high blood sugar level.
19	Hunt, 1997	Some said they had learned to carefully manipulate what they eat in relation to their insulin use thereby avoiding the unpleasant symptoms of falling blood glucose.

**Figure 6.3** Interactive health literacy – ‘Catalogue of extracts’

### **6.4.1.3 Critical health literacy**

Nutbeam's (2000) definition of critical health literacy is 'More advanced cognitive skills which, together with social skills, can be applied to critically analyse information and to use this information to exert greater control over life events and situations'.

At the critical level, Nutbeam's definition introduces a new context of 'life events and situations' which suggests that these skills are more advanced than the more routine self-management behaviours that are required 'everyday', which is the context of the functional and interactive health literacy levels. Nutbeam proposed definition for critical health literacy talks of 'more advanced cognitive and social skills' in the same way as at the interactive health literacy level. However, unlike at the functional and interactive levels, there is no explicit reference to literacy skills at this level.

There was one key issue that emerged during the development of extracts' for defining critical health literacy. This concerned BME participants' identification of their own bodies as the best source of information for self-management, emphasising the importance of personal experience.

#### **Emphasis on personal experience**

From the extracts (1 3 4 5 6 8) it can be seen that the emphasis was very much on learning over time. These observations indicate that the complexity of diabetes management leads to an emphasis on personal experience and the consequential, sometimes non-uniform approach to self-management. During the working sessions extract 1 was remarked upon as an unconventional view of critical health literacy, since the patient critically evaluated their symptoms as opposed to the more traditional view of a patient critically evaluating information. This illustrates the point that in the context of managing a lifelong condition, their own body becomes a person's best source of information and as such, management is individualised.

While the majority of extracts on the interactive level of health literacy made suggestion of 'cognitive skills' they had a heavier focus on 'social skills.' At the critical level of health literacy, every extract indicated participants' 'cognitive skills' where they evidenced proficient judgement and reasoning. Meanwhile only two

extracts (2-8) reflected 'advanced social skills' and both of these were concerned with critiquing health professionals' advice.

The operational definition arrived at for critical health literacy is *'Art of discrimination learnt over time alongside an emphasis on the personal experience'*.

	Reference	Extract
1	Adams, 2003	Discrimination of certain symptoms such as blurred vision and hunger was difficult because they are common to both hypoglycaemia and hyperglycaemia. According to participants, such knowledge was born of experience. Over time, they began to identify their particular responses.
2	Alcozer, 2000	Acculturated women mobilised available medical resources, seeking and questioning referrals when unsatisfied with their care.
3	Anderson-Loftin, 2000	Participants described learning over time the connection between behaviour patterns and diabetes consequences. Individuals described beginning to think about their disease differently and seeing options in the way they managed their disease; making cognitive, behavioural and affective changes that focused on promoting health.
4	Anderson-Loftin, 2000	Common strategies used by participants were based on experience and included trial and error.
5	Brown, 2007	Felt symptoms were more important than objective measures, took more notice about how they felt than the outcomes of a blood sugar test.
6	Culhane-Pera, 2007	The philosophy of treatment is to maintain balance. They felt sick when their sugars were high and low. They felt sick with and without medicines. They felt better with dieting and exercising but if they over-dieted or over-exercised, they also felt sick. Achieving and maintaining balance was a difficult personal struggle, as each body was different. Everyone must find their own actions that helped them, guided by how their body felt, and perhaps also by their blood glucose level.
7	Hawthorne, 1999	Literate patients were more likely to know of the link between tight glycaemic control and the prevention of complications.
8	Kokanovic, (2006)	Participants who had numerous medical procedures were critical of doctors' recommendations to increase medicines or to have more regular check ups. Argued the need to take control of their own bodies and to manage their condition, not in conformity of their doctor's view because they questioned medical expertise and expert knowledge, emphasising the personal experience of living diabetes and self-managing.

**Figure 6.4** Critical health literacy – 'Catalogue of extracts'



#### **6.4.1.4 Theoretical application of Nutbeam's framework**

Extracts 2 and 7 at the critical level made explicit reference to participants' higher levels of literacy while none of the extracts at the functional or interactive level did this, thus lending supports to Nutbeam's (2000) health literacy framework. As can be seen from Figures 1-3, fewer extracts from the catalogue mapped onto critical health literacy than they did functional or interactive health literacy. This tentatively suggests that more participants 'views' evidenced functional health literacy skills than critical health literacy providing support to Nutbeam's continuum.

Given the limitations of this small scale exploratory research it is difficult to make definitive statements however the research did identify some issues that challenged the hierarchical nature of the framework. Some critical health literacy extracts conflicted with some of the earlier reported functional health literacy extracts. For example, extract 5 (critical health literacy) states that the patient paid more attention to how they felt than the outcomes of a blood glucose test and this was categorised as critical health literacy, whereas in extract 11 (functional health literacy) the patient remarked on their gratification at seeing glucometer readings go down. Paying attention to glucometer readings as a functional health literacy skill and ignoring outcome of a blood sugar test are clear contradictions.

Similarly critical health literacy extracts 2 and 8 advocate the opposite of adherence as it is defined in functional health literacy. That is to say, that people can read medical instructions but make an informed decision not to comply with undertaking the behaviour. Although these patients may make choices that go against medical advice, they are making an 'informed choice' in the context, and as such the patient demonstrates critical health literacy.

This empirical work demonstrates that diabetes self-management requires a complex set of skills. The findings also suggest that it may be over simplistic to claim that an individual must sequentially progress in the acquisition of health literacy skills (from functional to interactive to critical health literacy).

## **6.4.2 Mapping the operational definitions onto existing interventions** *(objective 2)*

In this section, the results from mapping the trials included in the interventions strand of the review onto the operational definitions for functional, interactive and critical health literacy are presented. This is done by focusing on the trial's aim, outcomes and mode of delivery.

For each level of health literacy the aim, outcome and mode of delivery of a small number of trials are presented (Table 6.1 to 6.3). These trials were selected to illustrate the issues arising for each level. The wording for each trial is that of the authors of the paper. The rationale for the identified level of health literacy is then presented. Detailed information on the characteristics of the intervention in each of the included trials is provided in Appendix 4.1. Of the 28 trials in the review eight had interventions focused on functional health literacy (4, 9, 11, 14, 24, 28, 16, 19), 15 focused on interactive health literacy (3, 7, 8, 6, 13, 21, 17, 18, 22, 27, 1, 10, 23, 26, 20) and five interventions addressed critical health literacy (5, 12, 15, 25, 2).

### **6.4.2.1 Functional health literacy**

The operational definition '*Adherence which enables daily functioning*' was proposed for functional health literacy. In Table 6.1 seven trials are presented.

Trials targeting functional health literacy were predominantly identified by the fact that the intervention's aimed to develop knowledge of different aspects of self-management through education so as to develop patients' skills and improve adherence. In other words, trials targeting functional health literacy were characterised as having a clear focus on directing and instructing participants in how to undertake various self-management behaviours. The self-management interventions focused on improving behaviours, all of them necessary for daily functioning. Trials 4, 14 and 17 focused on a range of general self-management behaviours, trial 24 aimed to improve medication management, trial 12 focused on diet while trial 15 was concerned with weight management through the lifestyle behaviours of diet and physical activity. It is interesting to note that only trial 24 explicitly considered the patient's health literacy status and based on this, communication was individualised so as to improve comprehension.

**Table 6.1** Selection of trials mapping the operational definition for functional health literacy

Trial	Aim	Delivery	Outcome
4	To test whether culturally appropriate educational intervention could improve knowledge, attitudes, and some aspects of diabetes self-management.	<ul style="list-style-type: none"> <li>• Format of the educational programme was based on group education.</li> <li>• Learning process in the groups was a combination of didactic lectures in the patient's language and interactive group discussion where patients were asked to discuss some of their experiences and problems and then the educator explained relevant issues.</li> <li>• The educators used simple support material including visual aids, food examples, as well as leaflets and an information video in the patient's language.</li> </ul>	<p><i>Primary:</i> Knowledge</p> <p><i>Secondary:</i> Attitude toward seriousness and complications; practice of self-care.</p>
11	To determine whether multifaceted, culturally sensitive, primary care-based behavioural interventions implemented by a NCM and/or a CHW could improve physiological measures.	<ul style="list-style-type: none"> <li>• <u>Nurse case manager (NCM)</u>: Provided direct patient care, management, education, counselling, follow-up, referrals, physician feedback and prompted on regimen changes and implementing changes under physician's orders.</li> <li>• <u>Community health worker (CHW)</u>: Provided face-to-face home visits. Did not directly implement therapeutic strategies. CHW facilitated preventive care by offering to schedule appointments along with providing education. Responsibilities were to monitor participant and family behaviour, reinforce adherence to treatment recommendations, mobilise social support, and provide physician feedback on identifiable problems such as high blood pressure readings or dietary habits.</li> </ul>	<p><i>Primary:</i> HbA1c</p> <p><i>Secondary:</i> Lipid profile; blood pressure; dietary practices and physical activity levels.</p>
14	To develop and evaluate the effectiveness of culturally appropriate educational pictorial flashcards.	<ul style="list-style-type: none"> <li>• Education topics were appropriate diet, value of glucose monitoring, type 2 diabetes complications and services at type 2 diabetes clinic.</li> <li>• Each topic was structured with teaching objectives, interview questions and pictorial flashcards to understand points.</li> <li>• Participants were also taught to check their urine for blood sugar.</li> </ul>	<p><i>Primary:</i> Knowledge; self-caring skills; attitudes to diabetes and HbA1c.</p>

<p>24</p>	<p>To assess the impact of a pharmacist-led disease management programme on cardiovascular risk factors and HbA1c levels among a vulnerable population.</p>	<ul style="list-style-type: none"> <li>• One-to-one educational sessions including counselling and medication management.</li> <li>• Pharmacists applied evidence-based treatment algorithms to help manage glucose and cardiovascular risks by both initiating and amending blood pressure and glucose lowering medications.</li> <li>• Diabetes care coordinator (DCC) addressed patient barriers using telephone reminders and when necessary by addressing difficulties with transportation, communication, and insurance.</li> <li>• The pharmacist and the DCC were aware of patients' literacy status and communication was individualised using techniques that enhance comprehension among patients with low literacy including: picture-based materials; predominantly verbal education with concrete, simplified explanations of critical behaviours and goals as well as "teach-back" techniques to assess patient comprehension.</li> <li>• Main educational topics included treatment goals, identification of hypoglycaemic and hyperglycaemic symptoms, prevention of long-term complications and self-care.</li> </ul>	<p><i>Primary:</i> HbA1c; aspirin use; lipid levels.</p> <p><i>Secondary:</i> Diabetes knowledge and treatment satisfaction.</p>
<p>28</p>	<p>To test whether a simpler meal plan that emphasises "healthy food choices" (without emphasis on weight loss) would be as effective as an "exchange-based meal plan" (emphasising weight loss).</p>	<ul style="list-style-type: none"> <li>• Patients in the "healthy food choices" condition routinely received individualised instruction from a dietician based on 24-h dietary recall.</li> <li>• Patients in the "exchange based meal plan" condition were given low literacy educational material about eating healthy foods. Patients were instructed in food exchange and portion sizes. Patients classified as obese (&gt;120% of ideal body weight) were assigned meal plans that were 500 kcal below their estimated daily energy.</li> <li>• All patients were managed with a stepped care protocol that emphasised non-pharmacologic therapy and discontinued anti-diabetic pharmacologic agents for two months, at which point, if glycaemic goals were not reached, pharmacotherapy was reinstated.</li> </ul>	<p><i>Primary:</i> HbA1c.</p> <p><i>Secondary:</i> Weight change, serum lipids and blood pressure.</p>

<p>16</p>	<p>To assess the effectiveness of a pharmaceutical care model on the management of type 2 diabetes.</p>	<ul style="list-style-type: none"> <li>• Pharmacotherapeutic evaluation and dosage adjustments.</li> <li>• Comprehensive and individualised patient education regarding diabetes and its complications.</li> <li>• Medication counselling provided.</li> <li>• Specific instructions on dietary regulation and an exercise plan.</li> <li>• Training on the recognition and treatment of hypo and hyperglycaemia.</li> <li>• Training for self-monitoring of blood glucose and schedules with detailed written instructions for specific testing times relative to meal consumption were provided.</li> <li>• Patients instructed to record date and time of any hypoglycaemic events as well as symptoms experienced during these events.</li> <li>• Evaluations of current hypoglycaemic therapies were performed and where necessary adjusted during each clinic visit based on the self-tested blood glucose results obtained.</li> </ul>	<p><i>Primary:</i> Fasting plasma glucose; HbA1c.</p> <p><i>Secondary:</i> Blood pressure; creatinine; total cholesterol; triglycerides and lipoprotein concentrations.</p>
<p>19</p>	<p>To develop, implement, and evaluate a 1-year primary care based lifestyle intervention for weight management designed to improve metabolic control.</p>	<ul style="list-style-type: none"> <li>• The programme focused on moderate weight loss through nutritional and physical activity components.</li> <li>• Moderate weight loss was encouraged with a goal of 25% of calories from dietary fat and a minimum of 150 minutes of physical activity per week. Energy intake goals were added as necessary.</li> <li>• Regular use of group sessions, using simplified and reduced written materials, where there was encouragement of physical activity and inclusion of culturally appropriate nutritional examples.</li> <li>• Self-monitoring tools for diet and physical activity in a simple format.</li> <li>• Information regarding selected aspects of diabetes care (e.g. encouragement to monitor blood glucose at home) was incorporated, although the intervention retained a clear focus on diet and physical activity.</li> </ul>	<p><i>Primary:</i> Weight loss.</p> <p><i>Secondary:</i> HbA1c; lipid profile and blood pressure.</p>

**Table 6.2** Selection of trials mapping the operational definition for interactive health literacy

Trial	Aim	Delivery	Outcome
3	To test the effects of a practical, culturally competent, dietary self-management intervention on physiological outcomes and dietary behaviours	<ul style="list-style-type: none"> <li>• Professional group education with peer discussion and educational classes that emphasised planning, purchasing and preparing healthy low-fat meals and making healthy choices when eating away from home using ethnic food models.</li> <li>• Experiential teaching methods were used, such as assisting with meal preparation, reading food labels and making food choices.</li> <li>• Low literacy levels in the target population meant by focusing on one major dietary concept and simplifying the intervention meant the chances of behavioural change required for success were improved.</li> </ul>	<p><i>Primary:</i> HbA1c; lipids; BMI and dietary behaviours.</p> <p><i>Secondary:</i> Medication history; diabetes education and exercise.</p>
6/7/8	To compare two culturally competent diabetes self-management interventions: “extended” and “compressed”.	<ul style="list-style-type: none"> <li>• Weekly instructional sessions on nutrition, home glucose monitoring, exercise, and other self-care topics.</li> <li>• Support group sessions to promote behavioural changes through problem solving, goal setting.</li> <li>• Food preparation demonstrations.</li> <li>• “Extended” (24 h of education, 28 h of support groups) and “compressed” (16 h of education, 6 h of support groups) programme.</li> </ul>	<p><i>Primary:</i> HbA1c; FBG; diabetes knowledge</p>
13	To determine the impact of two culturally competent education methods (individual counselling only and individual counselling in conjunction with group	<ul style="list-style-type: none"> <li>• Group classes included various teaching methods such as didactic methods, mutual goal setting, situational problem solving, cognitive reframing and role-playing methods.</li> <li>• One of the key components of group education was nutrition therapy which is predominantly interactive and sensory-stimulating.</li> <li>• Throughout the nutrition classes, the dietician emphasised four key messages: (1) limited and consistent intake of carbohydrates at each meal; (2) adequate daily intake of fruits and vegetables; (3) lower</li> </ul>	<p><i>Primary:</i> Attitudes-subjective norms, perceived behavioural control, intentions towards nutritional adherence; self-</p>

	education) on nutrition adherence and glycaemic control. To compare and explain differences in outcomes between the two groups using the Theory of Planned Behaviour.	<p>intake of saturated fats (4) reduced fat in cooking.</p> <ul style="list-style-type: none"> <li>• Key messages were also emphasised in individualised counselling.</li> <li>• Nutrition therapy was based on an assessment of the individual's metabolic profile (i.e. blood glucose, lipid and blood pressure).</li> <li>• The frequency and duration of each individual follow-up visit depended on the patient's progress and their achievement of their metabolic targets and educational objectives.</li> <li>• At each visit patients' health status and priorities were reassessed. Mutually agreed management goals and nutritional care plans were established and noted.</li> </ul>	reported nutritional adherence and glycaemic control.
21	To examine the effects of patient choice between two education curriculums that emphasised either the standard or nutritional management of type 2 diabetes).	<ul style="list-style-type: none"> <li>• The experimental nutritional programme modified the ADA's recommended curriculum to devote 60% of its content to nutritional management practices and 40% to non-nutritional management.</li> <li>• Patients at the experimental nutritional programme were given a meal plan and advised to make many changes at once.</li> <li>• The standard nutritional programme did not provide a specific meal plan, but instead recommended that patients use a foods guideline and promoted gradual, continuous changes in eating habits.</li> <li>• Educators assigned to the standard nutritional programme took measures of blood glucose, blood pressure, and weight in class.</li> </ul>	<p><i>Primary:</i> Attendance and follow-up participation.</p> <p><i>Secondary:</i> Self-care behaviours; HbA1c; BMI; knowledge and cholesterol.</p>
20	To determine whether diabetes nutrition education that is more culturally appropriate improves metabolic control.	<ul style="list-style-type: none"> <li>• Intensive guidance was provided for three months, after which the care-providers gave guidance but with longer intervals.</li> <li>• Newly developed education materials were used, consisting of an audio-cassette containing general diabetes information recorded in Hindi and two booklets based on South Asian cooking.</li> <li>• These culturally appropriate education materials were expected to produce an improvement in the interaction between patients and care-providers. As a result, compliance with the therapy would improve.</li> </ul>	<i>Primary:</i> HbA1c, lipid profile.

#### **6.4.2.2 Interactive health literacy**

The operational definition '*Patient uses their initiative to solicit additional information from different sources so as to implement more control over their health from day to day*' was proposed for interactive health literacy. In Table 6.2 seven trials are presented.

What was interesting to note with the trials at the interactive level, is that they too were seeking to affect behaviours that are part of daily self-management. As detailed in the previous section as expected trials seeking to affect self-management behaviours necessary for daily functioning were already categorised at the functional health literacy level. However, here it was the detail in the method of delivery and context of the self-management behaviours that suggested the intervention to be targeting interactive health literacy skills.

The intervention tested in trial 3 included peer discussion which maps onto the operational definition for interactive health literacy '*solicit additional information from different sources.*' Furthermore the experiential teaching methods used in this intervention appeared to specifically target behaviours that would enable the participant to '*implement more control over their own health.*' Again mapping onto the operational definition for interactive health literacy.

Since delivery of the educational intervention reported in trials 7, 8 and 6 (all trials reported effects on a different primary outcome of the same intervention) was through support group sessions that required a more active role from the participant, as opposed to a passive role at the functional level, the intervention was considered to target interactive health literacy. Furthermore, since this intervention was delivered in a group setting it was conducive to encouraging behaviour change through information sharing and problem solving.

In trial 13, the participant was expected to engage and interact more with the information at their disposal so as to aid decision making through various techniques rather than simply adhere to key messages relayed in an education programme as was the case for trials at the functional level.

Trial 21 was a different case from those presented here as the intervention had two conditions. The first condition was the experimental nutritional programme



which required the participants to adhere to a meal plan and their role was a reactive one. For this reason the experimental condition was classified as functional health literacy. Participants in the standard nutritional condition however were advised to use the food pyramid as a guideline towards changing their eating habits. This active participant role and solicitation of information from a literary source meant this condition was seen as interactive health literacy. This trial highlights how even with the same aim, two conditions can map on to different levels of health literacy based on the intervention's style of delivery.

Finally, trial 20 was categorised at the interactive level because its style of delivery stated 'culturally appropriate education materials were considered to produce an improvement in the interaction between patients and care-providers' and the earlier work when developing the operational definitions using the 'views' data showed soliciting information from various sources including health professional's to be a skill at the interactive level of health literacy.

#### **6.4.2.3 Critical health literacy**

The operational definition '*Art of discrimination learnt over time alongside an emphasis on the personal experience*' was proposed for critical health literacy. In Table 6.3 five trials are presented.

Trials targeting critical health literacy were characterised as having a clear focus on the individual's personal experience of their condition; this was true for all five trials. At this level trials were recognised as being at the critical level both through the intervention's content and styles of delivery. Skills of discrimination were encouraged (5, 25), as was the importance of individualising self-management (25, 2) and learning over time (12, 2). Some interventions sought to empower participants by nurturing these skills (12, 15, 2). Detail for each trial will now be provided.

While the intervention in trial 12 was testing an educational workshop, it also had a psychological component aimed at improving coping with type 2 diabetes and thereby empowering the participant. Furthermore, it was categorised as a critical health literacy intervention because the emphasis was very much on learning over time since delivery focused on the 'ability to act in a valued direction' and 'working toward their goals'. It was agreed that this trial fitted best at the critical level since

the focus was very much on the individual's personal experience of their condition and how they can best deal with their circumstances.

For trial 15, the Socratic method of instruction was mapped onto the critical level. The Socratic method was a style of delivery that sought to empower the participants through emphasising the importance of their personal experience of the condition and that their own bodies are their best source of information.

Trial 25 was an intervention that was symptom focused and emphasised that participants respond to their personal experience. The delivery of the intervention was tailored to the participant's circumstances and beliefs, giving prominence to the message that management should be individualised. The trials education modules aimed to help people critically evaluate information through reasoning and making judgements, these skills were a further reflection of critical health literacy. The module that specifically focused on symptoms related to hypoglycaemia and hyperglycaemia suggested that there was an emphasis on the 'art of discrimination' as patients report symptoms to be similar yet it is essential to successful diabetes management that patients recognise both correctly and react appropriately.

The intervention in trial 2 aimed to educate participants using an empowerment-based programme, immediately suggesting that the trial fitted onto the critical level. Moreover, delivery emphasised personal experience and individualised management by tailoring medical advice to the results from participants' physiological tests. Furthermore, this was a lengthier intervention meaning participants had the benefit of learning over time.

Finally, trial 5 was also considered to map onto critical health literacy. Firstly, foot care skills the focus of the intervention require an ability to discriminate with an emphasis on personal experience, this suggested this intervention fit the operational definition for critical health literacy. Secondly, the intervention's objective was to improve patient self-efficacy, which by definition focused on the patient's personal experience.

**Table 6.3** Selection of trials mapping the operational definition for critical health literacy

Trial	Aim	Delivery	Outcome
12	To apply an acceptance approach to coping with diabetes.	<ul style="list-style-type: none"> <li>• Acceptance and commitment therapy (ACT) teaches individuals to experience difficult thoughts and feelings about diabetes rather than to attempt to alter or stop them, explores personal values related to diabetes and focus on the ability to act in a valued direction, working toward their goals.</li> <li>• A workshop based on the ACT manual covered the following educational topics: the type 2 diabetes disease process; nutritional management; physical activity; glucose monitoring; use of glucose results and complications.</li> </ul>	<p><i>Primary:</i> HbA1c.</p> <p><i>Secondary:</i> Self-management score, understanding of diabetes, satisfaction with treatment.</p>
15	To deliver a structured programme of diabetes self-management education based on nutritional standards.	<ul style="list-style-type: none"> <li>• Teaching strategies include a combination of audiovisual presentation, lectures and the use of the Socratic method of instruction, which uses questions in an exchange with patients to provide diabetes information that empowers them.</li> <li>• Educational content based on nutritional standards. from the ADA American Diabetes Association.</li> </ul>	<p><i>Primary:</i> HbA1c, perception of care, knowledge, foot care, diet, exercise and medication adherence.</p>
25	To test the effectiveness of an in-home, nurse-delivered, symptom-focused teaching/counselling intervention..	<ul style="list-style-type: none"> <li>• Tailor the intervention to an individual and incorporate personal and cultural beliefs and preferences based on an in-depth semi-structured pre-intervention interview.</li> <li>• The purpose of this interview was to provide each woman with an opportunity to discuss the meaning of diabetes for her and share her thoughts and feelings about her experiences with diabetes, successful and unsuccessful coping strategies, and preferences for support.</li> <li>• Participants individually received the four Diabetes Symptom-Focused Management Intervention modules in their homes. These modules</li> </ul>	<p><i>Primary:</i> Symptom distress, diabetes knowledge, Quality of life, HbA1c, diabetes self-care practices, satisfaction with intervention.</p>

		were: symptoms related to hypo and hyperglycaemia; numbness and tingling in the feet; stress and anxiety; and musculoskeletal aches and skin symptoms.	
2	To evaluate the impact of a problem-based empowerment patient education programme.	<ul style="list-style-type: none"> <li>• Used culturally specific educational materials, community-based programmes and the empowerment approach to facilitate self-directed behavioural change.</li> <li>• Initially, patients were given their clinical measure results in writing with handouts that provided basic information about normal values and five to eight behaviours that affect them.</li> <li>• Educators then spent two hours answering individuals' questions about the meaning of the values and the risk for complications (within a group setting).</li> <li>• Patients identified problems became the focus of guided problem-solving discussions based on the empowerment approach to facilitate self-directed behaviour change.</li> <li>• Educators provided short answers which facilitated discussion.</li> <li>• A further five sessions began with a group discussion of self-management experiments which participants tried in preceding week.</li> <li>• After a discussion, new questions were addressed.</li> <li>• Careful records were kept to ensure all diabetes-related topics required by the national diabetes education standards were covered.</li> </ul>	<i>Primary:</i> Clinical measures, diabetes empowerment scale, seriousness of diabetes scale.
5	To determine whether a culturally and linguistically appropriate intervention would improve foot care knowledge and behaviours.	<ul style="list-style-type: none"> <li>• One arm was a 15 minute self-care intervention that used educational and behavioural strategies designed to increase self-efficacy for foot self-care and ultimately change foot self-care behaviours.</li> <li>• Another arm involved a 5 minute foot risk assessment using a monofilament, designed to encourage patient's involvement in assessing their feet.</li> </ul>	<i>Primary -</i> Self-efficacy; self-care activities; acculturation; foot self-care knowledge.

### 6.4.3 Applying the operational definitions to potential interventions (objective 3)

In this section, the outcome of the cross-synthesis namely the nine potential implications for intervention development (see section 4.4.1) were considered alongside the developed operational definitions to see whether they mapped onto functional, interactive or critical health literacy. There were less data available to address objective three as compared to objectives one and two.

Table 6.4 presents the nine potential implications for intervention development and the level of health literacy they pertain to. Six of the implications were considered to address the functional (G, I), interactive (E, F) or critical (C, H) levels of health literacy. Although the remaining three potential implications for intervention development (A, B, D) were accepted as having a role in health inequality and arguably the broader concept of health literacy, they were not considered to be relevant to Nutbeam's framework of health literacy.

Each of the potential implications for intervention development that was considered to address one of the levels of health literacy as determined in Nutbeam's framework, will be discussed in turn in the following sections. Subsequently, the potential interventions will be compared with existing interventions in regards to the level of health literacy they map onto.

**Table 6.4** How potential implications for intervention development address health literacy

	<b>Potential implication for intervention development</b>	<b>Health literacy level</b>
<b>A</b>	Gender specific intervention	-
<b>B</b>	Support positive outlook towards spirituality and fatalism	-
<b>C</b>	Address patient attitudes, namely self-efficacy	Critical health literacy
<b>D</b>	Include family in intervention	-
<b>E</b>	Individual versus group education	Interactive health literacy
<b>F</b>	Support information sharing but regulate it for accuracy	Interactive health literacy
<b>G</b>	Practically, culturally and linguistically relevant education	Functional health literacy
<b>H</b>	Support a positive outlook towards diabetes	Critical health literacy
<b>I</b>	Improve knowledge of diabetes behaviours	Functional health literacy

#### **6.4.3.1 Functional health literacy**

The operational definition '*Adherence which enables daily functioning*' was proposed for functional health literacy. In Table 6.4 two potential implications for interventions address this level of health literacy.

Potential implication for intervention development 'Practically, culturally and linguistically relevant communication' (G) was considered to map onto the functional level since the focus was on the health professional delivering appropriate communication in a way that considered participants' identity. This highlighted the focus to be on an effective transfer of knowledge designed to improve adherence where the patient's role was a passive one.

The other implication 'Improve knowledge of type 2 diabetes self-management behaviours' (I), aimed to develop knowledge through education so as to improve adherence and develop patient skills. Due to this focus on dispensing directions and instructions in health education interventions particularly focused on issues where participants' views had demonstrated a lack of understanding.

#### **6.4.3.2 Interactive health literacy**

The operational definition '*Patient uses their initiative to solicit additional information from different sources so as to implement more control over their health from day to day*' was proposed for interactive health literacy. In Table 6.4 two potential implications for interventions address this level of health literacy.

Potential implications for interventions 'Individual versus group education' (E) and 'Support information sharing with peers but regulate it for accuracy' (F) both proposed delivery styles with elements of peer discussions and support groups. These components were understood to characterise interactive health literacy as they map onto the operational definition for interactive health literacy 'solicit additional information from different sources.' Whilst, like interventions at the functional level, these potential interventions were still focused on providing information the patient role had become a more active one.

#### **6.4.3.3 Critical health literacy**

The operational definition '*Art of discrimination learnt over time alongside an emphasis on the personal experience*' was proposed for critical health literacy. In

Table 6.4 two potential implications for interventions address this level of health literacy.

Both potential implications for interventions, 'Support positive outlook towards type 2 diabetes' (H) and 'Address patient confidence' (C), indicated that by enabling patients to embrace their evolving identity the individualised nature of diabetes would be emphasised, ensuring participants understood that they were able to manage their own condition, making behavioural changes more likely. Additionally, potential implication 'Address patient confidence' indicated that participants with strong feelings of confidence demonstrated an empowered perspective towards diabetes self-management. These components were understood to characterise critical health literacy as they mapped onto the operational definition '...emphasis on the personal experience.'

#### **6.4.3.4 Comparison between existing interventions and potential implications for interventions**

It was interesting to note of the potential implications for interventions there was an equal number dedicated to the three levels of health literacy i.e. two at each level. Of the existing 28 interventions (included in the review) however, there were eight interventions at the functional level, 15 at the interactive level and five at the critical level. This perhaps suggests that participants' views give an equal emphasis to the skills on all three levels whereas interventions to date have focused on interactive health literacy.

### **6.5. Discussion**

Whilst Nutbeam's framework has previously been considered in the context of type 2 diabetes (Levin-Zamir and Peterburg, 2001; Ishikawa et al, 2008b) this research is novel in that it attempted to refine the definitions for the three levels of health literacy. It was evident at the outset that the elements that comprised and differentiated Nutbeam's three levels of health literacy needed to be clearer, particularly with respect to the interactive and critical health literacy levels. The original definitions for interactive and critical health literacy were considered to be insufficiently specific with both definitions employing the broad terms 'social' and 'cognitive skills.' The definitions were refined by undertaking the following three steps (reflecting the three objectives in section 6.2).

First, each of Nutbeam's (2000) three levels of health literacy were 'imposed' onto data from the 'views' strand of the systematic review. From re-examining the primary studies, condition-specific extracts were teased out for each of the three levels of health literacy thereby distinguishing them further and enabling the development of clear operational definitions. Second, these operational definitions were tested by applying them to existing interventions included in the 'effectiveness' strand of the review. Third, the operational definitions were further tested by applying them to the potential interventions (the product of the cross-synthesis). The second and third steps were anticipated to enable interesting comparisons to be made between what levels of health literacy existing and potential self-management interventions for type 2 diabetes were targeting.

The results suggested that the functional level of health literacy tends to reflect a 'passive' patient role, which is strongly related to treatment adherence. Interactive health literacy reflects a more 'active' patient role where experiential learning was evidenced as well as the soliciting of information from various sources. For critical health literacy, patients placed emphasis on their personal experience and the skills of discrimination learnt over time. The operational definitions are enhanced as they go some way to remove the ambiguity that had been apparent in Nutbeam's (2000) original definitions. The operational definitions developed from this work are supported by research conducted by Ishikawa and Yano (2008c). They considered information seeking, information verifying and information provision to be patient communication skills at the interactive level of health literacy and confidence in decision making to reflect patients' skills at the critical level of health literacy.

By fulfilling the three objectives as outlined in Section 6.2 the subsidiary aim of the systematic review: *"To refine Nutbeam's conceptual framework of health literacy (2000) in the context of type 2 diabetes"* was achieved.

The following four sections will discuss key emerging issues arising from this work, all of these focus around a critique of Nutbeam's framework. These sections are entitled: 'Context specificity,' 'Hierarchical framework,' 'Condition-specific competencies' and 'Measurement'. Following this there will be a reflection on methodological challenges of undertaking this research, its strengths and limitations, principal implications of the findings and finally a summary of the chapter.



### 6.5.1 Context specificity

Nutbeam's framework has been applied in various health situations (Donelle and Hoffman-Goetz 2008a; Donelle and Hoffman-Goetz 2008b; St-Leger, 2001; Friedman et al, 2009; Ishikawa and Yano, 2008a) including type 2 diabetes (Levin-Zamir & Peterburg, 2001; Ishikawa and Yano, 2008b). The empirical work presented in this thesis found that it is particularly the use of the terms 'everyday' and 'life events' within Nutbeam's functional, interactive and critical health literacy definitions that enable the health literacy framework to be relevant in different contexts. 'Everyday' skills in the context of type 2 diabetes include testing blood sugar, eating appropriately, doing physical activity and adhering to medication. 'Life events' in terms of type 2 diabetes could mean for example, reacting appropriately to a hypoglycaemic attack.

The operational definitions for functional, interactive and critical health literacy developed from this research, as enhancements of Nutbeam's original definitions remained generic despite being operationalised in the context of type 2 diabetes. The operational definitions employed the terms 'daily functioning,' 'day to day' and 'over time,' which hypothetically might be applied across many health conditions. Indeed it would be a good test for a future study to see whether the revised operational definitions hold in the context of a different condition and population. This work acknowledges that while the operational definitions are likely to be transferable to other health conditions there are limitations.

Von Wagner et al (2009) noted the significance of context on the role of health literacy in their framework and review. They used the example of a single event decision, for example cancer screening to be different to making decisions regarding a complex long term condition such as diabetes. It is recognised that while the operational definitions have refined Nutbeam's conceptual framework and they have been seen to apply well to type 2 diabetes they may indeed be less appropriate for a single event health decision such as cancer screening. The transferability of health literacy skills to a novel health related situation in this way is questionable and would make for an interesting follow-up study.

### **6.5.2 Hierarchical framework**

The empirical work presented here emphasises that diabetes self-management requires a complex set of skills. The findings of this work challenged the theoretical assumption of the framework being hierarchical in nature (Nutbeam, 2000). This was done in two ways.

First, the research found some critical health literacy extracts to conflict with some of the functional health literacy extracts. For example, a critical health literacy extract reported that a patient ignored the outcome of a blood sugar test paying more attention to how he felt; this contradicted a functional health literacy extract where a patient remarked on his gratification at seeing glucometer readings go down. Findings such as these suggest that it may be over simplistic to claim that an individual must sequentially progress in the acquisition of health literacy skills (from functional to interactive to critical health literacy). Pleasant and Kuruvilla (2008) recognised a similar challenge when developing a health literacy measure that tested general health knowledge in the context of public health. They reported the subjectivity of 'knowledge' made it difficult to measure, in that what was 'true' for one person may not necessarily be 'true' for another.

A study by Gray et al (2005) that examined the experiences of adolescents' internet searching for health information supported the observation from this research that Nutbeam's framework may not necessarily be hierarchical in nature. Gray et al suggested that managing the amount of retrieved information and making judgements on its credibility were examples of critical health literacy skills. Whereas selecting relevant information and applying it to one self were regarded to be instances of interactive health literacy skills. These are not necessarily hierarchical behaviours since decisions made on the application of information are amongst other things, based on the credibility of information.

While the empirical work presented here does not wholly support the health literacy framework as being hierarchical (Nutbeam, 2000) it does seem clear from the findings that the basic skills of functional health literacy come first. These findings give partial support to Nutbeam's (2008) framework of health literacy which considers functional health literacy to be the foundation from which complementary skills can be developed.

Second, Nutbeam (2008) states that the ability to read and write is the foundation of health literacy from which complementary skills can be developed through formal education and informal personal experiences. It was therefore concluded that for the purposes of this empirical work that illiterate people could not be considered to have health literacy. However, this empirical work demonstrates that people without functional health literacy, can still display some behaviours reflecting interactive or critical health literacy. This brings back into question the hierarchical nature of the framework since some people could potentially be empowered and managing well (demonstrating critical health literacy) but without having any reading and writing skills at all or not in the language of the host country (functional health literacy).

Entwistle and Williams (2008) highlight the importance of visual images and how this has not been recognised in efforts to promote health literacy since the concept is usually associated with words. They further note how the WHO (2008) definition of health literacy encompasses issues relating to visual information. Nielsen-Bohlman et al (2004) noted in their influential USA report that even individuals with adequate literacy can have inadequate health literacy. By the same logic it could be possible that individuals with inadequate literacy have adequate health literacy. Further study is needed to clarify the important issue of what level of health literacy a BME individual who is literate in their indigenous language and is skilled at self-management but cannot speak the host language, would be considered to have in the host country?

Ishikawa & Yano (2008) noted that for populations whose indigenous language is different to the language of the host country, their health literacy is affected by their literacy in both their indigenous language and the host language, thus further complicating the relationship between literacy and health literacy. Sudore et al (2009) advised in their recent paper that interventional research should consider the impact of limited literacy and limited English proficiency in healthcare. Paasche-Orlow et al (2009) also commented that work remained to unite the field of health literacy across international borders. All three of these very recent articles are in support of the suggestion from this empirical work that further work is needed to examine the role of indigenous and host languages on health literacy.

### **6.5.3 Condition-specific competencies**

An alternative to a hierarchical framework may be a condition-specific list of competencies for each of the three levels of health literacy. This would mean that an individual's level of health literacy could be assessed without enforcing rules on the sequence of behaviours underpinning it. Since diabetes self-management requires many complex behaviours it is likely for them to be achieved in different ways from individual to individual and over time. In having a less prescribed view of how different levels of health literacy are achieved, a framework would take account of how people with type 2 diabetes manage their condition as they consider appropriate. Wider literature (Anderson, 1995; Funnel and Anderson, 2003; Winkelman and Choo, 2003) concurs that living with a lifelong condition involves what works for the individual with a deliberate move away from being prescriptive.

An example of a competency at the functional level would be 'maintaining glycaemic control'. Although this necessitates a complex set of behaviours, in the context of type 2 diabetes it is a basic skill "which enables daily functioning" as specified in the operational definition. A condition-specific example of a competency for interactive health literacy would be 'attendance at peer-led programmes', since this necessitates that the "patient uses initiative to solicit additional information from different sources," as specified in the operational definition.

A diabetic patient who is sophisticated in self-management would be considered to be at the critical level. An example of a competency at this level would be 'differentiating between the similar symptoms of hypoglycaemia and hyperglycaemia'. This represents the operational definition for critical health literacy as the "Art of discrimination learnt over time alongside an emphasis on the personal experience." In the context of type 2 diabetes the information required at the critical stage of health literacy is the patient's own physical responses to self-management efforts. The framework of Von Wagner et al (2009) lends support to the operational definition for critical health literacy since a key implication of their research was the role of experience, whereas the concept of experience was not dealt with directly in Nutbeam's (2000) framework.

In a related point, before embarking on the empirical work with the 'views' data, it was thought that daily self-management behaviours like diet and physical activity would map onto either the functional or interactive health literacy level. This was because, as previously noted Nutbeam's (2000) definitions for functional and interactive health literacy focused on 'everyday' management whereas critical health literacy focused on 'life events'. It was less clear what types of behaviours would map onto the critical level of health literacy. After undertaking the empirical work it became clear that the same self-management behaviours can be at any of the health literacy levels, as it is the context of the behaviour that determines the level of health literacy. For example, testing blood glucose is a basic behaviour required for daily functioning so it maps onto the function level. When participants share with others their strategies for controlling blood glucose then the same behaviour maps onto the level of interactive health literacy. In a context with blood glucose that requires complicated decision making such as reacting appropriately to a hypoglycaemic attack, the same behaviour maps onto the critical level.

#### **6.5.4 Measurement**

Health literacy has meant many things including patient comprehension and compliance, health education, patient reading abilities and patient ability to interact with health professionals (Zarcadoolas et al, 2003). Paasche-Orlow et al (2009) commented that much work remained in the area of measurement of health literacy because significant variation remained between definitions. It follows that by better conceptualising the three levels of health literacy this empirical work has illuminated steps that can be taken towards the improved measurement of the health literacy levels. As detailed in the previous section condition-specific competencies at the different levels of health literacy may be a useful way to measure health literacy. Wang (2000) has also said that health literacy is a construct that is population and context-specific meaning that no instrument can measure health literacy universally.

Most health literacy measures however are generic and have focused on the functional level (see section 2.3.4). Ishikawa and Yano (2008b) undertook a review in which they considered existing definitions and measures of health literacy and noted there to be no validated instruments at the interactive or critical levels of health literacy. The authors themselves developed a reliable and valid 14-item

psychometric test for diabetic patients. This was the first scale of its kind to measure the functional, interactive and critical levels of health literacy as conceptualised by Nutbeam (2000). Functional health literacy was assessed based on difficulty patients experienced in reading leaflets from hospital. The findings from this exploratory work have suggested that functional health literacy measurement should be broader than reading ability to also include basic understanding. Interactive health literacy was assessed by focusing on how well patients were able to extract and communicate information about type 2 diabetes since their diagnosis. While critical health literacy was assessed by considering to what extent patients were able to critically analyse and utilise diabetes information to make health decisions. The items at the interactive and critical health literacy levels were more in keeping with the findings of this exploratory study.

Mancuso et al (2009) had also reviewed the literature and criticised functional health literacy measures for being too basic and ignoring the wider context. They too recommended that a measure should be specific to one population e.g. people with diabetes, rationalising that if a person suffered with that condition he or she would exhibit a greater interest and perhaps a greater understanding of literature on that topic. That is to say, individuals with diabetes may successfully read and understand diabetes information but not other topics that have been written at the same level. The empirical work presented in this thesis supported the notion of Mancuso et al (2009) that the measurement of functional health literacy should be condition-specific by specifying that measures should include a test on basic understanding. This exploratory study suggests the way to measure understanding would be by employing a condition-specific tool based on the notion of 'daily functioning' i.e. a condition-specific list of competencies to assess whether a patient has functional health literacy.

Pleasant and Kuruvilla (2008) note that while health literacy is frequently related to knowledge across definitions this is not reflected in existing measures. Nutbeam (2000) theorises health literacy to be an outcome of health promotion, explicitly placing knowledge into a framework of health literacy by defining functional health literacy as the basic understanding of factual health information. Kickbusch (2001) has also called for health literacy measures that consider knowledge. Baker (2006) however argues that knowledge is a resource that

facilitates health literacy but does not constitute health literacy thereby contributing to the debate around conceptualisation and measurement. There remains no consensus on this issue. This work recognises knowledge to be a crucial component of health literacy at all three levels and makes an argument for condition-specific measures. In a recent publication, Nutbeam (2008) stated that it was plausible for health literacy measures to be specific to age and life stage noting that health literacy in students is quite different from assessing the health literacy of an older person living with a long-term condition thereby supporting the findings of this exploratory study that measure needs to be condition-specific.

Jordan et al (2010) undertook qualitative in-depth interviews to understand patients' perspective of what health literacy presents so as to identify constructs for a broader health literacy measure. While they identified key health literacy abilities that emerged at the healthcare and community levels they concluded that these could not be directly measured to assess health literacy. Perhaps the difficulty of measuring broader health literacy is related to the focus of health literacy at the individual level and considering health literacy as a patient problem and not as a healthcare problem.

### **6.5.5 Reflections on methodological challenges**

Due to the exploratory nature of this work methodological challenges have been presented at each stage of the methods. Perhaps the main challenge was that in the primary articles, trials and 'views' studies were rarely described by the authors as considering healthy literacy, let alone in terms of using Nutbeam's labels of functional, interactive or critical health literacy. It was therefore uncommon for included studies to fit neatly with the health literacy continuum. Post-hoc analyses were executed to make a retrospective assessment regarding their health literacy level. The actual process of identifying descriptive extracts and mapping trial interventions onto the framework in this way, by considering the various words researchers used to describe the levels actually provided useful insights and helped achieve the aim of the refining Nutbeam's (2000) conceptual framework of health literacy.

### **6.5.6 Strengths and limitations**

Extracts from 'views' studies as well as existing and potential self-management interventions that were targeting functional health literacy had been straightforward to identify because they targeted adherence directly and focused on daily functioning. Moreover the concept of functional health literacy was already well researched in the existing literature. A key strength of this work was that interactive and critical health literacy levels were better differentiated.

Interactive health literacy extracts focused on soliciting information. An interesting finding and one that was considered to perhaps be specific to the populations under study was that for these populations the best way to 'extract information and derive meaning' was by speaking with other people who also had diabetes. This is possibly a reflection of the typically high prevalence of type 2 diabetes (see section 2.2.2.1) and low levels of literacy in BME communities (see section 2.3.5.1). Through undertaking this exploratory study, critical health literacy came to be understood as involving skills of discrimination as learnt over time and from experience.

As noted in the literature review (see section 2.3.5) health literacy initiatives have been criticised for not concentrating on the root cause of a problem which includes socio-economic disparities and unequal access to quality healthcare and education. It should be emphasised that while health literacy has been employed as a conceptual framework for this exploratory study, social determinants have not been ignored. To the contrary, health literacy was deliberately selected as the conceptual framework for this thesis because it was considered to be useful for the investigation of health inequality. This was evidently found to be a strength of the study.

Conclusions are presented only tentatively because of the exploratory nature of the work and the methodological limitations detailed throughout this chapter. The methods from this research particularly in "selection of 'views' studies" for objective one should be more rigorously replicated in any future study. The method was only applied to half of the 'views' papers of objective one from the systematic review and extracts were not exhaustive. The method and results could be tested out with another population and health issue from another sample of papers to compare



findings. The majority of populations under review here were of ethnic minority, socio-economically deprived and hospital based groups. It would be especially interesting to compare similarities and differences with another population and condition.

Ishikawa and Yano (2008b) undertook a review in which they considered existing definitions and measures of health literacy in response to the review findings the authors recommended that future research considered population health literacy so as to explore the interaction between patient health literacy and its social and health context. While the empirical work discussed here was not in response to this recommendation, this research can be seen to contribute to this area since the focus has been on type 2 diabetes in BME groups. Marked socioeconomic disparities in ethnic groups in the west are widely recognised as being related to the higher prevalence of type 2 diabetes in these groups (Karter et al, 2002; Abate, 2003; Hippisley-Cox et al, 2004). Previous research that has addressed the question of whether differences in health literacy contribute to ethnic and socioeconomic disparities in health and healthcare has been inconclusive (Kripalani, 2006). While the relationship between social factors and health is well established (Goldman, 2004) it is difficult to report causal relationships between social determinants and health outcomes because the accumulative or additive correlations make the association complex (Blane; 2003).

### **6.5.7 Implications**

Having undertaken this exercise using Nutbeam's framework, operational definitions have been successfully developed using condition-specific examples, further distinguishing the three levels of health literacy. These findings suggest that if a list of condition-specific competencies were developed for the different levels of health literacy then this could help inform the development of an outcome measure for the different levels of health literacy. This is an important outcome in that it would help make the shift from the current focus on functional health literacy; more specifically reading and writing skills (Ishikawa et al, 2008) presumably because they are tangible, to measures to the interactive and critical levels; which include patients' abilities to take an active participatory role in their own health. Moreover, operationalising and measuring the three levels of health literacy is expected to

facilitate recognition of an individual's current level of health literacy and focus support to empower the individual and improve their health literacy.

### **6.5.8 Summary**

The innovative method employed in undertaking this exploratory study has served to achieve the subsidiary aim of Study One. The operational definitions that have been developed for the three levels of health literacy noticeably relate to different skill sets that are required for effective diabetes self-management. The levels of health literacy have, in the context of type 2 diabetes self management, been successfully refined. This is of particular importance in relation to the interactive and critical levels, at the outset these were considered to have a significant overlap but now they are considered as being suitably differentiated.

Along with findings from the systematic review, the operational definitions generated by this work, were used in the topic guide of Study Two which consists of primary qualitative empirical work. This was so as to encourage the participants to reflect on the different levels of health literacy in the context of their type 2 diabetes self-management. These findings are summarised in section 8.4.

## Chapter 7

### Study Two Methods

#### 7.1 Introduction

The second study in this thesis was a qualitative interview study that aimed to answer the research question “*How does having type 2 diabetes affect British-Pakistani women’s identity and how does this relate to subsequent self-management?*” This study had a subsidiary aim *to investigate the operational definitions for the three levels of Nutbeam’s (2000) conceptual framework of health literacy as developed in Study One.*

It is acknowledged that there are many theories around identity and while there is slight variation amongst these (e.g. Stryker, 1968; McCall & Simmons, 1978; Turner, 1978; Burke 1980; all cited in Terry et al, 1995) they are all underpinned by the same core concept. This core concept is that the self as a reflection of society is multifaceted and the different components of the self reflect the individual’s various roles. For example, an individual may identify with being a mother, a wife, an immigrant and a person with diabetes.

The research aims of this second study were directly informed by the findings of the first study, which was a systematic review of the literature on type 2 diabetes self-management in BME populations. Specifically, Study Two built on the findings of both the ‘views’ strand and the health literacy component of the systematic review. A description of how Studies One and Two link is presented in the following section. This is followed by a justification for choosing a qualitative research methodology and semi-structured interviews as the method of data collection. The choice of participants, sampling and information on sample size is then presented, followed by a description of the recruitment procedure. Method of data collection is then described with a focus on how the interview schedule was developed and the procedure of interview. Finally the methods of data analysis are presented with the aid of a worked example.

## **7.2 Link between Study One and Study Two of thesis**

In the systematic review, thematic synthesis of the 'views' data produced three analytical themes: 'importance of identity', 'being understood by others' and 'making sense of own condition'. For two of the analytical themes there was mostly consensus across studies but for the remaining analytical theme, 'maintaining identity,' there were some strongly conflicting views. On this basis the decision was made to pursue a line of enquiry in empirical work (i.e. Study Two) based on this theme, seeking clarification specifically on the two sub-themes that composed the points of difference. These two sub-themes were 'confidence' and 'roles,' each of these will be briefly presented here.

Views across studies emphasised the personal experience of living with type 2 diabetes in the sub-theme 'confidence.' For some patients this was a facilitator to effective self-management since they demonstrated an empowered perspective to embrace their new and evolving identity and felt confident in self-managing their diabetes. Other patients however, regarded their diagnosis and condition to have changed them in a negative way and as a result of their disorientated identity or feelings of rejections towards their new identity, they lost confidence in their body. For these participants these feelings came to act as a barrier to effective self-management.

Similarly, views across studies in the sub-theme 'roles' reported conflicting views. For some, roles as wives, mothers, etc acted as a facilitator to self-management as they felt it was important for them to effectively self-manage their condition and maintain their health, so as to sustain their identity, independence and sense of normality. Meanwhile other participants viewed their work, social and familial roles to be a barrier to successful self-management, since they made it physically and emotionally difficult to self-manage effectively.

It was considered useful to identify participants' reasons for holding contradictory views around the analytical theme 'importance of identity'. By undertaking primary empirical work it was anticipated that the issues underpinning participants' outlooks of how their diabetes affects their identity would be better explained. This in turn was expected to improve understanding of how identity could act as a barrier or facilitator to diabetes self-management.

As well as framing the research question around the analytical theme, Study Two also included questions that had emerging from the health literacy component of the systematic review. It was anticipated that the interviews would be used to further investigate the refined levels of Nutbeam's (2000) conceptual framework, as developed in Chapter 6. To do this, questions in the interview schedule were phrased adopting the wording of the operational definitions developed in Study One (see Appendix 7.1). This was anticipated to be a useful way to encourage participants to talk about different dimensions of their situation, abilities and skills. The researcher could then reflect on participants' responses in relation to the three levels of health literacy in the context of their own diabetes self-management. Additionally, it was expected that the critique provided of Nutbeam's framework in sections 6.5.1-6.5.4 would be further explored in the context of this empirical work.

To summarise, the second study in this thesis further explored the two sub-themes 'confidence' and 'roles' and the operational definitions for the three levels of health literacy as developed in the first study.

### **7.3 Justification for choosing a qualitative methodology**

There were three reasons for selecting a qualitative approach for Study Two

Firstly, as detailed in the previous section, the 'views' strand of the systematic review revealed there to be some conflicting views within the sub-themes 'roles' and 'confidence'. While it was unsurprising that the 'views' strand, which was composed of 57 studies, would include some conflicting views, it was considered to be interesting and useful to try to identify the reasons that lead to participants' contradictory views. Qualitative methods seemed to be the appropriate choice for such an investigation, since in contrast to quantitative methods, qualitative research methods typically provide an in-depth perspective of human behaviour (Lincoln and Guba, 2000).

Qualitative research is a form of social inquiry that can study the way people make sense of their experiences from their descriptions about the research subject (Taylor and Bogdan 1984; Holloway, 1997). Qualitative research thereby uncovers the participant's own perspective (Jensen, 1989; Marshall and Rossman 1989) and explores how they define the subject of research (Jensen, 1989; West, 1990;

Crabtree and Miller, 1991; de Vries et al, 1992;). This enables the researcher to better understand the participant's world (Oiler 1993; Secker et al, 1995). This ability to access participants' own definitions and interpretations is a key strength of qualitative research that generates an authentic insight into the participants' experiences (Murphy et al, 1998). This is particularly useful when the subject under study is not observable such as thoughts, feelings and intentions (Patton, 1990), making qualitative research ideal for Study Two which focuses on participants' perceptions of their identity and the influence that type 2 diabetes might have on this.

Secondly, since none of the primary 'views' studies included in the systematic review had had the objective of addressing identity per se, an exploratory study seeking to gain a deeper understanding of the issue seemed most appropriate. By so doing, it was anticipated that the issues that underpin participants' outlook towards how diabetes affects their identity would become better understood (and how the effects on identity can subsequently act as a facilitator or barrier to self-management). To do this, a qualitative method seemed the most rational choice as it would allow participants to share their narrative in their own way in contrast to a quantitative method that is best suited to testing hypotheses. A strength of qualitative research is its' ability to be flexible (Murphy et al, 1998) making qualitative studies especially suitable for exploratory research. Since qualitative interviews enable the researcher to consider new dimensions and follow interesting yet unanticipated leads (Britten, 1995).

Finally, it was anticipated that by greater exploration of participants' different responses to their condition through a dissection of their views, the complex relationship of why people respond in such different ways would begin to be addressed. The possible explanations of relationships between the variables may enable a greater understanding of the contextual factors that may influence how self management is enacted in this population.

### **7.3.1 Study design**

Study Two was a cross-sectional, semi-structured, face-to-face interview study. Ethical approval was granted by the School of Healthcare's (University of

Leeds) Research Ethics Committee (SHREC). The approval letter was received on 29<sup>th</sup> of October 2009 and the ID number of the application was (SHREC/RP/165).

## **7.4 Justification for choosing semi-structured interviews**

Either focus groups or interviews could have been used to collect data in Study Two. Focus groups were initially considered since all study participants would be of the same sex and share similar backgrounds (Nichols, 1991) meaning that data could feasibly be collected in this, traditionally efficient, manner. Eventually however, individual, face-to-face, semi-structured interviews were selected. Interviews were considered to provide a better opportunity for collecting in-depth data from individual women relating to their own experiences of managing and living with type 2 diabetes and how this influences their perceptions of their identities.

Interviews are considered to be conducive to the building of rapport between the interviewer and participant (Nichols, 1991) whereas focus groups may pose problems in that one person may dominate conversation or some individuals may feel unwilling to share their experiences with the rest of the group (Wimmer and Dominick, 1997). This was an issue since the study aimed to explore the potentially sensitive topic area surrounding women's views on how they felt their diabetes had affected their identity and their personal experiences. It was thought that although interviews may have been more time-consuming they would provide the level of depth appropriate to the study of this sensitive and private subject area.

Another reason for selecting semi-structured interviews as the research design was that since they did not have a standardised question order respondent's answers were able to lead the direction of the interview, this was advantageous since it gave the impression of a loosely structured conversation (Wimmer and Dominick, 1997). This was considered to be a particularly suitable way to talk about a potentially sensitive and personal subject matter such as living with a long term condition. Moreover, while a semi-structured interview design enabled a predetermined key set of questions to be asked albeit with flexibility, additional interesting yet unanticipated topics were also able to emerge and be explored for participants individually.

### **7.4.1 Participants**

Pakistani women diagnosed with type 2 diabetes were recruited to this study. There were two key reasons for recruiting participants from one BME and gender group in Study Two. Firstly, the study was pursuing a line of enquiry in this empirical work that was based on sub-themes from the systematic review findings

that had composed points of difference. Since a heterogeneous sample was included in the systematic review conclusions were limited as to the reasons for the differences in their finding. By employing a homogeneous sample in the second study it was expected that the findings would have more certainty. Moreover, because the research question was concerned with how diabetes impacted on participants' identities in particular it was useful that participants shared certain identities i.e. they were from the same ethnic and gender group. This meant that inferences from the results were facilitated. Secondly, there were pragmatic reasons for recruiting British-Pakistani female participants: the researcher's background and language skills meant access to and recruitment from this community was assisted.

#### **7.4.2 Sampling**

Having chosen an overall sample of British Pakistani women, maximum variation sampling was used to ensure that a range of characteristics were reflected in the sample of women to be interviewed. This was achieved by developing a recruitment grid (see Figure 7.1). As can be seen there was purposive sampling according to whether the woman was a first generation or a second generation immigrant. The reason for choosing to sample across generations of British-Pakistani women was so as to broadly explore women's perceptions and investigate the effect of generational status on views about type 2 diabetes and the effect this has on their identity. Moreover, none of the studies included in the systematic review that had focused on a South-Asian BME sample, had compared the views of first and second generation immigrants.

Another variable included in the recruitment grid was educational status this was qualified differently for first and second generation women. First generation women were sampled according to their ability to read and speak English. Second generation women were sampled according to whether or not they had obtained educational qualifications of G.C.S.E's and above. The reason for choosing to sample across women with different language abilities and educational qualifications was so as to be able to reflect on the effect health literacy may have on their views about type 2 diabetes and the effect this has on their identity.

While it is noted in the literature review that the terms 'literacy' and 'health literacy' are not interchangeable (see section 2.3.1) it is acknowledged that there is a



clear overlap. The existing measures for health literacy that focused on the functional level and were predominantly English language were critiqued in the literature review (see section 2.3.4). For these reasons it was decided against employing existing measures to ascertain participants' levels of health literacy. However it was anticipated that by employing maximum variation sampling based on women's educational qualifications and ability to read, then women with a broad range of literacy and health literacy would be recruited.

**Figure 7.1** Recruitment grid

1 <sup>st</sup> generation immigrant		2 <sup>nd</sup> generation immigrant	
Read and speak English well	Do not	Have GCSEs+ educational qualifications	Do not

### 7.4.3 Sample size

In a qualitative inquiry the data set comes from a carefully selected and usually small sample that is studied in-depth (Patton, 1990; Miles and Huberman 1994; Kvale, 1996 and Mason, 1996). Since qualitative studies yield a lot of data, too many cases can become unwieldy (Miles and Huberman 1994; Sapsford and Jupp, 1996) and sample sizes are therefore typically small as compared with quantitative studies.

The initial aim was to recruit twenty women, ten first generation and ten second generation immigrants. However, after having conducted 15 interviews, no new information was arising; women were giving familiar explanations around the same themes. A key point in qualitative research is to collect data until saturation occurs (Morse, 1989). Unlike in quantitative research where there are formulas designed for estimating the sample size, there are no published guidelines in qualitative research for the purpose of saturation. Saturation was therefore discerned by the researcher from the adequacy and comprehensiveness of the results (Morse, 1995).

Originally, an equal number of first and second generation women were to be recruited but in the final sample there were more first generation women than second generation women. Generation status was also a proxy for age and it proved more difficult to recruit second generation women with type 2 diabetes. This is

understood to be due to the migration patterns and the typically adult-onset of type 2 diabetes.

The migration pattern of the Pakistani community in Britain was one of 'chain migration' largely from the early 1950s until the end of the 1970s when the British economy was short of labour (Ballard, 1996). Initially, men left their families in Pakistan to come to Britain but from 1964 wives and children began to join their now settled men (Shaw, 1998). This meant there are currently fewer second generation women that have reached the ages from which type 2 diabetes is typically diagnosed. This challenge in sampling was tackled by amending the criteria. Second generation was originally defined as being born in the UK but it was changed to include women who had moved to the UK as children aged 12 or younger. This change was justified in that it was more accurate to consider these individuals as second generation immigrants since they were raised in the host culture.

#### **7.4.4 Recruitment**

The researcher put up posters advertising the study and seeking participants in mosques and Asian food shops in Middlesbrough. Participant information sheets in English and Urdu (see Appendix 7.2) were also left at these venues for any women who were interested in taking part in the study.

Women were also recruited via a local community initiative whereby a series of weekly health education classes were being run for Pakistani women, over a period of two months, focusing on a different health issue every week. One of the sessions was on type 2 diabetes. Each session was two hours long. The format was that for the first hour invited speakers would give a presentation in the Urdu language and the second hour would be a more social event where refreshments were provided and the women could stay and chat at the community centre.

The organiser of the health education classes was approached by telephone and she agreed to give the researcher a five-minute slot at the end of the first hour. In this time the researcher introduced herself and the purpose of the research in Urdu. The verbal explanation included information on the estimated time that might be needed to complete the interview, that the interview would be tape recorded and how the results of the study would be used. All participants were informed that they

could terminate the interview at any time if they changed their minds. In addition, all of the women were provided with the participant information sheet, in both English and Urdu (Appendix 7.2). Following this, a paper was passed around on which any women who were willing to be contacted by the researcher, placed their contact details.

Women providing their contact details were not assumed to be consenting to participate in the study but as agreeing to be contacted by the researcher with more information about the study. Potential volunteers were contacted by telephone in the following week and any questions about the study, arising from the information sheet or otherwise, were answered. If the women were still interested in participating then an appointment was made to conduct the interview.

## **7.5 Data collection**

### **7.5.1 Developing the interview schedule**

The interview schedule with probes and follow-up questions (see Appendix 7.1) was developed based on some of the key findings from Study One. Questions in sections one and two were framed around the analytical theme, 'importance of identity' (and in particular its sub-themes 'confidence' and 'roles') from the 'views' strand of the systematic review. There were questions in section three around the findings of the exploratory study which had refined Nutbeam's health literacy framework in the context of type 2 diabetes.

The interview schedule began with an introductory question exploring the woman's early experiences of diabetes and diagnosis. This was to allow time to develop rapport with the participant before asking more personal questions about identity and roles. Section one of the interview schedule was comprised of questions relating to the current experience of diabetes and the feelings the woman had about this. These questions addressed the participant's confidence level and from this it could later be inferred how these affected diabetes self-management. Section two explored the participant's personal roles in relation to her family, friends and work, particularly investigating how these linked to her identity. Again, it was anticipated that by better understanding how participants' roles affected their identity, then their influence on diabetes self-management would also be better understood.

The third section of the interview schedule explored the relationship between the participant's health literacy and self-management. The operational definitions for the three levels of health literacy (functional, interactive and critical) developed in Study One were used to inform these questions. For example '*Can you think of any occasions when you experienced a new situation because of your diabetes?*' was used to encourage the participant to reflect on the critical level of health literacy. These questions provided opportunity for further investigation of the operational definitions as developed in Study One and also to further refine the conceptual framework in the context of type 2 diabetes.

A pilot interview was conducted with one participant. This was done in order to check the wording of the interview questions so as to determine whether they were phrased in a simple way so that participants would understand the questions as they were intended. Doing a pilot interview also indicated that the ordering and length of questions worked well. Since the interview schedule was found to work well the data from the pilot interview were kept as part of the overall set for analysis. The interviews were undertaken between January and March 2010.

### **7.5.2 Procedure of interview**

A time and place for interview convenient to the women was arranged. In all instances interviews were undertaken at the women's own homes. The women appeared to be relaxed in their familiar surroundings and this afforded a conducive environment for interviewing. Before the interview commenced, the researcher went through the participant information sheet again, and answered any questions the woman may have had.

Participants were reminded that the content of their interview was confidential and would only be discussed with supervisors. English speaking interviewees were also told that the anonymous recordings would be heard by a transcriber. No participant objected to this. At the start of each interview, participants were reminded that they need not answer any question that they did not want to answer, and that they could stop the interview at any time. No participant refused to answer any questions or exercised their right to stop the interview.

These participation protection issues regarding the participant's anonymity, the participant's right to voluntarily participate in the study and the participant's right to

withdraw at any time were all presented in the consent form (see Appendix 7.3). Before the interview began participants were asked to sign two copies of the consent forms. They kept one copy and the other copy was filed by the researcher. No participant withdrew from the study after having signed the consent forms.

Also, before each interview began, demographic data about the women were collected by asking the participant a series of questions and noting her answers. Casual conversation was always initiated in the time before the interview commenced. Discourse felt easy and spontaneous, suggesting the situation to be a comfortable one. All interviews were audio recorded and later fully transcribed for analysis. Occasionally one word notes were made during the interview as a reminder to revisit an important issue. No other notes were made so as to maximise eye contact with the participant and demonstrate interest in what she was sharing.

During the interview the researcher made observations of the participants' behaviour, surroundings and remained aware of her own feelings and interaction with the participant. Immediately after leaving the interviewee's home, brief reflective notes were made about the impression given by the participant during the interview. This was generally if the women appeared agitated or distressed when discussing a certain topic.

There were two key challenges that emerged. The first being that it was not always easy to anticipate how relevant the information women were giving was going to be. The second was that since interviews were conducted at participant's homes, there were some cases of interruptions. In these cases care had to be taken to remind the interviewee what we had been discussing and what she had last been saying so as to avoid incomplete narratives.

### **7.5.3 Translation and transcription**

Within five days of having undertaken the interview, the recording was listened to and further notes were made about the interview. Then, if the interview had been conducted in Urdu, it was translated and fully transcribed into English by the researcher. If the interview was conducted in English an electronic file of the recording was e-mailed to a transcriber for verbatim transcription. The transcriptions were read over and compared with the recording to check for accuracy

and any mistakes were corrected. These were most often in regards to mention of religious terms like “masha’Allah,” use of single Urdu or Punjabi words even within English interviews or the result of a strong accent.

## **7.6 Data analysis**

The key aim of qualitative data analysis is to elicit the vividness of descriptions of phenomena as provided by participants. Thematic analysis is a method for identifying and reporting themes from a data set and it was employed in Study Two. The distillation of patterns of data is also referred to as thematic analysis (Taylor and Bogdan, 1984; Aronson, 1994). Thematic analysis is recognised as forming the core of many other forms of qualitative analysis (e.g. content analysis, grounded theory) and for this reason it has been criticised as not being a method in its own right, but rather a tool to be employed across various other methods (Ryan and Bernard, 2000). Braun and Clarke (2006) disagree with this and while they acknowledge the method as having theoretical freedom and flexibility, they consider these to be its key advantages. They outline in their paper six phases for the undertaking of thematic analysis that were consequently followed in Study Two. These six phases are: familiarisation with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes and producing the report.

### **7.6.1 Worked example**

A worked example of the analysis process is illustrated in Figure 7.2. The interview excerpts provide supporting evidence and an understanding of how thematic analysis was undertaken. Figure 7.2 presents extracts that focus primarily (but not exclusively) on the theme ‘Role of social support’ and its sub-themes and categories in terms of how they were exhibited in the data and where they were originally coded on the coding framework (see Appendix 7.4). The detail from the worked example will also be used to illustrate the first five phases from Braun and Clarke’s (2006) six phase guideline for undertaking thematic analysis, which will be briefly presented here.

*Phase one: Familiarisation with the data* - This phase related to listening to the recordings, translating and transcribing and re-reading of the transcripts. As

detailed in sections 7.4.3 this stage was built into the data collection procedure when an initial list of ideas about what is interesting about the data is generated.

***Phase two: Generating initial codes*** - Coding of data is a key step in qualitative analysis (Cuba 1988; Strauss and Corbin, 1990). Coding is done in stages (Strauss, 1987; Lofland and Lofland, 1995) and is lead by the research objectives. At this phase, initial codes were produced from underatking line-by-line coding of the entire data set using a coding framework (see Appendix 7.4) the N-Vivo software programme was used to manage the data. A code is a label that assigns meaning to information collected within a study (Miles and Huberman 1994). See Figure 7.2 for an example of initial codes that were applied to a segment of the transcript.

***Phase three: Searching for themes*** - Once all the data had been initially coded the provisional stage of analysis began where consideration was given to how different codes may combine to sort into potential themes. Relationships between codes, between themes, and between different levels of themes were considered. While it was detailed that some initial codes may go on to form themes and sub-themes it was accepted others may be discarded. This phase ended with a collection of candidate themes. At phase three there where seven candidate themes that had emerged from the data: 'Feelings about diabetes;' 'Diabetes experiences;' 'Understanding of diabetes;' 'Family life and diabetes;' 'Social life and diabetes;' 'Work life and diabetes' and 'Other people's diabetes.' These categories largely reflected the questions included in the interview schedule but this first step was useful to organise the data.

***Phase four: Reviewing themes*** - This phase involved the refinement of the candidate themes. Here the seven candidate themes were collapsed into each other or broken down into separate themes. To do this all the codes for each theme were re-read with the aim of exploring whether they formed a coherent pattern. Validity of the reviewed themes were considered by relating them back to the data set. At phase four more detail was obtained from the data set and greater interpretation of the data was introduced. Moreover, significance of patterns in the data and their broader implications were theorised (Patton, 1990). An example of this was that women talked about how their responses to diabetes improved with time, it was

theorised that this may be related to an adjustment to their illness identity (Heijmans and de Ridder, 1998; Paterson, 2001) over time.

The outcome of the refinement of the candidate themes in the fourth phase resulted in the following five themes: 'Familiarity with condition (own and other peoples);' 'Level of support received;' 'Perceived change in herself;' 'Circumstances and context' and 'Outlook.' At the end of this phase, Braun and Clarke (2006) state that the researcher has a good indication of how the different themes fit together and the overall story they tell about the data. These candidate themes reflect the themes that were eventually arrived at in the final phase.

*Phase five: Defining and naming themes* - At this point themes were further defined and refined by determining what aspect of the data they captured. It was key to identify the 'story' that each theme told, as well as how it fitted into the broader overall 'story'. Part of the process of refinement was identifying whether or not a theme contained any sub-themes. Sub-themes were essentially themes-within-a-theme that were useful for giving structure to a particularly large and complex theme.

It was at this phase of thematic analysis that the candidate theme 'Circumstances and context' from the previous phase was removed. It was decided that this theme was descriptive of the 'story' rather than explanatory of the 'story'. 'Circumstances' in this theme detailed information about the effect generational and educational status had on participants' views. 'Context' referred to the woman's wider health status, for example her being pregnant or having co-morbidities. While 'Circumstances and context' was not retained as a theme in itself, it proved useful in describing the other themes and sub-themes.



**Figure 7.2** A worked example demonstrating stages of thematic analysis for the analytical theme ‘Role of social support’

<b>Transcribed data from interview with Participant 11</b> (I=Interviewer R=Respondent)	<b>Codes</b>	<b>Sub-themes</b> (and categories)	<b>Theme</b>
<p><i>I=Do these social roles have any effect on your diabetes management?</i></p> <p>R=No. No because um... not really because if I want to socialise with everyone, you know, I do, you know. Because as I say I’ve controlled it. I keep my medication on me and everything if I need it. The friends I’ve got they always, you know, instead of me reminding myself they remind me [laughs].</p> <p><i>I=Oh okay, that’s nice.</i></p> <p>R=And they say, have you had your medication before you come out? Have you brought it with you, you know. And every hour and they’d say, have you had your medication, you know, have you done it, I say okay I have, you know, thank you but I’ve done it. But um, much or all my friends you know, I’ve got a load of Asian but most of them are English friends and they’re very good you know, they support me a lot.</p>	<p>Friends (social situations)</p> <p>Understanding (medication)</p> <p>Friends (help)</p> <p>Friends (help)</p> <p>Friends (help)</p>	<p>Friends</p>	<p>Role of social support</p>

<p>R=If you've got a good family you know, and then you get a lot of support. Like my family you know, I'm number one priority to them now, you know. They said, you've done your bit for us and now it's our turn to pay you back. So like that, you know, all my family, my nephews, my cousins and my brothers, everyone, you know, they do their bit for me. But um, some families, even they have their family round them, they're still alone, you know, looking after themselves. And when you're picking all that up yourself, you know, all on your own, and that's the hard part I think, I couldn't... I think that's my weakness, if I don't have my family around me I think I'd be broke, you know. Where I've got five years I'd be at two years of my life. I think if you've got a good support behind you, your family, and to give you courage and everything, like my son gave me courage, no mam, stick to it, you know, I'm there for you. I mean when I'm feeling sickly with it and everything, he's there for me. He will sit with me and sometimes I'll cry like a baby, you know, and you know, he will cuddle me and he'll say, mam, come on, stop being a baby now, you've been through a lot and this is nothing, come on, you know. And I say, why me, you know, let me give up, and</p>	<p>Family (help)</p> <p>Others diabetes (friends)</p> <p>Family (help)</p> <p>Family (help)</p>	<p>Family (Diagnosis influenced level of perceived support)</p> <p>Family (Diagnosis influenced level of perceived support)</p>	<p>Role of social support</p> <p>Role of social support</p>
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<p>he says, no I'm not going to let you give up on it. When I've wanted to give up but because as I say, if you've got a good family, you know, you can fight it, but it depends on what kind of support you've got, you know. And the main thing is, if you've got support, no matter what illness you've got, you can fight it, yeah.</p> <p><i>I=It's very important.</i></p> <p>R=Yeah, that's the main thing...I mean I've got a niece, she's four, and if she comes around on the evening or I call around her house and um if I'm going to eat and she says, don't eat yet, have you put your thing on? You know, she can't say the Byetta and she's, have you done your thing on your belly, do that first and then eat. And you know, like things like that, you know, like things, when a kid can do that, you know, and it gives you a smile and a buzz, you know.</p>	<p>Empowered perspective</p> <p>Family (help)</p> <p>Understanding (medication)</p> <p>Empowered perspective</p>	<p>Family (Diagnosis influenced level of perceived support)</p>	<p>Role of social support</p>
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## Chapter 8

### Study Two Results

#### 8.1 Introduction

This chapter will present the results of the qualitative interview study which aimed to address the research question “*How does having type 2 diabetes affect British-Pakistani women's identity and how does this relate to subsequent self-management?*” First, the characteristics of the participants will be detailed. Following this, four themes and an over-arching theme, the product of the thematic analysis, will be presented and discussed. This study had a subsidiary aim: “*To investigate the operational definitions of the three levels of Nutbeam's (2000) health literacy framework as developed in Study One, so as to further refine the conceptual framework in the context of type 2 diabetes.*” Where appropriate in the results, health literacy will be considered.

#### 8.2 Characteristics of participants

There were 15 participants in Study Two. Four women responded to posters, six women were recruited via the community educational class and the remaining five women were recruited through ‘snowballing’. The demographic details of the women are presented in Table 8.1. All of the participants had type 2 diabetes and were British-Pakistani Muslim women with children, living in Teesside. The age of the participants ranged from 31-76 years old, with a median age of 54. Five of the women were second generation immigrants and ten were first generation immigrants. Immigrant status was also related to participant age. The age of the first generation participants ranged from 43-76 years old (median age of 55) and of the second generation participants ranged from 31-55 years (median age of 45).

Three of the second generation women had obtained G.C.S.E.s (or equivalent). Four of the first generation women spoke English fluently and with all of these women the interview was conducted in English. Four of the first generation women spoke in Urdu and one spoke in Punjabi. With all second generation women the interviews were also conducted in English. All but two of the participants had co-morbidities. Eight women reported experience of being in paid employment.

**Table 8.1** Description of participants

Participant	Generation status	Years since diagnosis	Age (years)	Speaks English well	GCSEs +	Work	Marital status	Co-morbidities
Saliha	2 <sup>nd</sup>	6	31	-	Yes	No	Married	High blood pressure
Sughra	1 <sup>st</sup>	5	55	Yes	-	Retired	Married	Arthritis
Shanaz	1 <sup>st</sup>	18	61	No	-	Retired	Widow	Arthritis, thyroid, hernia
Zakia	1 <sup>st</sup>	19	48	No	-	Yes	Married	None
Sajida	1 <sup>st</sup>	7	55	No	-	No	Divorced	Arthritis, thyroid.
Khalida	1 <sup>st</sup>	22	54	No	-	No	Married	Arthritis, high blood pressure
Maleha	2 <sup>nd</sup>	9	47	-	No	Voluntary	Married	None
Asifa	1 <sup>st</sup>	4	62	Yes	-	No	Married	M.E., Cancer
Shazia	2 <sup>nd</sup>	6	38	-	Yes	Yes	Married	None
Zohra	1 <sup>st</sup>	12	76	Yes	-	No	Widow	Arthritis, Cyrisis
Aysha	1 <sup>st</sup>	10	53	No	-	No	Divorced	Arthritis
Asiya	2 <sup>nd</sup>	10	49	-	No	Voluntary	Divorced	Arthritis, cholesterol, asthma, ulcers
Mariam	1 <sup>st</sup>	25	71	Yes	-	Retired	Married	High blood pressure, cholesterol
Shakrah	2 <sup>nd</sup>	15	55	-	Yes	Yes	Married	High blood pressure, cholesterol
Khadijah	1 <sup>st</sup>	1	43	No	-	No	Married	Heart problems, iron deficiency

To protect the identity of participants, all the women have been given pseudonyms that will be employed throughout this chapter.

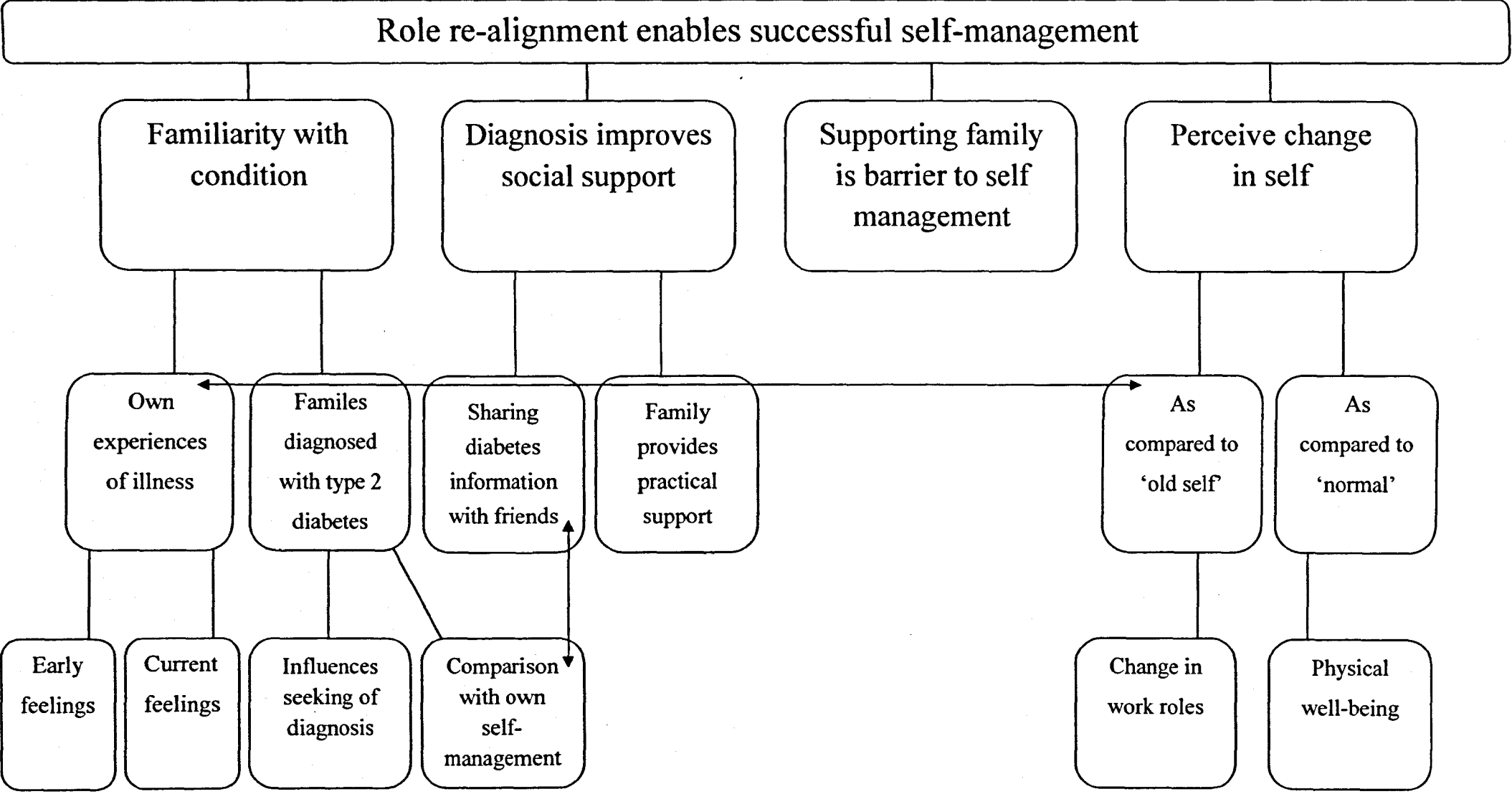
### 8.3 Thematic analysis

After completing the six phases of thematic analysis (Braun and Clarke, 2006), four themes and one over-arching theme emerged from the interview data in relation to the research question. These four themes with their related sub-themes and categories are visually presented in a thematic map in Figure 8.1. The thematic map also displays the links between different themes with arrows. These links are detailed narratively in the appropriate sections as they arise.

As the findings are presented, differences or similarities of significance within the sample will be noted according to the characteristics employed with the maximum variation sampling. These characteristics were: whether the woman was a first or second generation immigrant and her educational status. Educational status was qualified differently according to the woman's generation status. For first generation women educational status referred to their ability to speak English, while for second generation women it was whether or not they had obtained educational qualifications of G.C.S.Es (or equivalent) and above.

The reason for choosing to sample across generation and educational status was to enable investigation of the study's subsidiary aim which was *to investigate the operational definitions for the three levels of Nutbeam's (2000) conceptual framework of health literacy*. Furthermore, by recruiting first and second generation women with different educational qualifications, reflection on the effect level of health literacy may have on women's views about their type 2 diabetes and self-management was enabled. The effect of these variables, generation and educational status, on identity was also to be considered. Hence, where appropriate within the results, health literacy will be considered in relation to the emerging themes. To reiterate, the focus of the thesis was to understand the self management of type 2 diabetes in BME groups using health literacy as the theoretical framework.

Each of the four themes will now be discussed, using their subthemes and categories for clarity. Finally, the over-arching theme 'Role re-alignment enables successful management' will be presented.



**Figure 8.1** Thematic map of themes and sub-themes (and how they interlink)

### **8.3.1 Familiarity with condition**

This theme refers to participants' own experiences of ill health and other people's type 2 diabetes prior to their own diabetes diagnosis. Consideration is given to how a family history of diabetes may influence how participants seek their own diagnosis and how participants make comparisons with others. The change in participants' feelings over time after being diagnosed with diabetes is also considered.

This theme's two sub-themes 'Own experiences of illness' and 'Family's experiences of illness', and the categories within these sub-themes will now be discussed.

#### **8.3.1.1 Own experiences of illness**

Participants talked about how they had adapted to their diabetes over time and commented that as they became better adjusted their self-management improved. Participants' emphasised a process of learning to recognise the symptoms of low and high blood sugar and ways to overcome this.

*I think after three or four years now I know when my blood sugar is high, how I feel if it is low... I'm much prepared now. In a way I'm much organised comparing to the first time when I was diagnosed with diabetes. And I think for the first year it wasn't that bad, but with the time the diabetes become difficult and only way you learn how to control it. (Sughra, 1<sup>st</sup> generation, speaks English well)*

This sub-theme relates directly with the concept of learning over time, alongside an emphasis on the personal experience, as previously operationalised at the critical level of health literacy. This demonstrates that participants can become empowered and develop critical health literacy over time. It should also be noted that this sub-theme can be seen to have links with the sub-theme 'As compared to 'old self'' (see section 8.2.5.1) where women also emphasise a perceived change in themselves over time.



In addition to participants' own reflections on how they had adapted to diabetes over time, their accounts of how they felt soon after diagnosis as compared to how they felt currently also can be inferred to demonstrate this adjustment. The categories of 'Early feelings' and 'Current feelings' will now be presented.

### *Early feelings*

Participants' recollections of their feelings soon after diagnosis were divided. Eight of the women described their early feelings as being positive while the other seven women described negative feelings. There was no clear pattern regarding the generation and education characteristics of participants in terms of whether their early feelings were positive or negative. Early feelings towards diabetes appeared to involve complicated relationships amongst a variety of factors, including those not considered in the purposeful sampling for Study Two for example, years since diagnosis, age at diagnosis and experience of diagnosis. Findings presented in this category support this proposition.

Women describing positive feelings soon after diagnosis tended to speak about their familiarity with ill health either from their own experience of co-morbidities or from family members' experiences of living with diabetes. These women reported these experiences as constructive since they meant there was less of a fear of the unknown when receiving their diagnosis and some of the women added that this meant they were able to quickly put their energies into practical management.

*Interviewer- How did you feel at that time [diagnosis], when you first found out?*

*Shanaz- Nothing, what can you feel? Because from the start I have been having many operations and the like before. I don't worry too much about anything. (Shanaz, 1<sup>st</sup> generations, does not speak English well)*

*Interviewer- How did you feel at that time [diagnosis]?*

*Maleha- Like my dad had it, like he was 60 years old when he found out and he died when he was 65. And I was a bit too close to him. So I don't know, but like we've been through all that, we used to cook separate for him, we used to make separate... and I knew like what it does to you and how you can*

*control it because we had it in the house before. (Maleha, 2nd generation, does not have G.C.S.E.s or equivalent)*

Interestingly, women who described negative feelings soon after diagnosis mentioned the same factors as being influential to them as the women who described positive feelings. These factors were familiarity with ill health either from their own experience of co-morbidities or from family members' experiences of living with diabetes. Women spoke about how their own negative experiences with ill health meant that they were concerned about what to expect after diagnosis.

A few women noted previous experience with diabetes due to their family's medical history. Two of these women felt concerned when they got their own diagnosis because they had seen problems of diabetes in their mothers; one whose mother had died young and the other's mother currently suffered from severe and painful complications. Both of these women also commented that diabetes added to their co-morbidities.

*Interviewer-How did you feel at that time [diagnosis]?*

*Khadijah-What can I say? I already had heart problems from before and I had real iron deficiency and obviously when they told me about this I thought, well I'd seen the state of my mother. My mother has such pain, such problems of sugar, her kidneys are suffering and I was thinking these things could happen to me as well later in life. (Khadijah, 1<sup>st</sup> generation, does not speak English well)*

Another woman noted that because both her parents and two older sisters had diabetes she had expected a diagnosis. However, she added that because she lived a very healthy lifestyle she did not expect to have been diagnosed so young (diagnosed at 40) and it was because of this that she reported feeling 'devastated' at diagnosis. The other two women who reported negative feelings said these were due to their concern for their unborn child since they were pregnant at the time of diagnosis.

### *Current feelings*

In contrast to the divide when participants described their early feelings, the majority of participants were more positive when describing their current feelings in regards to their diabetes. Participants generally expressed satisfaction at currently feeling in control of their condition through good self management.

*Yes, in the start I used to, it was difficult to control. I used to wonder how am I going to control it, what am I going to do to control it, why should I control it? Thankfully now its controlled so I don't think about it. (Shanaz, 1<sup>st</sup> generations, does not speak English well)*

*I'm ok now. I know what to do, how to control it. (Sajida, 1<sup>st</sup> generations, does not speak English well)*

This finding suggests that with time and experience at self-management, women were better able to accept their condition and this may be related to their feeling of being back in control over time.

Only four participants related their current feelings as being negative. Two of these women, Khalida and Aysha, had limited English and relayed being unhappy due to feelings of dependency on others and experiencing confusion regarding their condition. Moreover, both Khalida and Aysha were using insulin and talked about the restrictions they felt this placed on their lives, so this may also have contributed to their negative feelings.

*In an entire week I feel ok only one or two days. I eat the same thing, one day I feel ok but the same food makes my blood pressure high the next and I can't do anything. Then I get confused, what did I eat yesterday, what did I eat today? I was ok yesterday, I'm not today. (Khalida, 1<sup>st</sup> generation, does not speak English well)*

*It's made it very difficult. I need help with everything, if I go to town I need help, if I go to the doctors or the hospital I need help, sometimes I need help cooking the dinner, I need help for that sometimes. I cant get up all the time. I need help for everything but the person to help isn't there [laughs]. All the*

*children need to get on with their own jobs. (Aysha, 1<sup>st</sup> generation, does not speak English well)*

Another participant reporting negative feelings was Shakrah, she was currently trying to avoid moving onto insulin and described how despite consistent efforts her blood glucose levels were proving difficult to control. The other participant who relayed negative feelings was Saliha, the youngest participant in the study. Saliha said she was worried about the future for herself and her young children.

### **8.3.1.2 Families diagnosed with type 2 diabetes**

As already indicated in the previous sub-theme, participants were often familiar with type 2 diabetes before receiving their own diagnosis. This is further notable by the frequent mention of other people's diabetes when participants were recounting their own experience of diagnosis. Overall, ten of the interviewees remarked on having first degree relatives with type 2 diabetes. This is not a surprising finding given the high prevalence of type 2 diabetes in this BME group (National Office of Statistics., 2001).

This familiarity with the condition suggests that the women may experience diagnosis with a greater degree of expectance and acceptance. The categories in regard to others experiences of diabetes were 'Influences seeking of diagnosis' and 'Comparison with own self-management.' These will now be presented.

#### ***Influences seeking of diagnosis***

Women's recollections of their experiences of diagnosis varied greatly. These early experiences suggest there to have been an effect on their confidence and subsequent self-management. For six participants their family history was suggested to be a catalyst for seeking a diagnosis. These women demonstrated an alertness to symptoms and presented these to a health professional asking them to test for diabetes.

*Um, I think it was about 9, 10 years ago. Um, I didn't really know... well I had a sort of idea because my mother had it and um I sort of knew what diabetes are because I was already um looking after a person with diabetes.*

*Um, but I didn't know I had it myself and that's a whole different thing when you have it yourself. And even I had it I used to still eat... well I didn't bother with looking after what food I'm eating or why is it happening until after a year or so um I thought I'd get tested, checked out. (Asiya, 2nd generation, does not have G.C.S.E.s or equivalent)*

*In the morning when I used to wake up, and when I got up it would become dark in front of my eyes. So I told my doctor, he said 'No, no, its ok, its ok, its nothing like this'. Then I complained again, and the same day he said to his nurse, 'Check her blood', so the nurse was there and she called m. You know they prick you, and she said 'Oh, you have diabetes' and then she said 'keep your control'. I had suspected it a bit before. (Sajida, 1<sup>st</sup> generations, does not speak English well)*

One participant's family member actually suggested that she seek a type 2 diabetes diagnosis.

*I felt like two or three times that I was going to faint when I was in the house. I thought its because of my iron deficiency and thought one of these days I will go to the doctors and get a check up but no. Then one day my sister-in-law called, she said your Mum's sugar has gone really low, it got to 2. She called me in the morning to come round, I went there at about nine after dropping the children off to school. And my sister-in-law asked me, she said 'You go often to the doctors, you already have heart problems, have you ever had your diabetes checked?' I said no, I never have and they have never said. You know the doctors can also say your mum's got diabetes, your dad had diabetes, but they never asked me. And I never said give me a blood test for diabetes. I didn't even think I had diabetes. So what I did when I was at my sister-in-laws she said, come here let me check you . That day at 9 am, half 9 it was at 20. She said, you're sugar is very high why don't you go to the doctors? Even then, I waited a whole day and thought it might settle down but all day I felt dizzy. Then in the evening I went back to my mums and my sister-in-law checked it again. It was 20.5. It had gone up, it hadn't gone down.*

*Then I made an appointment straight away and went to the doctors the next day. (Khadijah, 1<sup>st</sup> generation, does not speak English well)*

Another three participants presented their diabetes symptoms to a health professional who then performed a diabetes check. Four other interviewees learnt of diabetes through a routine blood test during pregnancy. Unlike the rest of the women in the study, three of the interviewees had experienced prolonged poor health related to their diabetes before they were actually diagnosed with the condition.

Interestingly, these three women were the first generation women with the weakest English language skills in the study. Shanaz explained how she had been experiencing symptoms of 'garmee' previous to her diagnosis but had not presented these to her doctor. She eventually discovered she had diabetes by doing a 'chance' diabetes test because her husband who had ill health was also doing one. 'Garmee' is literally translated as 'hot', its use here is related to the Asian traditional health belief that ill-health can result from the imbalance of hot and cold (Bhopal, 1986). Khalida had experienced bad health for a couple of years which she had been worried about. Eventually she was admitted to hospital with a high fever, at this time her brother asked that she be checked properly as 'she was always ill'; they found her to have very high blood glucose levels and she was diagnosed with diabetes and prescribed insulin immediately. Aysha said she had presented to the doctors with her symptoms but no-one had checked her for diabetes. She described how on one occasion when her health had considerably worsened her husband took her to the doctors and insisted they check her for diabetes and that was when she was finally diagnosed.

These varied experiences around diagnosis perhaps demonstrate participants' approaches towards their health. These behaviours, ranging from the proactive to the reactive may also be a reflection of the woman's current level of health literacy. A positive experience surrounding diagnosis may serve to empower the woman, facilitating self-management while negative experiences may disempower the woman and become a barrier to self-management.

Indeed, a positive experience surrounding diagnosis may be the result of an already empowered health perspective, whereas a negative experience may be the result of a disempowered outlook. That is to say, if a women has critical health literacy in relation to her general health then she may more readily achieve functional health literacy in relation her diagnosis of diabetes and progress through the three levels of health literacy which requires increasing autonomy, as according to Nutbeam's (2000) framework.

### *Comparison with own self-management*

This category demonstrates that knowledge which is developed within a family and community context where there is a prevalence of type 2 diabetes can be a facilitator to effective self-management if the knowledge is sound or a barrier to self-management if the knowledge is not sound. Since evidence suggests that type 2 diabetes self-management is poor in British South Asian populations (Shaw and Cummings, 2005), exposure to a population with notoriously poor self-management could hypothetically be considered to be a barrier to sound knowledge. It is encouraging however that the findings of Study Two appeared to contest this.

The majority of references to family members with diabetes were in the context of how the interviewee managed her own diabetes in a different and better way. These participants tended to recognise the shortcomings in their families' self-management and said that their own self-management was improved as result of this prior experience with the condition.

*Since I have had diabetes I have been using sweetener, my mother doesn't like it, she won't have anything else. She will use just normal sugar. Even though doctors have really tried to explain to her, we have said to her as well that Mum this is not good for your health. But my Mum says that when I have that in my tea I don't like the smell and I can't drink my tea, so she won't take sweetener. But I have made these changes as soon as I found out I had diabetes. (Khadijah, 1<sup>st</sup> generation, does not speak English well)*

Shazia was an interesting negative case in this context. She said her management was less strict as result of previous experience with the condition

where despite strict control her father-in-law died five years after being diagnosed with type 2 diabetes.

*My father-in-law was diabetic and he was type 2 as well, he was just on medication. And with him we all took it to heart that it was a big illness and everything and we totally cut down all fats and all his sugars. And we thought it wasn't really fair, we stopped him from a lot of stuff, you know, like a lot of food which oh that's no good for you, you know, he totally cut down on everything. And with me I think I find it easier if you stick to everything but everything has a limit. (Shazia, 2nd generation, has G.C.S.E.s or equivalent)*

Some participants attributed their improved self-management as compared to members of their family to living in better circumstances.

*I think diet plays a big role in it. Whereas like we weren't educated that... like wheat and chapattis can cause you diabetes to go quite high because we didn't understand that carbohydrates were causing it. And I just thought, as a child since I've watched my mam have diabetes I've grown up with her and she's always just thought, you do not eat sweet things like desserts and things. But she's never ever thought of fat and carbohydrates all play a part. (Saliha, 2nd generation, has G.C.S.E.s or equivalent)*

*You know in Pakistan the diet isn't right. Obviously you have to eat roti or you eat a bit of rice, or a bit of fruit. (Sajida, 1<sup>st</sup> generations, does not speak English well)*

This category can be seen to relate to the concept of soliciting information from additional sources, as previously operationalised at the interactive level of health literacy. This familiarity with diabetes appears to suggest that participants have a predetermined idea of how they would be affected meaning they may be in a better position from which to effectively self-manage. This category has links with the sub-theme 'Shared diabetes information with friends' (see section 8.2.3.2) since they both emphasise the importance of sharing diabetes knowledge with others.



### **8.3.2 Diagnosis improves social support**

This theme shows that women get social support, mostly practical, from their family and friends. Family are mentioned more often, specifically they tend to help complete household chores. Friends tend to be useful for sharing diabetes information and experiences with. This theme incorporates two sub-themes 'Family provides practical support' and 'Sharing diabetes information with friends,' which will be considered here.

#### **8.3.2.1 Family provides practical support**

When participants talked about the influence family had on their self-management, participants generally said that their diagnosis of type 2 diabetes led to an increase in the level of support they sought and received from their families. This was mostly from their children and husbands, siblings were also mentioned although more infrequently, as were parents and the extended family. Women's attitudes towards the support they received were mostly positive.

Emotional support was only mentioned by five interviewees. In four of these instances this was provided by the participant's children who were said to be caring. One woman said that her husband showed understanding of her condition. Participants most commonly stated that their family supported them in a practical way. By far the most common practical support women received from their families was in completion of household chores, presumably this helped them to achieve their familial roles. Half of the women in the study reported that they received practical support from their families in this way.

Only a few participants said they had familial support with actually managing their condition. Saliha said her husband knew what to do in case of a hypoglycaemic attack. Sajida said her daughters would advise her on appropriate diet. Finally, the two women in the study with the most limited English, Khalida and Aysha, said that their families helped translate medical advice. The practical support women reported their families gave them in terms of managing their diabetes was far less direct than the way the women in the study reported men received familial support with their diabetes management (see section 8.2.4).

Albeit far more infrequently and indirectly, some participants talked about how they perceived their family to be unsupportive in helping them achieve effective self management for their diabetes. Participants always interpreted this to be unintentional on their family's part. Maleha and Asiya talked about how the general worry of family problems made their diabetes worse. Khalida and Aysha, the two participants with limited English talked most strongly about sometimes feeling unsupported by their families. They felt that their families did not help them in a timely manner.

*At first they (family) didn't take notice that much. Only when I get really ill, they think she's ill, she needs help. They don't do it straightaway. They can't feel it, how bad that persons doing. They cannot feel it. It makes you sad that why aren't people in the house realising what I'm going through. (Khalida, 1<sup>st</sup> generation, does not speak English well)*

*It's a worry. I have to go to the doctor more. I can't speak English. All the children are at work and I need to go to the doctors. I have to go to the hospital, I've got a kidney infection too. I need to go to the doctors to get medication. But I haven't been able to go. Will try to make an appointment for Monday when a child is at home. The doctor's our own [Asian and speaks language] but now they have this system with the computer and you have to write your D.O.B. write your name [laughs] and I can't do it. Before they used to do it if you tell them your name they check on the computer but now you have to do it yourself. On Monday I say I'll do it, I'll go with my next door neighbour, I need to go to the doctor desperately. (Aysha, 1<sup>st</sup> generation, does not speak English well)*

Perhaps families were perceived as less supportive by these two participants because they had limited English and as a result were in a position that required more support. Similarly, It may be that inadequate support contributes to their lack of self-management and therefore affects these patients' roles the most.

Extended families, namely less close relatives, were perceived as less supportive by some participants. These participants still appeared to want to be seen as doing the right thing, as according to cultural etiquette.

*Some days I want to meet people and I will but often I don't go out because of the diabetes. Worried I will get ill when I am away from home and what will the extended family say, she was ill so why did she go out. I think that, so I don't bother going out too often. Stay at home and read namaz [prayers]. Do a bit of housework. (Khalida, 1<sup>st</sup> generation, does not speak English well)*

*It's like last time somebody passed away and I had to go to London. And you know when we went there and the food they gave us I wasn't happy with it but I went along and I thought, well that's no good for me, you know. And the flour they'd used was white and you know, the curry they gave us it was like loaded with a pile of fat on it and I'm looking it and thinking 'I can't eat this'. And then I can't remember who was next to me and she goes, 'shut up and just have it'. And I'm like, I can't have it [laughs], it's not good form. (Shazia, 2<sup>nd</sup> generation, has G.C.S.E.s or equivalent)*

This finding fits with what is already known about health diet management of South Asian communities in the UK that patients can be reluctant to refuse inappropriate foods at the homes of other people (Hill, 2006). However, the women in Study Two suggested this to be the case only at more 'formal' events, with closer family and friends shown to demonstrate more understanding.

### **8.3.2.2 Sharing diabetes information with friends**

Friends were mentioned significantly less often than family in the context of managing diabetes. It is interesting to note that the comments on how friends helped were made either by second generation participants or by first generation women who explicitly articulated that they, as immigrants, did not have a large family network around them. It is possible that for these first generation women, friends substitute the absent familial support that appears to be otherwise common in this study group. The finding that second generation women talk about friends as a source of support, suggests there to be a degree of acculturation because friends are supplementing what is traditionally a familial role.

All of the women who mentioned their friends in the context of providing support said that they provided them with practical support. A couple of participants

added that they also provided emotional support through being understanding and caring. Practical support was very strong in Aysha's case who as a result of her limited English reported being very dependent on others.

*My eyes wouldn't open, I had no energy in my body. I didn't know my sugar was low. Then one day I couldn't get up and my friend who lives near by came round and she said to me 'drink coke and you'll be ok'. I said 'how is coke going to make me better?' I never really used to drink it. She said to me 'just try it', and indeed as I drank it, it felt like energy was returning to my body. My eyes opened wide, before they were shutting because I didn't even have the energy to open them. (Aysha, 1<sup>st</sup> generation, does not speak English well)*

The benefits of talking to friends appeared to exist for the wider sample not just those with limited English. One participant who demonstrated a good understanding and keen self-management talked about her experiences of getting information from friends.

*Because a few people, they said they have the same problem, their feet get hot, you know, diabetic people. Especially I had one friend her husband was an eye specialist in Middlesbrough and he's passed away, God rest his soul, and she said, 'He used to always keep his feet, you know, out of the covers'. So this is a common thing. But when you are diabetic your feet, you know, get hot in the night time, not in the daytime. And I thought you know, there's nothing I can do with it. Once I told doctor and he gave me tablets but they never worked. After that I don't bother to say, you know, this happens. You know, all the medicine, you know, you take it then have the side effects, don't want too many medicines you know. (Zohra, 1<sup>st</sup> generation, speaks English well)*

Similarly, there was a lot of talk around the value of traditional remedies in this population. Several women's views emphasised the sharing of knowledge on this topic with one another and testing recommendations.

*I do everything to stop me getting worse, anything. I even tried having raw kerela [bitter gourd] and even tried having rotten medication somebody brought from India – it was disgusting. You put it in water and mix it with a*

*spoon and have that, you know, like um herbal remedies, I'll try anything. Herbal remedies and all sorts. (Shakrah, 2nd generation, has G.C.S.E.s or equivalent)*

*Now if anyone tells me they have diabetes I tell them to eat cinnamon sticks and that it will help reduce your sugar... Or if a friend tells me she has sugar, or women talk about somebody with sugar trying an alternative remedy. Then I listen and think perhaps if I do this I too will be relieved. (Shanaz, 1<sup>st</sup> generations, does not speak English well)*

*Other people say after taking this and that, you know, like herbs and they get better, and I always find out which herbs they are taking, what they are doing. Then I do that myself. Because you know, from your heart you want to get better. (Zohra, 1<sup>st</sup> generation, speaks English well)*

However, women's views on the effectiveness and the uptake of these behaviours was mixed.

*Our people [Asians] they don't eat natural herbs and that, don't eat fruits. You know, we have people that just sit down with their illness, just with their prescribed medications, just sit with them. 'Got to take my tablets because my sugars gone high' this and that. You should also do natural things. (Sajida, 1<sup>st</sup> generations, does not speak English well)*

*Some eat kerela [bitter gourd], drink kerela water. That's homeopathic, I don't know. No that won't do anything, just eat sensibly, you must have chapatti right, eat roti nicely and have a cup of tea, have your tablets and you will be okay. (Asifa, 1<sup>st</sup> generation, speaks English well)*

This sharing of knowledge with friends relates to the concept of soliciting information from additional sources, as operationalised at the interactive level of health literacy. This category has links with the sub-theme 'Comparison with own self-management' (see section 8.2.2.2) since they both emphasise the importance of sharing diabetes knowledge with others.

### 8.3.3 Supporting family is barrier to self management

This theme relates to participants' reports that their providing support to family members was the main barrier to their self-management. It highlights the importance women in Study Two assigned to their familial roles. The main issue that was explicitly cited as a barrier to self-management by the women was that they put other people in their family first, before themselves. Asiya and Shanaz had acted as carers to members of their immediate family.

*I used to look after my mum and I controlled... you know, well my mum's was controlled first and then it just went out of hand and you know, god bless her, um but I didn't control mine, I just... because I had a load on my plate, I didn't think of my health, I didn't put my health first, I put my family first .... And I was the only one in the family who could bring them back, so I didn't think about my health. At that time I didn't think about my health so I got worse and worse and worse. (Asiya, 2nd generation, does not have G.C.S.E.s or equivalent)*

*Looking after him would affect my health. Sometimes I would be unwell in my self and I would be tired and would not want to do any work. But my husband was so poorly that I had to. He stayed in hospital a lot, going, coming back, visiting, doing everything. (Shanaz, 1<sup>st</sup> generations, does not speak English well)*

Other women commented more broadly that their family roles and responsibilities in general meant their self-management could sometimes suffer.

*There is some times if I'm too busy, then I will just eat what everybody... what I've cooked for everybody, because I don't have some time to make something for myself. (Maleha, 2nd generation, does not have G.C.S.E.s or equivalent)*

*Sometimes it does get stressing as well, you've got too many people around you and you know, you have to think about everyone. (Shazia, 2nd generation, has G.C.S.E.s or equivalent)*

The women in this sample considered the most important familial responsibility to be the care of young children. Mothers with young children talked about often feeling rushed and having conflicting priorities. Other women recalled that management was harder when their children were younger. Some of the women who had been diagnosed in later life noted how it must be harder for young women to manage their diabetes alongside the responsibility of having young children. From this it might be inferred that diabetes potentially affects the family role of women with young children more than the roles of women with older or no children.

Moreover, women with grown-up children talked about feeling generally supported, although there were two women who offered an alternative view. Khalida and Aysha were these two women, they had the most limited English of everyone in the study and while they identified this to contribute to their feeling unsupported at times their narratives suggested a larger problem. Their views suggested that their viewpoints could sometimes be undermined by their families.

*Didn't ever see the peace of being a wife [laughs]. I didn't have a good husband. That's been a major worry in life. He left. Now the children are grown up, they do what they like. That's a worry for me. A mother's role, I've done well, I've done a lot. Tried to give my children everything I could. I've always thought about them and neglected myself. Now it's finished. The children are all grown up and I am all alone. (Aysha, 1<sup>st</sup> generation, does not speak English well)*

*Things looked blurry, lop-sided. I was laying in bed, and the pictures hanging on the wall, I couldn't see them well. I told my daughter 'I can't see well'. Before they all used to think I was just saying it, just joking, but one day I was sitting and I said 'Seriously I can't see, take me somewhere' and they took me to the optician. The optician said 'Yes, its leaking at the back', now they are trying laser treatment but its not working. (Khalida, 1<sup>st</sup> generation, does not speak English well)*

Women also frequently commented that men with diabetes sought and received a lot of practical family support with their self-management, especially

from their wives. Mariam and Shakrah's husbands also had type 2 diabetes and they spoke from that experience.

*I mean my husband had diabetes after I got it. He got it later on you can say 10-12 years back. But I can say that I'm not going to eat this one because I had this in the morning. But if I give him he can have same amount I think three times a day. So I have to control his diet and his things, 'You should take care of your feet. You should go for a walk. You should eat this. You should eat not this one.' So my experience is that um men they don't care for you but you have to care for them. (Mariam, 1<sup>st</sup> generation, speaks English well)*

*Men are worse I think, they're babies. Men think oh just because you've got diabetes you're really ill. My husband is diabetic and he thinks he's really ill, oh I can't do this I'm diabetic. But he will eat everything. He will eat anything and everything, sweets, barfi and all that, he'll eat anything and everything. He thinks everybody should pity him. Even though I'm higher diabetes than him I take more tablets than him, and um he wants people to say, 'Oh poor thing, he's diabetic, you know, he's not very well' [laughs]... I think he does want people to do things for him, especially the boys, even the children he wants them to do things for him. (Shakrah, 2nd generation, has G.C.S.E.s or equivalent)*

On the one hand, several participants noted that it was harder for women to self-manage because, unlike men, they put their families first and did not get help directly with self-management from their spouses. On the other hand, some women talked about how self-management was more difficult for men because they had the added pressure of doing paid work outside the home. None of the women who said this had any experience of doing paid work themselves and all but one of these women was a first generation immigrant.

Where men were helped with their self-management from their spouses, women were not (see section 8.2.3.1) and this issue was more important when women were also working outside the home. It may be as result of this that women who had paid work were less sympathetic to men with diabetes than those who did



not do paid work. All the women who did do paid work, were doing so in addition to looking after their home and family.

It is evident from the data in this category that supporting the family was an important role for participants in Study Two. This role appeared resilient to change despite the diagnosis of type 2 diabetes. What is more, these women demonstrated awareness that their familial roles tended to worsen their self-management.

### **8.3.4 Perceive change in self**

Participants' interviews suggested that they felt there to have been a change in themselves since their type 2 diabetes diagnosis. This theme has two sub-themes 'As compared to 'old self' and 'As compared to 'normal''. The sub-theme 'As compared to 'old self'' had two categories.

#### **8.3.4.1 As compared to 'old self'**

In women's interviews they made comparisons with their 'old self' suggesting they felt that diabetes had changed them. Women talked about changes in their work roles inside and outside the home. Women also talked about changes in their physical well being over the course of their condition due to their age and their co-morbidities. These two categories will now be presented. It should also be noted that this sub-theme can be seen to have links with the sub-theme 'Own experiences of illness' where women emphasised a perceived change in themselves over time in terms of their bodies response to their condition for example understanding their symptoms.

#### ***Change in work roles***

The most commonly remarked on change, made by almost half of the women, was that they noticed their not having the stamina for housework as they had before diagnosis. Participants reported a variety of reasons for this.

*Yes, I get tired, yes, you know, I can't stand and do work the way I used to do, you know, good job you know now my daughter-in-law, she does the cooking and everything. (Zohra, 1<sup>st</sup> generation, speaks English well)*

*The house also used to be clean, clean it, do this, do that, do everything. Now not as much. I still do it! But not like before, when I eagerly did this, did that, did my gardening, did everything, now not as much. That's happened, that's changed a lot. Not doing things through enthusiasm, but doing things through necessity. (Shanaz, 1<sup>st</sup> generations, does not speak English well)*

Some women talked about using strategies to overcome this.

*I used to do a lot before, but I've had to slow down a bit, you know. I have to sort of plan it out and do this today and I'll do that tomorrow, I can't do everything like I used to. (Shakrah, 2nd generation, has G.C.S.E.s or equivalent)*

*So before I had the diabetes I used to work a lot, do everything, now I get tired more so I try to do some and then rest a bit and then do some more. (Maleha, 2nd generation, does not have G.C.S.E.s or equivalent)*

*But I think the way I organise my day I take so many mini-breaks in between so I do... in the past when I got up in the morning I did all the housework in one go, but now I know I can't do that so the way I have managed, I just choose one or two chores a day. So okay I will do ironing today, I will do vacuum cleaning the next day. (Sughra, 1<sup>st</sup> generation, speaks English well)*

Only eight women reported experience of being employed outside the home. These women gave mixed views on the effect diabetes had on their work. Half of the women reported that diabetes did not influence their work and the other half said that diabetes did affect their work as compared to before their diagnosis.

Women reported a range of reasons for how diabetes affected their work as compared to before diagnosis. Shakrah reported being lethargic and needing to take more breaks, she also said that when she got very tired her sight suffered and since she worked as a seamstress she would often have to stop and take breaks. Sughra said she felt less active as a secondary school teacher and began to request the same ground floor rooms for lessons. She also began to feel exhausted when she came home from work and was too tired in the evenings to do house chores; she

eventually took early retirement. Asiya reported her work to have a positive effect on her diabetes since she worked with people with mental health problems and she said this gave her courage to 'fight' her own condition. Shazia said that the main struggle in her job was not being able to take regular breaks to eat since she worked in a shop so she could not stop if it was busy.

Women's indications that, as a result of their condition, they could no longer complete the roles they used to, might be interpreted as leading to a feeling of disempowerment. In the context of Study Two's findings the paramount importance that women place on achieving their self-identified roles can be perceived as reflecting the phrase 'emphasis on the personal experience' from the operational definition for critical health literacy. This enforces the points that while diabetes may affect a patient's achievement of their self-identified roles, it is the shift of these roles over time and their subsequent achievement that is crucial for effective self-management and for achieving critical health literacy.

### *Physical well-being*

The notion of age was raised by Maleha and Shazia, who expressed some confusion as to whether they were unable to successfully undertake tasks they could previously complete because of their diabetes or because of their increasing age.

*So before I had the diabetes I used to work a lot, do everything, now I get tired more so I try to do some and then rest a bit and then do some more. And sometimes if I think too much, I have something on my mind and then I get a lot of headaches. So I do feel like ten years... like I know it's age as well, but still I feel okay, I'm a lot different than what I was then. My life has gone a lot like it's changed a lot, yeah. (Maleha, 2nd generation, does not have G.C.S.E.s or equivalent)*

*But it does get you down, it's not like you're always going to be perfectly well and jumping around. It does, your body... it's not your fault because your body won't accept as much now as we go on in age as well. I was only 22 then when I was diagnosed first [gestational] and I never took it in that it was something. But now as I say, if you start comparing it, normal people by this*

*age, you know, I'm like coming up to 36, but I don't really feel as though I'm old, but sometimes when I can't do things it just gets me wondering why can't I do it. (Shazia, 2nd generation, has G.C.S.E.s or equivalent)*

Another woman questioned whether a symptom she was experiencing was related to getting old or diabetes.

*It takes me a long time to go to sleep. Maybe when you become old this happens, it's not that I'm in pain or anything, because every night, you know, most nights I take one or two paracetamol for my arthritis and stuff. (Zohra, 1<sup>st</sup> generation, speaks English well)*

As Zohra and Khadijah's quotes indicate, in a similar way to getting older, co-morbidities made it hard for some women to infer cause and effect.

*When I'm tired I have to rest, but I don't know if I'm tired now with the diabetes or with the M.E. [Myalgic Encephalopathy]. I love cooking, you know, and when I'm cooking wandering round with this and that it keeps me busy, but I'm tired. Even now my legs are pins and needles, you know, 24 hours they are aching. I think it's not the sugar it's the M.E. yes. (Asifa, 1<sup>st</sup> generation, speaks English well)*

*In those days I had made it my routine that in a week apart from one or two days I'd do exercise in the house on the machine or on the Wii. Since I have had the dizziness I have left both things, because I can't understand it. When I feel dizzy, I feel sick too. Because of that I cannot exercise....It was the iron deficiency causing the dizziness. (Khadijah, 1<sup>st</sup> generation, does not speak English well)*

#### **8.3.4.2 As compared to 'normal'**

Women's comparisons with being 'normal' and wanting to stay 'normal' suggested they felt their roles had changed or could change. The range of the four views where women talked about being 'normal' illustrated the range and complexity of the relationship between diabetes and identity. On one hand Khalida and Saliha relayed quite strong feelings of deficiency as compared to 'normal'

people. On the other hand, Shazia and Mariam said that they tried not to worry too much and tried to continue as 'normal'.

It is important to note that two interviewees, Khalida and Saliha, were mother and daughter, and both used insulin. Both of their views detailed not feeling 'free' to socialise because of the demands of their condition such as remembering medicines before going out, eating on time and the possibility of becoming unwell. These descriptions suggested they felt less able to be impulsive and spontaneous.

This finding, where mother and daughter share views can be seen to bear a similarity with the category 'Comparison of own self-management with family's.' It supports the notion that participants can have a predetermined idea of how their lives will be affected as a result of previous exposure to the condition in their families or communities. This example highlights that depending on the nature of the informal learning, the acquired information can act as a barrier or a facilitator to subsequent self-management.

### **8.3.5 Role re-alignment enables successful self-management**

The over-arching theme that emerged from the interview data was 'Role re-alignment enables successful self-management.' This over-arching theme provides answers to the research question "*How does having type 2 diabetes affect British-Pakistani women's identity and how does this relate to subsequent self-management?*" by capturing how women themselves considered diabetes to have affected their identity and the subsequent changes they felt needed to be made both by themselves and by significant others to enable effective self-management.

A theme to arise from the data was 'Perceive change in self'. This suggested that women's role re-alignment was a conscious process that they adopted to overcome the changes that had resulted from being diagnosed with diabetes and had made them feel different from their 'old self', and different to being 'normal.' The theme 'Familiarity with condition' also related to participants' adjustment to their roles over time which enabled effective self-management. The data from the theme 'Diagnosis improves social support' can be interpreted as meaning social support helped the women accept changes in themselves due to their diabetes. This

recognition appeared to help women subsequently self-manage. In the theme 'Supporting family is barrier to self-management', as with the others, women acknowledged diabetes to have led to a change in themselves. This theme however was slightly different, while elsewhere women spoke of re-aligning certain roles so as to improve self-management, although here they recognised that supporting their family was a barrier to self-management the role was resilient to being re-aligned.

It was clear from participants' views that their competing roles challenged self-management. Indeed, diabetes self-management was seen to add to their already competing roles as mother, wife, friend, neighbour, employee, colleague etc. Central to how diabetes affects an individual's identity is how the individual is able to balance and revise existing roles alongside the integration of new roles. This enforces the point that while diabetes affects a patient's roles, it is the process of suitably re-aligning those roles that is crucial for successful self-management.

From women's accounts it appeared that re-alignment of roles was a continuous process. Women talked about changing factors in their health (e.g. their own aging, the development of new symptoms, co-morbidities and side-effects of medicines) alongside various issues in their personal life (e.g. children becoming ill, losing their job and bereavements) made it a challenge to sustain effective self-management.

Although some of the women's self-identified roles, particularly those surrounding the family, competed with self-management for the women's time and energy it was clear from women's accounts that successful achievement of these roles were an important aspect of their identity and resistant to change. Women valued the support they received from and provided to others and this composed an important reciprocal role within their identities.

This emphasises the point that diabetes as a life-long illness needs to be managed alongside other aspects of women's lives; women do not see their diabetes in isolation. Facilitating effective self-management needs to be considered in the wider context, with its implications, both negative and positive, in the long-term and the short-term.

## 8.4 Summary

Thematic synthesis of the interview data resulted in four themes: 'Familiarity with condition;' 'Diagnosis improves social support;' 'Supporting family is barrier to self management' and 'Perceive change in self. These four themes were conceptualised in the over-arching theme 'Role re-alignment enables successful self-management' providing answers to the research question "*How does having type 2 diabetes affect British-Pakistani women's identity and how does this relate to subsequent self-management?*"

The subsidiary aim was: "*To investigate the operational definitions of the three levels of Nutbeam's (2000) health literacy framework as developed in Study One, so as to further refine the conceptual framework in the context of type 2 diabetes.*" To this end, health literacy was considered in relation to the emerging themes. There were two key findings.

The first key finding was in relation to the two links observed between the sub-themes. The first link was between 'Comparison with own self-management' and 'Shared diabetes information with friends' where participants emphasised soliciting information from additional sources. The second link was between 'Own experiences of illness' and 'As compared to old roles' where participants emphasised the importance of learning over time as based on personal experience. These findings tentatively support the operational definitions developed at the interactive and critical levels of health literacy in Study One reasons for this are detailed in Chapter 9. Moreover, these findings demonstrate how health literacy as the theoretical framework of the thesis has helped understand self management of type 2 diabetes in BME groups by demonstrating exactly how they emphasised the importance of these behaviours in developing a more empowered perspective.

The second key finding was the message of the over-arching theme that diabetes is not regarded in isolation but within all aspects of women's lives which are subject to constant change. This finding emphasises that critical health literacy is not something that can be simply achieved, rather once relevant critical health literacy skills are obtained circumstances can change and continued efforts are required to sustain or return health literacy to a critical level.

## Chapter 9

### Study 2 Discussion

#### 9.1 Introduction

This qualitative interview study aimed to answer the research question "*How does having type 2 diabetes affect British-Pakistani women's identity and how does this relate to subsequent self-management?*" This study had a subsidiary aim: "*To investigate the operational definitions of the three levels of Nutbeam's (2000) health literacy framework as developed in Study One, so as to further refine the conceptual framework in the context of type 2 diabetes.*"

Fifteen interviews with British Pakistani women living with type 2 diabetes were undertaken. Thematic analysis of the interview data produced four themes and an over-arching theme (see section 8.3): 'Familiarity with condition'; 'Diagnosis improves social support'; 'Supporting family is barrier to self-management' and 'Perceive change in self.' The over-arching theme was 'Role re-alignment enables successful management.'

A brief summary of these four themes and the over-arching theme will be provided and discussed with regard to how they answer the research question and their significance in the context of published work. Following this the study findings will be considered in the context of the operational definitions developed in study one for the three levels on Nutbeam's (2000) framework of health literacy. This will be followed by a discussion of the strengths and limitations of the study with a focus on methodological challenges that were faced in undertaking the research. The implications of the findings and recommendations for future research and practice are discussed in Chapter 10.

#### 9.2 'Familiarity with condition'

This theme referred to participants' talk of their previous experiences with their own ill health in general and their family members' type 2 diabetes. Here, an interesting finding was that about half of the participants had positive feelings soon



after diagnosis with diabetes while the others had negative feelings. There were no differences between the two groups according to the characteristics on which participants were purposively recruited i.e. generational and educational status. Women's early feelings towards their diabetes as being positive or negative were considered by the researcher to be related to their early experiences of diagnosis.

This view was supported by the research undertaken by Peel et al (2004) on patients' emotional reactions to diagnosis of diabetes and their views on information provision. The authors considered there to be three different routes that participants took in being diagnosed: 'suspected diabetes' route; 'illness' route and 'routine' route. Each of these routes is comparable to the results of Study Two. These three routes will now be detailed with a focus on the similarities between the research findings of Peel et al (2004) and the findings of Study Two.

In Peel's (2004) study the 'suspected diabetes' route was taken by participants who presented symptoms that they suspected as being related to diabetes to the healthcare services. This was, amongst other reasons, due to familiarity with the condition amongst friends and family. The general reaction to diagnosis amongst these participants was one of acceptance and relief at having learnt of their diagnosis and that it was not of a more serious health condition. In Study Two, while the 'suspected' route did seem to facilitate acceptance of their diagnosis the participants' emotional responses were mixed depending on the nature of their previous experiences with ill health.

The majority of participants in Study Two had taken the 'suspected diabetes route' and as with the research findings of Peel et al (2004) this had often been prompted due to familiarity with type 2 diabetes in their community. An explanation for why Study 2 participants reported mixed emotional responses to receiving a diagnosis may be related to their previous experiences with other people's diabetes. If participants had been familiar with poorly managed diabetes which had led to negative health outcomes then they would be more likely to experience a greater level of concern and possible fear when confronted with their own diabetes diagnosis, than people who had been familiar with well managed diabetes.

Participants in Peel's study taking the 'illness' route had experienced symptoms of bad health that were not initially attributed to diabetes, these symptoms ranged from the mild to the more serious. In Study Two, three participants would be assigned to the 'illness' route. All three were unable to speak English and consequently were considered as having low health literacy. Two had experienced very severe diabetic symptoms for a prolonged period.

In Peel's study the 'routine' route referred to obtaining a diagnosis during 'routine' medical testing. The 'illness' routine mentioned earlier and the 'routine' route were reported as having greatest variation in participants' experiences, ranging from shock to relief. The women who learnt of their diabetes through the 'routine' route in Study Two had all been pregnant and they spoke of having negative feelings at diagnosis for this reason because they were concerned for their baby.

There are some clear parallels between Study Two and that of Peel et al (2004), namely that the initial emotions of extreme shock, despair and anger at diagnosis are less inevitable than is sometimes suggested by other literature (Buckman, 1992; Faulkner, 1998). This also suggests that Study Two's theme 'Familiarity with condition' is not necessarily attributable to ethnicity, religion or culture as Peel et al (2004) had recruited participants of varied ages and socio-economic backgrounds living in Scotland.

In Study Two women often compared their own diabetes experiences with those of their families, generally considering their own self-management to be better. The data suggested that social comparison in this way might act as a barrier or a facilitator to effective self-management. This finding may be explained by the principles of social comparison theory which suggest that individuals, particularly when distressed, make comparisons between themselves and others so as to evaluate their own abilities and feelings (Festinger, 1954).

On one hand it was encouraging that women referred to how their self-management was better than a family member's, often parents, ability to self manage as it suggested diabetes knowledge and possibly diabetes related health outcomes were improving in this study group. On the other hand however there is a potential danger in making 'downward social comparison'. Helgeson and Gottlieb

(2000) noted that downward social comparison (making comparisons with someone who is perceived to be managing less well) can be used to enhance one's own self-esteem, comparisons can also be upwards (where the individuals compares themselves with someone who is perceived to be managing well) and this can lead to self-improvement behaviors.

In a study with cancer patients Sparks and Mittapalli (2004) found self-esteem was reinforced by making comparisons with those who were coping unsuccessfully with their illness. Furthermore, Osborne et al (2008) reported that social comparison was particularly likely to have a negative effect where individuals were unable to make positive comparisons. Since evidence suggests British South Asian populations have poor diabetes self-management (Shaw and Cummings, 2005) there may be cause for concern that this group are susceptible to making downward social comparisons.

### **9.3 'Diagnosis improves social support'**

This theme showed that the social support women received from their family and friends was mainly practical in nature. Family were mentioned most often in assisting with household chores while friends were useful for sharing diabetes information and experiences.

This theme demonstrated a clear difference between the findings of Studies One and Two. In Study Two participants overwhelmingly reported that their diagnosis of diabetes had led to an increase in the level of support they received from their families and that they valued this support. In Study One, the systematic review of 'views studies' had reported mixed responses from participants about the level of support they had received from family and friends in the analytical theme 'Being understood by others' (see section 4.3.3.2).

The difference in sample size and primary or secondary nature of research between Studies One and Two is expected to be partly responsible for this difference. Study One was a systematic review including 57 'views' studies with a total of 1735 participants as compared to Study Two which was a qualitative interview study with 15 participants. Moreover, this finding may be related to the

characteristics of the population under study. While the systematic review included the views of males and females from 10 different BME groups from five different countries, in this primary study the sample was much more homogenous since it was composed of British-Pakistani women.

The suggestion that participants' views on social support were a feature of their cultural or religious identity as British Pakistani females will now be discussed. Useful comparisons are able to be drawn between the findings of Study Two and an exploratory study that was undertaken to examine the experiences of cardiac rehabilitation and nature of family support across a sample of South Asian and white cardiac patients and their carers (Astin et al, 2008).

Astin et al noted that one way in which families were able to support patients was by adopting a healthier diet. Responsibility for food preparation was found to vary across ethnic groups. In white families, food preparation was more commonly shared and this meant spouses could help their partners to modify their diet. In South Asian families the food preparation was generally the responsibility of the mother/wife. In Study Two, British-Pakistani female participants also talked about their principal role in the preparation of meals.

Astin et al reported that in South Asian families, family were more likely to adopt dietary modifications for a male patient than for a female patient. In Study Two British-Pakistani women talked about the difference in the support men received as compared to women. Many of the participants recognised that men received direct support with their self-management from their families, particularly from their wives, whereas women did not consider themselves to receive the same levels of support from their spouses. The findings of Astin et al and Study Two suggest that the individual who takes the responsibility for cooking is in a better position to provide support in terms of adapting a suitable diet as part of a lifestyle change. The findings of Study Two further demonstrated that women perceived themselves as very busy and suggests why additional tasks such as preparing a separate meal for themselves may become a barrier to their self-management.

While the research of Astin et al identified these cultural and ethnic differences across their South-Asian and white samples they also demonstrated similarities

irrespective of ethnicity. For example, they found that most families offered emotional support whereas their ability to provide patients with practical support varied. In Study Two however families provided the women with some emotional support, although practical support was noted much more frequently and this was generally in terms of managing their household chores which can be interpreted as allowing them more time to self-manage their condition.

In Study Two, the role of friends was mentioned significantly less than that of family. It is interesting that all comments on how friends help were from either second generation participants or from first generation women who articulated that as immigrants they did not have a large family network around them. For these first generation women it seems possible that friends have substituted the family support that is common in this cultural group. In regards to second generation women, this finding is perhaps an example of acculturation where the focus had moved from receiving support just from family to also from friends. This suggests an inter-generational difference in the role friends play in providing support.

A key finding in this theme was that participants liked to share diabetes-related information with their friends. First generation participants shared knowledge particularly on traditional alternative remedies. It may be, for these first generation immigrant women, that a reliance on Western medicines was uncomfortable and possibly at odds with how they identify themselves as a Pakistani. It may be as a response to this that these women liked to speak with peers with whom they shared cultural health beliefs. In this way women may be able to retain aspects of their cultural identity in their approach to health, rather than relying solely on a western model.

Study Two's finding that these British-Asian women were interested in traditional medicine are supported in the wider literature (Bhopal, 1986; Pieroni et al, 2008). Bhopal (1986) had interviewed British-Asians to determine the role of traditional medicine in the healthcare context and found knowledge of traditional remedies to be the norm. A notable finding in Study Two was the inter-generational difference in regards to interest in traditional medicines. Study Two supports the findings of Pieroni et al (2008) who investigated how knowledge of traditional

medicines had changed over generations and waves of migration. They found, like Study Two, traditional medicines to be popular amongst British-Pakistani and also that knowledge had decreased amongst younger generations and in time since migration.

#### **9.4 'Supporting family is barrier to self-management'**

This theme relates to participants' reports that their providing support to family members was the main barrier to their own self-management. This included caring for ill family members but most frequently young children and husbands. It highlights the importance that women in Study Two assigned to their familial roles. It is evident from the data in this category that supporting the family was an important role for the participants in Study Two. Women demonstrated awareness that their roles within the family such as preparation of meals, housework, looking after young children and elderly relatives monopolised their time and energy, this consequently had a negative effect on their ability to self-manage. It may be that by successfully fulfilling family's expectations and personal feelings of obligation towards families that women were enabled to preserve their self-identified roles.

As detailed in the previous theme there was a perceived gender difference in the support received by men and women when they had diabetes. The role of men was raised again when participants noted that, while men with diabetes received support from their families and wives, women did not get the same level of support from their spouses. These findings demonstrate well how in this group, supporting the family was a core role for a woman suggesting it to be an important component of her identity. Diabetes self-management must essentially compete with these existing roles.

For some women these existing roles also included doing paid work. An interesting finding was the divided perceptions amongst participants on how men with type 2 diabetes managed their condition. Mainly first generation women talked about how self-management was more difficult for men because they had the added pressure of doing paid work outside the home. None of the women who said this had been engaged in paid work themselves. This finding suggests there are inter-

generational differences in terms of how type 2 diabetes can affect identity. Second generation women were more likely to work outside their home in addition to maintaining their traditional roles.

While it cannot be discounted that ethnicity has some influence on this finding since, it is known that women across ethnic groups have the major responsibility for caring for the household, the children, and other family members in addition to paid work (Coltrane, 2000). It is possible the mixing of western and traditional values places an additional burden on second generation women. By comparison older first generation women tended to report that their self-management was facilitated because they lived with and were looked after by their son and his family, as was traditional for this study group (Choudhry, 2001).

Gallant (2003) undertook a systematic review which demonstrated that published literature has focused on social support as being a facilitator to the self-management. Glasgow et al (2001) reviewed research on psychosocial barriers to diabetes self-management and found the most strongly and consistently related barriers to be low self-efficacy and low levels of family social support. The issue of the individual with the condition providing support to others and this acting as a barrier to their diabetes self-management is far less reported. Literature on barriers has focused on internal factors such as motivation, confidence and understanding (Chlebowy et al., 2010). The findings of Study Two are supported however by primary study results that have noted the detrimental affect that family demands can have on diabetes self-management, particularly that of women again irrespective of ethnicity (Anderson et al, 1998; Dunn, 2008; Mian and Brauer, 2009).

## **9.5 'Perceive change in self'**

This theme emphasised that participants felt there to have been a change in themselves since their type 2 diabetes diagnosis. Women made comparisons with their 'old self' focusing on changes in their work roles both inside and outside the home. Women also talked about changes in their physical well being over the course of their condition largely due to their getting older and developing co-

morbidities. Some participants talked about wanting to stay 'normal' while others emphasised no longer feeling 'normal'.

Although investigations into the effects of barriers to self-management on health outcomes have focused on single diseases (Bayliss et al, 2005), multi-morbidities are receiving growing attention in literature as their prevalence increases particularly in the UK primary healthcare setting (Smith and O'Dowd, 2007). In the USA, prevalence rates have reported approximately one in four adults as having two or more chronic conditions, and half of older adults as having three or more chronic conditions, furthermore as the population ages these figures are expected to rise (Anderson, 2002). The critical position of multi-morbidities as an independent predictor of adverse health outcomes is becoming better understood (Gijzen et al., 2001; Fortin et al. 2005). Furthermore, the major chronic diseases including heart disease, diabetes, arthritis and stroke have been shown to frequently co-occur (Weiss et al., 2007).

Since twelve of the participants in Study Two had multi-morbidities it is perhaps unsurprising the frequency with which participants remarked on how this affected their diabetes self-management. These findings are supported by another qualitative investigation (Bayliss et al., 2003) where it was noted that, in addition to experiencing the self-management barriers reported by persons with a single long-term condition, persons with multiple long-term conditions perceived additional barriers to self-management. Bayliss et al (2003) reported that these participants experienced a compounded effect of living with multiple conditions and taking their relative medicines as well as limitations resulting from the burden of a single dominant condition that affects management of the other conditions allowing them to worsen in turn (Bayliss et al., 2003).

The findings of Study Two lend support to the growing focus in research on the issue of multi-morbidities and how people self-manage several conditions differently to type 2 diabetes in isolation (Kerr et al., 2007). Moreover, since Bayliss et al (2003) had recruited 16 white male and female participants with various long-term condition, another general similarity with the experience of living



with diabetes and multi-morbidities is emphasised i.e. not in relation to gender, culture or ethnicity.

## **9.6 'Role re-alignment enables successful management'**

'Role re-alignment enables successful management' was the over-arching theme. This over-arching theme was considered to address the research question, "*How does having type 2 diabetes affect British-Pakistani women's identity and how does this relate to subsequent self-management?*", most directly. This was because it captured participants' notions of how diabetes led them to perceive themselves and consider where in their lives they wanted to or felt able to make modifications, where they encouraged family and friends to make adjustments and just as importantly what components they were opposed to changing.

Re-alignment of roles was considered to be a continuous process whereby achievements needed to be sustained. Participants' notions regarding different roles could vary over time for example if their personal circumstances change. Also with time there may be physiological changes, for example as the individual becomes older they can develop complications and co-morbidities. Central to how diabetes affects an individual's identity is how successfully the individual was able to balance and revise their existing roles as well as integrate new roles.

Much research exists on long-term conditions self-management and the nuanced effects of identity, indeed the discussion already provided has drawn on this. The notion presented in this over-arching theme however, of the fluid nature of people's roles and the potential effect of this on self-management is believed to be a novel component of this work. Certainly, the notion is entirely original in the context of the theoretical framework of health literacy. Practical and theoretical implications of this research will be discussed in Chapter 10.

## **9.7 Study findings considered in the context of health literacy**

Study Two had a subsidiary aim: "*To investigate the operational definitions of the three levels of Nutbeam's (2000) health literacy framework as developed in Study One, so as to further refine the conceptual framework in the context of type 2*

*diabetes.*” In Chapter 8 where Study Two’s results were presented, reflections on the different levels of health literacy were combined within the themes as appropriate. Here Study Two’s findings will be discussed separately in relation to the operational definitions of health literacy (as developed in Study One).

Each of the levels of health literacy will be discussed in turn in the following three sections. Each section will begin by presenting the operational definition followed by a commentary based on the findings of Study Two.

### **9.7.1 Functional Health Literacy**

The operational definition developed for functional health literacy in study one was *‘Adherence which enables daily functioning.’*

The participant Saliha’s interview was a particularly interesting case in terms of improving understanding of functional health literacy. Saliha admitted adapting medical advice regarding the prescribed routine for administering insulin; she said she regularly missed insulin and a meal at lunchtime in order to free up time to complete chores. However, Saliha demonstrated critical health literacy skills in other parts of the interview, for example when she outlined how she had learnt to interpret symptoms that indicated that her blood glucose was becoming low, enabling her to anticipate and prevent a hypoglycaemic attack.

This finding highlights that in the context of type 2 diabetes ‘textbook self-management’ is not always realistic. Rather, the successful patient is often one that is able to employ a style of self-management that suits the individual so as that it can be maintained. In light of this finding the operational definition for functional health literacy developed in study one is supported.

Moreover, the case presented here of Saliha reiterates the critique from study one (see section 6.5.2) that questioned the hierarchical linear nature of Nutbeam’s (2000) framework. Saliha demonstrated making an informed decision not to adhere with medical advice but this did not necessarily mean that she did not have functional health literacy rather she had arguably demonstrated critical health

literacy skills. Based on her personal experience Saliha was able to deduce what suited her and adapt medical advice accordingly.

### **9.7.2 Interactive Health Literacy**

The operational definition developed for interactive health literacy in study one was *'Patient uses initiative to solicit additional information from different sources so as to implement more control over own health'*.

Two of the sub-themes that emerged, 'Comparison of own self-management' (of the theme 'Familiarity with condition') and 'Sharing diabetes information with friends (of the theme 'Diagnosis improves social support'), largely reflected this level of health literacy. 'Familiarity with condition' emphasised social learning that occurred regarding self-management behaviours, while 'Diagnosis improves social support' noted the frequency with which participants talked about sharing knowledge on alternative medicines with friends. This emphasised the importance that belonging to a group with a high prevalence of type 2 diabetes had on participant identity and self-management. Nutbeam (2008) has recently stated that the progressive autonomy in decision making is dependent on different forms of communication with varied message content as well as cognitive development. Study Two's findings emphasise the importance of social learning and lend support to this statement.

Jordan et al. (2010) undertook a similar qualitative study using in-depth interviews to understand patients' perspectives on health literacy so as to identify constructs for a broader health literacy measure. Participants' key abilities were identified as well as broader skills that emerged at the healthcare and community levels. At the community level the broader factors that influenced health literacy skills were: lifestyle commitments (work and family); support networks that helped patients to know when and where to seek information as well as helping with processing and retaining information, educational background and previous experiences.

A similarity is apparent between the health literacy skills on support networks presented by Jordan et al (2010) and Study Two's themes 'Familiarity with

condition' and 'Diagnosis improves social support' both of which were considered to reflect the interactive level of health literacy. Detail on implications regarding social support from known peers is presented in Chapter 10.

### **9.7.3 Critical Health Literacy**

The operational definition developed for critical health literacy in study one was *'Art of discrimination learnt over time alongside an emphasis on the personal experience'*.

In Saliha's interview she had spoken about having learnt how to recognise symptoms of negative health outcomes and how to react to them in a timely manner so as to avoid them. Participants in Study Two demonstrated that they had developed different strategies that suited them. This finding is supported in the wider literature where the lived experience of becoming proficient in diabetes self-management is described as being non-linear (Moser et al., 2008). It has also been suggested that strategies for achieving glycaemic control are mastered through the restructuring of experiences and perceptions of one's condition (Thorne et al., 2002). This learning over time, with an emphasis on the personal experience, also reinforces and supports the operational definition developed for critical health literacy in study one.

The other key point to emerge at the critical level of health literacy was that of empowerment. The finding that participants who reflected an empowered perspective in their interview also described self-managing effectively supports the basis of Nutbeam's (2000) framework that greater autonomy in decision making is associated with higher levels of health literacy and better self-management. However, this is not based on empirical evidence and would need follow-up work to support the assertion.

Equally, several women described hypoglycaemic incidents with visible distress at their recall. These events appeared to be disempowering for women and to have challenged their feelings of independence. This was particularly true for two of the participants, Khalida and Aysha, who generally demonstrated a poor understanding of their condition. Khalida and Aysha demonstrated several other

similarities. They both: had no understanding of the English language; had co-morbidities; used insulin; experienced bad health before eventually being diagnosed with type 2 diabetes; felt their family and grown-up children did not support them as they would like. Poor health literacy in these women may have contributed to these negative outcomes.

It is interesting to note that in context of Study Two's findings the over-arching theme 'Role re-alignment enables successful self-management' can be seen to relate best to critical health literacy. Drawing again on Saliha's case where she stated in her interview that she routinely missed her lunch and insulin as this gave her time to complete household chores while her children were at school. While developing this skill can be seen to reflect critical health literacy since it is based on personal experience and was likely to have been learnt over time, there is an additional dimension that is important to note in relation to the over-arching theme. Central to how well diabetes is self-managed is how successfully the individual is able to balance and revise their existing roles as well as integrate new roles. This finding emphasises successful self-management, critical health literacy skills, are framed in a broader context. Implications regarding this notion will be presented in Chapter 10.

## **9.8 Strengths and limitations**

It is important to place the findings of Study Two within its strengths and limitations. In this section the following aspects of the study will be discussed: the trustworthiness of qualitative interview data; the influence of the researcher; language of interview and participation bias. The limitations of not having a gender or ethnic comparison group and participants' generation status as proxy for age and years since diagnosis will also be discussed.

### **9.8.1 Trustworthiness of qualitative interview data**

Qualitative interviews have been criticised as a data collection method since one can not be sure that what participants say actually represents reality (Murphy et al 1998). Silverman (1993) questions whether interviews actually uncover personal experience or whether people just behave in socially desirable ways. A limitation of

interview data is that the researcher is only able to access what participants choose to share (Athens, 1984). Stimson and Webb (1975) found inconsistencies between reports given by patients about interactions with their doctors with what was actually observed.

These limitations can be overcome by establishing trustworthiness of the interview data. To do this, it is crucial for the context in which the data were produced to be sufficiently detailed so that potential biases can be understood (Hammersley and Atkinson, 1995). The credibility of qualitative data can be ascertained by: checking the inquiry process (Erlandson et al 1993); judging the transferability of the findings of a particular inquiry to other contexts (Lincoln and Guba, 1985) and assessing the consistency by considering whether the results would be repeated if the investigation were to be replicated with similar participants in a comparable context (Howe and Eisenhart, 1990; Jensen, 1989). In discussing the results of Study Two comparisons have been successfully and usefully made with studies in the wider literature, suggesting these findings to be trustworthy.

It has been largely understood for some time that for a qualitative study to be considered well done it needs to be replicable and display analytical rigour (Denzin 1978), meaning that the reader should have many opportunities to examine the processing and analysis of the data (Chenail, 1995). The quest is for 'traceable variance' (Erlandson et al, 1993). In Chapter 7 a precise report of the process of inquiry the researcher undertook was detailed. A strength of this research is that an external check on the inquiry process can be conducted.

#### **9.8.1.1 Coder consistency testing**

Another way trustworthiness can be achieved in qualitative research is by assuring the reader that: data records have been examined; categories have been detected and consistently applied; collected information has been well documented and these processes of cohering the data are transparent (Richards, 2009). Coding of data was an important stage where these methods for achieving reliability were carefully considered.

In Study Two data were collected and coded over a short period of time by one coder; for these reasons it was felt that intra-coder consistency tests were unnecessary since the researcher remained familiar with earlier coding. Nevertheless, it was fundamental to be aware of the level of coding consistency, so as to be able to place coding-dependant analysis in context. To illuminate inter-coder reliability, two researchers' coded one transcript and then these codes were compared and differences were documented.

There were eighteen points of difference between the two researchers' codes. Eleven of these differences were considered to be a result of different coding styles. While the researcher tended to code large passages of the transcript at one or two codes the other researcher (CJ, supervisor) had a richer style of coding, in that she coded shorter passages of the transcript and often refined these to sub-codes. The other seven of these points of difference were due to the researchers having applied different codes to the same passage of text. On these occasions, codes applied by both researchers were relevant and appropriate.

An additional reason for these points of difference was that coding was an iterative process, with more sub-codes emerging as more interview transcripts were coded. The initial and final version of the coding framework can be seen in Appendix 7.4. The initial coding framework had 10 codes and 30 sub-codes. The final coding framework had eight codes and 46 sub-codes. Related to this point, the transcript that was used to test coder consistency was of the second interviewee.

The researcher was satisfied that some of the differences in codes generated between the two researchers were because CJ used the final coding framework with codes that had not existed when the first researcher had been coding the same transcript. In light of this it was concluded that coder consistency was satisfactory. There were no instances where one researcher had coded data that the other researcher had not and this was reassuring as it suggested none of the data were lost.

### **9.8.1.2 Respondent validation**

The decision was made against employing respondent validation which is a procedure that re-involves participants during the analysis stage of a project. Respondent validation involves consulting the participants for their opinion on the adequacy of the interpretations and explanations generated by the data analysis. Respondent validation demonstrates there to be an agreement between the respondent's description and the researcher's analysis.

However, a shortcoming of this approach is that in some cases the analysis may be incomprehensible or unacceptable to the respondents, not as a result of inaccuracy or invalidity but due to different political or ideological stances. Furthermore, it is a high expectation of the participant to read through the analysis. Even where participants' are willing to spare their time and effort, their impression of the research findings is subject to constant change. The participant may consider specific aspects of the research as being important and ignore the central topic, which would result in support for the findings for the wrong reasons (Bloor, 1997). For these reasons respondent validation was not employed in this study.

### **9.8.1.3 Negative cases**

Another important consideration in terms of the validity of qualitative data analysis is the conscientious search for, and presentation of negative cases, i.e., instances that oppose the emerging analysis (Glaser and Strauss, 1965; Athens, 1984; Lincoln and Guba, 1985; Marshall, 1985; Phillips, 1987 ; Mechanic, 1989; Henwood and Pidgeon, 1993). The inclusion of negative cases strengthens the credibility of research findings (Silverman 1989) as it limits holistic bias, which is when data are made to look more patterned than they are (Sandelowski 1986). Furthermore, negative cases ensure careful examination of data to determine how they could be incorporated in the analysis (Secker et al, 1995). The inclusion of negative cases has been likened to the careful search for falsifying evidence in science, which eliminates error and adds weight to the truth claims of an investigation (Phillips, 1987). Negative cases have been presented where appropriate throughout Chapter 8.



### **9.8.2 The influence of the researcher**

It is important to be aware of the possible influence of the researcher on the results of an investigation since in a qualitative investigation, the researcher's role is more than just one of data collection. Interviewers, the same as interviewees, obtain their sense of identity from various sources, including: age; gender; culture; religion; nationality; ethnicity; race; educational qualifications; social class; language; health status and employment (Grewal and Ritchie, 2006). These elements of the researcher's background can affect the relationship with the participants and have a bearing on the final product of the investigation (Sword, 1999).

Matching of language is paramount to enable successful understanding although a 'language-of-interview' effect has been documented (Lee et al., 2001) where an interviewer may be more likely to judge the interviewee's performance differently and the interviewee may question the legitimacy of the interviewer differently than if the interview was conducted in English. Matching of ethnicity is encouraged as with any form of peer matching, where it fosters a sense of shared experience which can also serve to restore a power imbalance caused by the interview situation. Feminist researchers have used this argument for matching female interviewees with female interviewers (Finch, 1984). It is accepted however that empirical evidence has demonstrated both support and opposition to this standpoint. The interviewer's 'insider' status has been shown to facilitate rapport thereby yielding data that is rich (Egharevba, 2001). There has also been research suggesting an interviewer's 'insider' status to have drawbacks. These include respondents feeling more judged which can mean they are less willing to share their views, furthermore the interviewer may think that they know how the respondents will answer leading to assumptions being made about the data (Merton, 1972).

This was particularly an issue in Study Two since the sample was recruited from the researcher's home town, so some of the women were known personally by the researcher's family. This may have increased women's reluctance to talk about certain issues. There might have been participants who, as result of these personal relationships, felt less inclined to talk openly about what they regarded to be private

matters, even with the assurance that findings would be anonymised and all interviews would be treated confidentiality.

Since it is accepted that the identity of the interviewer can affect research outcomes it was decided that despite potential drawbacks it was appropriate to match the researcher and the participants in Study Two. Being aware of some of the limitations of matching interviewer with interviewee, the researcher remained mindful of reflexivity and avoided appearing judgmental during the interview. The researcher was also careful not to make assumptions of the data during the study design, data collection and data analysis stages i.e. when developing the interview schedule, when undertaking the interview process and when undertaking thematic analysis of the data.

Moreover, it was accepted that while the researcher shared gender, ethnicity and religion, she did not share age or educational qualifications with the respondents. In an attempt to promote acceptance the researcher dressed in a smart, but casual manner for the interviews with second generation women and in traditional Pakistani clothes when talking with first generation women. Reflecting on the process, it is believed that the researcher's background as a Muslim, British-Pakistani female was an aid in recruitment and in developing rapport, impacting on the way that women interacted with her during the investigation. All women who participated in the study appeared to be relaxed and talked candidly about their feelings and experiences. Women appeared to find it therapeutic sharing their experiences and most women offered to be contacted again if more information was needed although it was not.

### **9.8.3 Language of interview**

A strength of Study Two was that the researcher was bi-lingual, this meant Urdu speaking participants as well as English speaking participants were able to be included in the study. This meant that interesting comparisons were able to be made and some low-literate, harder to reach participants were able to be recruited. While the researcher could speak Urdu fluently she was only able to understand Punjabi. Aysha, a Punjabi speaking woman wanted to take part in the study. She was able to

have an efficient conversation with the researcher as she was able to understand Urdu and she said she spoke to her doctor in the same way. Furthermore, the community education class from which she was recruited was delivered in Urdu.

The inclusion of Aysha in the study highlighted a limitation the researcher was already aware of, that the Urdu language was a proxy for level of education. While there are many languages in Pakistan, Urdu is the national language and the ability to speak Urdu is arguably a proxy for education amongst Pakistanis. Aysha used insulin and spoke at length about her feelings of dependency as a result of her inability to speak in English. A limitation of this project is that fourteen of the included participants were potentially more educated, Urdu speakers. This highlights the danger of treating all Pakistanis as a homogenous group.

#### **9.8.4 Participation bias**

A strength of Study Two was that the recruitment grid ensured that a diverse sample was included in the study, for example second generation women were targeted through snowballing. However, as in all research of this type, a limitation of the research was that only those who gave consent and were willing to participate could be interviewed. Those amenable to participating in research of this type may differ in ways, including identity, from those who were not but it is not possible to examine these differences. Moreover, it is worth considering that those who were very ill as a result of their diabetes also may not have been involved in the study. This factor may have biased the results of the study since the responses of those hard-to-reach patients may have differed in some way from those that are reported.

A further limitation was that study bias may have been increased because over a third of the participants were recruited from the same diabetes education classes. Moreover this sample of six women composed the majority of the first generation immigrant women who were interviewed in Urdu. The women attending the education class may have been more likely to be motivated to self-manage than the general population because they were sufficiently motivated to attend a type 2 diabetes education class and learn more about their condition. However, a strength of the women's only education class was that the researcher was able to introduce

herself and the project verbally in Urdu. This was anticipated to have helped recruit women that may not have been interested otherwise.

### **9.8.5 No ethnic or gender comparison group**

It is acknowledged that participants in Study 2 will have different identities in different contexts and amongst these are their cultural (British-Pakistani) and religious identities (Muslim). Diabetes affects these different identities in different ways and they may influence each other. The analysis tried to reflect this complexity by focusing on how women talk of their different roles and multiple identities. The study has tried to emphasise how issues beyond the diabetes itself affect the women's self-management and how they perceive themselves, their different roles and their different identities. Analysis has aimed to avoid a simplistic view of the data by teasing out these different relationships and testing assumptions by going back and utilising the data with arising critical questions.

However, it is important to highlight that a limitation of the study is the lack of a comparison group, e.g. British-Pakistani males meaning gender differences could be better examined, or white-British females meaning it could be inferred when ethnicity was responsible for mediating the relationship between factors and when it was not. While comparisons with the broader literature have been made and this has proved helpful in overcoming the problem of having no comparison group, follow-up research may be well placed to have such comparison groups. Agyemang et al (2010) made an interesting recommendation on comparing data on groups that share the same ethnicity but have migrated to different countries. They suggest this would provide a valuable insight of the contribution the host countries context itself had on health inequalities. This would be an interesting future research direction.

### **9.8.6 Participants' generation status as proxy for age and years since diagnosis**

Study findings emphasise that a strength of Study Two was the purposive recruitment of first and second generation women as it enabled interesting points of difference to be drawn. However, while as anticipated, age was a proxy for

generation status, an additional pattern that was identified from undertaking Study Two was that generation status was also a proxy for years since diagnosis. The years since diagnosis of first generation participants ranged from 1 to 25 years whereas there was only one second generation participant who had lived with diabetes for over ten years.

A limitation of this was that participant's years since diagnosis added another dimension to this already complicated context making the disentanglement of the effects of these different variables increasingly difficult. The study design enabled reporting of patterns in the data according to characteristics the participants shared, namely generation status and level of education. However the fact that generation status overlaps with age and years since diagnosis complicates this relationship and prevents knowing whether any of the variables are having an independent effect. This suggests that the inter-generational differences that have been discussed through Chapter 8 may instead be wholly or partly attributed to age or years since diagnosis. This study design does not allow one to know if any of the variables are having an independent effect.

## **9.9 Summary**

A particular point of interest from the findings of Study Two has been the, at times, profound inter-generational differences amongst participants. These results pose an interesting question, of how health inequalities may be affected in this BME population as it ages. Migration patterns in the South-Asian community (Shaw, 1998) demonstrate that a wave of second generation immigrants are arriving to the age where diagnosis of type 2 diabetes, which is typically late-onset (Karlsen and Bru, 2002), is increasingly common.

This research area is beginning to be addressed in the UK. Smith et al (2009) considered coronary mortality in first and second generation South-Asian immigrants. Their findings indicated a complicated relationship remains between biological and socio-economic determinants, and additionally acculturation factors. This further evidences the worthwhile nature of this avenue for future research as has been suggested by the findings of Study Two.

## Chapter 10

### Final discussion

#### 10.1 Introduction

The motivation driving this research was to gain an improved understanding of type 2 diabetes self-management in BME groups, using health literacy as the conceptual framework. The health literacy framework seemed a rational choice for the investigation of diabetes self-management which is composed of various complex behaviours that require patient knowledge and motivation to maintain glycaemic control. Although low health literacy has been linked to diabetes related health inequalities in terms of prevalence, disease knowledge and levels of self-management (Rothman et al, 2002; Schillinger et al, 2002) there has been little research in the relationship between health literacy and health inequality (Paasche-Orlow and Wolf, 2010). It was considered plausible that by investigating self-management using the health literacy framework some of the reasons for health inequalities in BME groups would be suitably explored.

The thesis contains two studies. Study One was a systematic review, which asked the question: "*What is known about the barriers to, and facilitators of, self-management of type 2 diabetes amongst ethnic minority groups?*" The systematic review comprised two strands that were synthesised individually and then the findings were integrated in a cross-synthesis. One strand reviewed the effectiveness of self-management interventions for type 2 diabetes delivered to BME patients. The other strand reviewed 'views' studies on type 2 diabetes self-management in BME patients. Following this, there was a cross-synthesis, where the findings of both the intervention and 'views' strands were integrated.

A subsidiary aim of the systematic review was *to refine Nutbeam's conceptual framework of health literacy (2000) in the context of type 2 diabetes*. The exercise was to produce clear operational definitions for functional, interactive and critical levels of health literacy in the context of type 2 diabetes self management.

The systematic review demonstrated what was already known about the research area and usefully indicated areas for further investigation that would contribute to existing knowledge. These areas came to be considered as the next stage of primary empirical work which was the focus of Study Two.

Study Two was a qualitative interview study that built on the analytical theme 'maintaining identity' identified through the 'views' strand of the systematic review which contained two sub-themes comprising conflicting views. The overarching research question driving Study Two was "*How does having type 2 diabetes affect British-Pakistani women's identity and how does this relate to subsequent self-management?*". Study Two had a subsidiary aim *to reflect further on the operational definitions that would be developed for the three levels of health literacy from Nutbeam's (2000) framework in Study One.*

In discussing the main findings of the thesis, a brief summary of the results of both studies will be presented. Alongside this, recurring methodological issues will be discussed. Finally, informed by the results of the systematic review and the qualitative interview study, practical implications to facilitate BME patient's diabetes self-management will be proposed.

## **10.2 Results summary**

In this section a summary of the results for the different components of the systematic review (Study One) will be considered first. This includes the intervention strand, the views strand, the cross-synthesis and the health literacy component. Following this, the key findings for the qualitative interview study (Study Two) will be presented and considered according to the health literacy component. The main findings of the thesis will be discussed with a focus on any methodological issues. Finally, the results of the interview study will be considered with the findings of the analytical theme 'maintaining identity' from the 'views' strand of the systematic review.

### **10.2.1 Interventions strand**

Twenty-eight trials were included in the interventions strand of the systematic review. Various sources of heterogeneity prevented a meta-analysis and made synthesis of the findings challenging. Secondary analyses suggested that an intervention was more likely to show a positive effect on physiological outcome measures if it was: culturally competent; based on a theoretical framework; delivered at both an individual and group level; delivered in a primary health care setting; and had both educational and practical components. The effectiveness of an intervention was not influenced by its duration or by whom it was delivered. Results on the other sub-sets of trials and the other three outcomes (attitudinal, behavioural and knowledge) produced inconclusive results.

There are other published systematic reviews that have considered the effectiveness of type 2 diabetes self-management interventions in BME groups (Sarkisian et al, 2003; Whittemore, 2007; Khunti et al, 2008a; Hawthorne et al, 2008; Saxena et al, 2007). The strength of this review was that it included any outcome for type 2 diabetes self-management. While this made synthesis challenging it enabled judgements to be made on the effectiveness of various sub-sets of trials which the other published systematic reviews were unable to do.

### **10.2.2. 'Views' strand**

As with the intervention strand the key methodological challenge of the 'views' strand was that the systematic review was broad, complex and inclusive. The synthesis of 57 studies examining BME patients' views on self-management of type 2 diabetes resulted in three analytical themes: 'Importance of identity;' 'Being understood by others' and 'Making sense of own condition' and one over-arching theme 'Sense of self.' The over-arching theme suggested that learning was acquired through living with type 2 diabetes and from actually experiencing and overcoming situations.

An interesting question was also posed regarding how much the findings were specific to the condition of type 2 diabetes and belonging to a BME group, and how much they would be true of any long-term condition and any socially and



educationally disadvantaged population. This question was considered further in Study Two.

A strength of the 'views' strand was that while there were examples of published systematic reviews undertaking a qualitative synthesis of the diabetes experience (Paterson et al., 1998; Campbell et al., 2003), there was an absence of any qualitative systematic reviews such as this one that focused on BME people's views of diabetes self-management. Another strength, as a result of undertaking synthesis of the 'views' strand, has been the contribution it has made to the development of the thematic synthesis method. Methods for reviewing qualitative research are still emerging and so there are continuing enhancements to the method (Sandelowski, 2007); the work presented here has been able to provide an original contribution to this knowledge.

Thematic synthesis was developed at the EPPI centre where it has been applied within several systematic reviews (Thomas and Harden, 2008). Each of these reviews however, has synthesised fewer than ten 'views' primary data studies (Harden et al, 2004; Harden et al, 2006; Thomas et al, 2003; Thomas et al, 2007). When applying the method of thematic synthesis to a larger systematic review, such as reported in this thesis, it was thought appropriate to add another step to the method so as to better organise the large data set. This additional step was the development of three *a priori* broad questions, with these being applied after the line-by-line coding stage to help develop categories from which descriptive themes could be better developed. This process has been detailed in section 4.3.3.

Furthermore, this additional step is also considered to have gone some way in addressing the criticisms made of thematic synthesis by Dixon-Woods et al (2004). The view was held that the thematic synthesis method lacked transparency and that the thematic synthesis style did not offer theoretical structure from which to develop more conceptual themes. In this research, efforts had been consciously made to overcome this limitation as set out in the methods (see section 3.1.7.1). This was in part achieved by means of a thorough reporting of the methods and in part by adopting the additional step to the methods which brought further procedural explicitness.

### 10.2.3 Cross-synthesis

The final stage of the review was a cross-synthesis of the key findings from the two review strands. From the analytical themes (end product of the 'views' strand) nine potential implications for the content and delivery of interventions were developed and these were considered alongside the eleven sub-sets of trials (end product of the intervention strand). This process enabled gaps and matches to be identified between what participants would favour an intervention to address and what existing interventions had actually addressed. This process allowed existing interventions to be critically analysed according to the 'views' data.

Of the nine potential interventions identified, cross-synthesis identified five matches. There was enough evidence in only two of these instances (education that was culturally competent; individual versus group education) to determine whether effectiveness of interventions matched patients' views. Cross-synthesis endorsed both interventions that were designed in a culturally competent way and interventions that employed a style of delivery combining individual and group elements. This was because 'views' studies suggested that these components of an intervention would be valued by participants. Evidence from trials showed that culturally-competent interventions were having a positive effect. Trials delivered with a combined individual and group effect suggested a positive effect but this conclusion is tentative because of the small number of trials in this sub-set.

Cross-synthesis identified gaps in two of the potential interventions (supporting information sharing amongst peers; supporting a positive outlook towards spirituality and fatalism). These two potential interventions would be valued by participants since views were positive towards experiential learning from known others who also had the condition. Participants' views towards spirituality and fatalism were demonstrated as having the potential to act as a barrier or a facilitator to effective self-management. The finding that both of these perspectives have been overlooked by diabetes services appears to be a missed opportunity for intervention. These results suggest that interventions supporting information sharing amongst peers and interventions taking consideration of participants' spiritual and fatalistic beliefs would be promising avenues for the future development.

#### **10.2.4 Health literacy**

The systematic review's subsidiary aim was novel in that it involved undertaking empirical work to refine the definitions for the three levels of Nutbeam's (2000) health literacy framework in the context of type 2 diabetes. Refining the definitions of the interactive and critical health literacy levels was thought to be particularly necessary since both employed the similar and broad terms 'social' and 'cognitive skills.'

This empirical work suggested that the functional level of health literacy was strongly related to treatment adherence. At the interactive level of health literacy experiential learning was evidenced as well as the soliciting of information from various sources. For critical health literacy, patients put an emphasis on their personal experience and over time they developed skills of discrimination between symptoms. The operational definitions that were developed here go some way to remove the ambiguity that had been apparent in Nutbeam's (2000) definitions.

The operational definitions developed from this work are supported by a literature review conducted by Ishikawa and Yano (2008c). They had retrieved published papers that had been designed to conceptualise or measure health literacy and they assessed them according to one of the three levels of health literacy from Nutbeam's (2000) framework. From this work, Ishikawa and Yano (2008c) considered 'information seeking' and 'information verifying' to be patient communication skills at the interactive level of health literacy, while 'confidence in decision making' was considered to reflect patients' skills at the critical level of health literacy. This work can be seen to reinforce the definitions developed in this thesis.

In addition to operationalising Nutbeam's (2000) definitions for the three levels of health literacy in the context of type 2 diabetes, a critique was provided questioning the hierarchical nature of the conceptual framework and suggesting the merit of a context-specific list of competencies for each level of health literacy as likely to be an appropriate alternative. This will be discussed here.

In light of the more precise operational definitions, this work indicates pathways for future work. The empirical work suggested that to measure the different levels of health literacy, the measure would need to be condition-specific. While it is emphasised that this is only a recommendation, it would be useful to pursue since it may rebalance the current focus of measurement tools on the functional level of health literacy (more specifically reading and writing skills, (Rootman et al. 2006)) and move it to the interactive and critical levels. These levels include patients' abilities to extract, communicate, critically analyse and use health information, so as to actively participate in the maintenance of one's own health.

Definitions developed from this research were enhancements of Nutbeam's definitions and so they remained generic, despite being operationalised in the context of type 2 diabetes. The use in the operational definitions of the terms 'daily functioning,' 'day to day' and 'over time,' are able to be interpreted in other contexts. Indeed it would be a beneficial test for a future study to see whether the operational definitions stand when applied to another condition and another population. To clarify, this research provides generic operational definitions but suggests that measurement may need to be condition-specific.

Conclusions are presented only tentatively because of the methodological limitations as a result of the small scale nature of this exploratory study, which was seeking to refine Nutbeam's health literacy framework in the context of type 2 diabetes. The method from this research should be more rigorously replicated with other populations and conditions to compare findings. The majority of populations under review here were of ethnic minority and hospital-based groups, and they were often reported as being socio-economically deprived. It would be especially interesting to compare similarities and differences with other populations and conditions.

### **10.2.5 Study Two**

The second study in this thesis was a qualitative interview study that aimed to answer the research question "*How does having type 2 diabetes affect British-Pakistani women's identity and how does this relate to subsequent self-*

*management?"* This study had a subsidiary aim to investigate the operational definitions that had been developed in Study One, for the three levels of Nutbeam's (2000) conceptual framework of health literacy.

A group of 15 British-Pakistani women were recruited. A combination of first and second generation women of varying levels of education were purposefully recruited. Thematic analysis of the 15 interviews produced four themes and these were: 'Familiarity with condition'; 'Diagnosis improved social support'; 'Supporting family was barrier to self management'; and 'Perceived change in self.' There was one over-arching theme, 'Role re-alignment enables successful self-management.' These themes will now be considered in terms of how they relate to the findings of the systematic review and to the operational definitions for the three levels of Nutbeam's (2000) conceptual framework of health literacy that had been developed in Study One.

With the theme 'Familiarity with condition' participants noted how they adapted to their diabetes over time and as they became better adjusted, their self-management improved. This relates to the 'concept of learning over time with an emphasis on personal experience', as operationalised at the critical level of health literacy. This suggests that to develop critical health literacy participants need time to adapt to their condition and accept the change to identity.

In the theme 'Diagnosis improved social support' the majority of participants reported that their diagnosis of diabetes resulted in them feeling very supported by their families. This was different to the systematic review findings which had mixed views on feeling supported. However, consistent with the review findings, participants talked about the benefits of speaking with their friends about their condition and sharing information. This was related to the concept of 'soliciting information from additional sources', as operationalised at the interactive level of health literacy.

This theme demonstrated that consistent findings in Studies One and Two suggested that this theme may be unrelated to gender and a specific BME group, since the systematic review included the views of both males and females, from 6 different BME groups, living in 5 different countries.

The theme 'Supporting family was barrier to self management' had similarities with the systematic review which also found that women particularly have a caregiving role that could act as a barrier to their own self-management. This comparison between the two studies suggests that this finding may be related to the female identity and not the other possible variables.

In the theme 'Perceived change in self' women made comparisons between themselves currently and the 'normal' or their 'old self'. These comparisons suggested women felt a change in their identity. In the operational definition for critical health literacy the phrase 'emphasis on the personal experience' is used; this can be perceived as reflecting the paramount importance that the role of identity plays in achieving critical health literacy.

'Role re-alignment enables successful management' was the over-arching theme and this suggested that while diabetes affects a patient's identity, it is the re-alignment with the new identity that is crucial for effective self-management. The over-arching theme emphasised the ongoing nature of type 2 diabetes self-management, where achievements need to be sustained. This suggests that in the context of type 2 diabetes, critical health literacy had to be maintained, due to the progressive nature of the condition. The over-arching theme emphasised a central component of how an individual is affected by diabetes, and successful self-management, to be how well the individual is able to manage continually balancing and adjusting existing roles alongside integrating new roles.

### **10.2.6 Comparison of Study One and Study Two**

From the 'views' strand in the systematic review the analytical theme, 'maintaining identity,' incorporated two sub-themes, 'confidence' and 'roles,' with strongly conflicting views. On this basis, Study Two pursued a line of enquiry seeking clarification specifically on the two sub-themes that composed these points of difference. This forms a natural point of comparison between the two studies.

In Study One the sub-theme 'confidence' emphasised views relating to the personal experience of living with type 2 diabetes. Some patients demonstrated an empowered perspective towards their changed identity and this facilitated self-

management. For other patients, diabetes resulted in their having a disorientated identity and this became a barrier to effective self-management.

In Study Two participants also demonstrated mixed views on confidence which seemed to be linked with their experience around diagnosis. Women who had been alert to symptoms and had presented them to a health professional were the most confident, perhaps as would be expected. Those who had suffered bad health due to a late diagnosis had the lowest confidence of the women in the study. Perhaps less surprisingly, women's experience of management was also linked to their levels of confidence. Women who said their diabetes was easily or well managed were the most confident while women who had been struggling to manage their diabetes were the least confident.

The women in Study Two also demonstrated that their confidence tended to improve with time. This suggests that one reason for the mixed results in Study One was that the 'views' studies had included participants from different stages since diagnosis. An implication of this is that studies should report on participants' time since diagnosis and consider how this may affect results.

In Study Two there was another link between confidence and women's roles. Women who had experienced a change in work roles due to their diagnosis demonstrated feelings of disempowerment. Women talked about how some roles were adapted over time whereas other roles, particularly familial ones, were more resistant to change. This finding emphasises that a participant's confidence is related to their general feeling of well-being and a person with diabetes does not consider their condition in isolation.

In Study One the sub-theme 'roles' had contained conflicting views. There were some views to suggest that social and familial roles encouraged self-management because participants wanted to sustain their identity. Other participants viewed these roles as making their self-management difficult.

In Study Two participants talked extensively about their roles within the family. In this study however, participants consistently recognised that supporting

their families was a barrier to their self-management but they did not demonstrate any willingness to change this role. This demonstrated the importance of family to the women in this study. Participants' feelings were more mixed regarding the value they placed on the role of friendship. This research reinforced the finding that diabetes has different effects on separate identities and how one identity is affected can influence another.

Roles were an important outcome in Study Two and fed into the over-arching theme 'Role re-alignment enables successful management.' The driving motivation of this research was to gain an improved understanding of type 2 diabetes self-management in BME groups. It was understood that while competing roles challenged self-management, the successful achievement of roles that the participants themselves defined as important were crucial for a patient to maintain their identity. This re-iterates the implication that type 2 diabetes is only one aspect of a person's identity and a successful intervention would need to recognise this.

Study Two further suggests that participants' outlooks were affected by a number of issues including time since diagnosis, stage of condition, and feelings on the day of interview. Paterson's (2001) 'Shifting Perspectives Model of Chronic Illness' emphasises that individuals have different outlooks depending on their chronic condition orientation. Some patients' perspectives focus more on their health (i.e. wellness) than illness, and with time any one perspective can take precedence over the other. When the wellness outlook is in the forefront it can be productive because the individual can develop an accord between the self-identity and the illness identity; this can enable changes in their relationships with their environment as a result of their condition. A positive outlook and feelings of confidence are considered to be essential not only in setting self-management goals, but also in achieving them (Hogg, 2000).

The findings of this thesis are similar to the published literature that proposed long-term conditions impact on a person's identity necessitating adaptation over time (Charmaz, 1995; Tilden et al, 2005). Illness identity has also been also called illness representations and has been defined as an individual's beliefs about their illness based on their previous experiences and future expectations of health and



illness. Illness representations determine health care decisions, coping behaviours and adherence to medical advice (Heijmans and de Ridder, 1998).

As well as framing questions around the two sub-themes containing conflicting views, 'roles' and 'confidence' from Study One, in the second study there were also questions regarding the health literacy component of the systematic review. It was anticipated that the interviews would be used to further investigate the refined levels of Nutbeam's (2000) conceptual framework, as developed in Chapter 6, by phrasing questions around the operational definitions. This was predicted to be a useful way for participants to personally reflect on the three levels of health literacy in the context of their own diabetes self-management. Additionally, it was expected that the critique provided of Nutbeam's framework in Chapter 6 would be further explored in the context of this empirical work.

It was considered that, by learning how to support health literacy, recommendations on how to improve self-management could be made. For health literacy to be supported it needed to be better conceptualised, this related to the second aim of the thesis which was for type 2 diabetes self-management to serve as an exemplar condition for the analysis of Nutbeam's (2000) health literacy framework.

## **10.3 Implications**

### **10.3.1 Theoretical Implications**

In this section, the key health literacy findings of the two studies will be considered according to how they relate to existing research and current theories. Detail has already been provided on how they related to each other. In light of new insights, the results and their implications for theory are considered.

As demonstrated here, understanding of the three levels of health literacy was further illuminated when reflections of the findings of Study Two were related to the operational definitions of health literacy (as developed in Study One). Study Two reinforced the findings from Study One that an example of critical health literacy could be to make an informed decision not to adhere to medical advice but rather to

find out what suits the individual and adapting the advice accordingly. This reiterates the criticism that Nutbeam's (2000) framework is not necessarily hierarchical. It also adds to the critique that while functional health literacy skills are basic skills that are built upon, with time these skills evolve and the basic skills can become redundant. Study Two findings regarding the learning process of type 2 diabetes self-management suggested it to be non linear, occur over an extended period of time and with an emphasis on the personal experience.

The other key point to emerge at the critical level of health literacy was that participants who reflected an empowered perspective in their interview appeared to self-manage well; this supported the basis of Nutbeam's (2000) framework that greater autonomy in decision making was associated with higher levels of health literacy and better self-management.

Paasche-Orlow and Wolf (2010) noted that the fields of health literacy research and health disparities research have remained largely separate and they recommended a research agenda that promotes the elimination of health inequalities by focusing on the role of health literacy. They emphasised the role of self-management was particularly underexplored in relation to health literacy and health inequalities. The work presented here has made a start towards doing this by examining self-management in a group that is known to have a higher prevalence of diabetes and its complications (National Office of Statistics., 2001) as well as recommending avenues to pursue in future research

Also, while recruiting second generation immigrants in Study Two was a challenge as a result of the migration patterns and the general age range for type 2 diabetes onset (see section 7.4.3) it enabled some useful commentary on inter-generational differences which may also relate to health inequalities. Study Two demonstrated that there were some issues that appeared to be different for first and second generation British Pakistani women. Due to migration patterns to the UK and the general age of type 2 diabetes onset it is likely that most of the papers with a British sample have recruited first generation immigrant women. The changing BME demographic in the UK means it is important to consider health inequality research and it is important to pursue this avenue in the future.

Difficulties were experienced in the process of operationalising health literacy across both studies. Some of these difficulties appeared to result from a lack of clarity around how health literacy is conceptualised. Health literacy can be used as a trait for describing or 'measuring' people, either individually or in groups. Health literacy can also be considered to describe a behaviour that an individual or a group of people exhibit. Furthermore health literacy can be employed as a framework for the designing or assessment of healthcare services or interventions. Health literacy is able to be conceptualised differently, sometimes broadly to mean all or some of these things and sometimes narrowly to just mean one of these things. This means that its operationalisation in research is not straight forward and is also related to the notion of functional health literacy versus wider health literacy that has been previously discussed.

The process of operationalising health literacy across the two studies has raised some important questions about the application of Nutbeam's (2000) conceptual framework. These are:

- How is health literacy distinct from absolute literacy? If a patient is illiterate is he/she able to be health literate or has limited literacy?
- If a patient is highly skilled at self-management in their indigenous country and highly literate in their indigenous language but at migration is not literate in the language of the host country, what level of health literacy is the patient considered to have in the host country?
- What level of health literacy would a patient who has not needed to seek extra information, due to a recent diagnosed or good self-management, be considered to demonstrate? Functional health literacy does not seem appropriate because it suggests the person is only able to demonstrate functional health literacy. Interactive health literacy does not seem appropriate because the individual has not demonstrated seeking additional information. Critical health literacy is not appropriate either because it is unknown how the person would respond to new challenges.

These questions highlight the importance of context to health literacy, within a condition. The importance of context between conditions had already been noted in Study One when the suggestion was made that a measurement tool would perhaps need to be condition specific (see section 6.5.1). It would be useful for future research to consider these important but relatively unconsidered questions, as they may tighten the conceptualisation and understanding of health literacy.

### **10.3.2 Implications for research, policy and practice**

The studies in this thesis have enabled new insights into type 2 diabetes self-management in BME groups and as a result of these some useful research questions and implications for policy and practice have been highlighted. These are listed and then discussed below.

#### **Future research questions:**

- Do friends and families have different roles in supporting people with type 2 diabetes?

An interesting finding noted in Study Two was that family and friends provided different types of support to participants. Friends provided support in the form of information while families provided practical support in completing other duties such as household chores. To the researcher's knowledge no published literature has noted the different roles of friends and families in the lives of people with type 2 diabetes. It would therefore be worthy of follow up research particularly to see if the finding is replicated in other gender and ethnic groups.

- What is the relative contribution of ethnicity, gender and social class to type 2 diabetes self-management?

Whilst this thesis contributes to a greater awareness of when ethnicity is an important variable by emphasising the impact of generational differences on identity, recommendations for future research are for further exploration of the relative contribution of these variables to the style of diabetes self-management. It is important to note that some of the findings from this research may be applicable to other ethnic, gender and social groups living with any long-term condition. Study

Two suggested health outcomes were influenced by the participants' familiarity with condition, perceived change in self and traditional health beliefs. It is likely these issues are not exclusive to South Asian women.

It may be possible to elucidate interplay between ethnicity and social class through further analysis of the differences between an ethnic group living in the least deprived areas as compared with those living in the most deprived areas. Future work such as this would provide useful information for healthcare providers in terms of targeting treatment interventions.

- Do the revised operational definitions for functional, interactive and critical health literacy hold in the context of a different health condition or population?

Definitions developed from this research were enhancements of Nutbeam's definitions and so they remained generic, despite being operationalised in the context of type 2 diabetes. The operational definitions employed the terms 'daily functioning,' 'day to day' and 'over time,' all of which are able to be interpreted in other contexts. It would be a beneficial test for a future study to see whether the operational definitions would stand when they were applied to another condition and another population. This work acknowledges that while the operational definitions are likely to be transferable to other long-term health conditions there may be limitations when they are applied to health decisions made at a single time point e.g. choosing pain relief in labour. This would be a useful area for further research.

- Should health literacy measures be context specific?

In light of the more precise operational definitions developed from this work, a pathway for future work has been indicated. Having identified which skills indicate each of Nutbeam's three levels of health literacy in the context of type 2 diabetes self-management, developing measures may be beneficial. The empirical work suggested that a measure for the different levels of health literacy would need to be condition-specific. This line of research would be useful to pursue since it may help rebalance the current focus of measurement tools from the functional level of health literacy (Rootman et al. 2006) to the interactive and critical levels also. By

considering these questions regarding health literacy in future research, the conceptualisation and understanding of health literacy may be enhanced further.

**Implications for policy and practice:**

- Self-management interventions for BME groups should be culturally competent and delivered at both an individual and group level.

Study One (the systematic review) made clear recommendations for self-management interventions for BME groups. The systematic review's intervention strand suggested that an intervention was more likely to show a positive effect if it was: culturally competent; based on a theoretical framework; delivered at both an individual and group level; delivered in a primary health care setting and had both educational and practical components. Cross-synthesis further endorsed interventions that were designed in a culturally competent way and delivered to both individuals and groups. This was because 'views' studies had also suggested that participants would value these components of an intervention. The testing of the effectiveness of such an intervention is proposed for future research and depending on the findings this may be a useful implication for policy and practice.

- Empower patients newly diagnosed with type 2 diabetes by informing them to expect some learning to naturally occur as their experience with the condition develops.

The over-arching theme of the 'views' strand 'Sense of self' suggested that learning was acquired through living with type 2 diabetes and from actually experiencing and overcoming situations. Implications for policy and practice may be to inform newly diagnosed patients of this at the outset so as to reassure and empower them.

- Be aware that generational status affects how diabetes influences British-Pakistani women's identities and self-management. Ethnicity is a more important variable for first generation immigrant British-Pakistani women.

Study Two (a qualitative interview study) asked the research question "*How does having type 2 diabetes affect British-Pakistani women's identity and how does*

*this relate to subsequent self-management?"* An important implication from this for policy and practice was that generational status (which was a proxy for age) affected to a large extent how diabetes influenced women's identities and self-management. This is because the same generation British-Pakistani women in Study Two tended to speak in the same language and faced similar challenges. First generation women talked in Urdu or Punjabi about feeling a greater uncertainty with increasing age and the development of co-morbidities; they also talked most about traditional alternative therapies. Second generation women talked in English about finding their other roles to compete with diabetes self-management, particularly paid work outside the home along with housework and the care of elderly relatives or young children. Differences between first and second generation women are a novel consideration of this work.

This suggests ethnicity was a more important variable for first generation women than it was for second generation women, suggesting first generation British-Pakistani women are more at need for services developed with consideration of their ethnicity. Advantages of tailoring an intervention to an individual's identity have been noted in the wider literature irrespective of ethnicity (Craig et al, 2008; Osborne et al, 2008; Stets et al, 2000). It is known that social comparison processes occur more frequently between similar individuals (Taylor and Lobel, 1989).

Amongst other things the tailored intervention for first generation British-Pakistani women could focus on the use of alternative therapies that were known to not be harmful, alongside the use of biomedicine. In Study Two these women had commonly spoke of the medicinal properties of eating 'kerela' (bitter gourd) or cinnamon to control symptoms of hyperglycaemia. There is empirical evidence to show both of these alternative therapies to have an effect (Krawinkel and Keding, 2006; Crawford, 2009). Acknowledgement of traditional health beliefs may empower the patients by making them feel better understood and their traditions better valued.

- Harness naturally occurring peer support groups and encourage upward social comparisons.

Similarly to the findings of Study Two, Tillotson and Smith (1996) found people with diabetes sometimes showed a reliance on family and friends for learning about the condition. They considered this to be a risky strategy because they may have limited or factually incorrect information. A further drawback would be if after such informal learning, the women considered themselves to be sufficiently knowledgeable about their condition and so did not seek further advice. On the other hand Conrad (1987) noted the advantage of collecting information from various means as resulting in patient independence, although it was accepted biomedical accuracy may become mixed. A potential implication for social and informal learning would be for interventions to harness this naturally occurring peer support group amongst high prevalence populations.

An intervention that utilises existing social support networks would have the same advantages as those noted of peer support groups in general. Peer support groups are generally effective because they provide information, and opportunities for social comparison, emotional support, and a place for patients to express their own feelings by communicating with others (Tyler and Blader, 2001). This is particularly true when there is the uncertainty of novel or stressful situations (Helgeson and Gottlieb, 2000). Through soliciting information from others, subjective uncertainty is reduced (Hogg and Terry, 2000). Another recognised benefit of belonging to social support groups is that they incorporate the patient's own cultural and social needs, more than is possible in clinical encounters with health professionals which can be greatly empowering (White and Dorman, 2001). A clear use of support groups is their provision of disease specific information (Winkelman and Choo, 2003).

Using existing social support networks would have the added advantages that even after the intervention women could continue to remind and reinforce each other's positive behaviours. Moreover, it may improve uptake of the intervention if the women were known to one another as barriers mentioned in Study One and



Study Two of transport and language limitations may be overcome, as well as issues around safety and the cultural appropriateness for women to go somewhere alone.

Furthermore, in Study Two when participants' talked about how family members managed their diabetes, the comparisons they made were largely downwards. A further implication for an intervention may be to focus on encouraging upward social comparisons. According to the social identity theory, identity can be explained in relation to the motivation of self-categorisation with groups (Terry et al, 1999; Van Knippenberg, 2000). Social comparison principles refer to how individuals compare themselves with others to evaluate their feelings and abilities particularly when they are distressed (Helgeson and Gottlieb, 2000). Such comparisons can be upwards and initiate self-improvement behaviors while downward comparisons are used to enhance self-esteem (Tyler and Blader, 2001).

Thorne and Paterson (1998) undertook a meta-analysis of the literature which revealed that the themes of research on chronic illness had shifted from suffering, loss, biographic disruption and sick role to being courageous, maintaining hope, restructuring illness, reframing and reshaping the self, regaining control, redefining health, empowerment, transformation, patient expertise and normality. The implications for policy and practice as well as the future research direction suggested by this work fit with the shift in research focus.

#### **10.4 Knowledge transfer and dissemination plans**

The dissemination of key findings upon project completion is an important final step in research (Richards, 2009). Researchers have an ethical obligation to ensure that research findings are disseminated to research participants, as well as other individuals and institutions (Chenail, 1995). It is understood that research-based knowledge needs to be conveyed to potential users groups so as to inform and influence policy and practice development. Effective knowledge transfer is achieved through communication between those who produce research-based knowledge with those who use it (Mason, 1996).

The target audiences for this work are the South-Asian population, health professionals and the wider health research community. Since the audience's needs vary it will be important for the different outputs to be tailored to using appropriate language.

A letter (in English and Urdu) will be sent to all participants from Study Two thanking them for their involvement in the study. This opportunity will be used to share key findings from the study. Participants will be given the researchers' mobile number so that they can make contact if they have any questions.

Oral and poster presentations have already been given at national and international diabetes and health literacy conferences (see list of publications, p.IV). This provided an opportunity to disseminate the research findings to audiences of both academics and health professionals. Building on this, four articles for publication are planned. The papers will present the findings of the 'views' and interventions strands from the systematic review; the qualitative primary empirical work and the exploratory health literacy study. Possible journals are being considered, these include *Health Expectations* and *Ethnicity and Health*.

## 10.5 Conclusion

This research has demonstrated health literacy to indeed be a useful conceptual framework with which to examine health inequality. This thesis has contributed to understanding in terms of the theoretical conceptualisation of Nutbeam's health literacy framework in the context of type 2 diabetes self management.

From the mixed methods systematic review, by thematically synthesising patients 'views' studies barriers and facilitators to self-management as perceived by BME patients were better understood. No existing systematic review to the researcher's knowledge had addressed this previously. From undertaking secondary analyses effectiveness of interventions according to ten different sub-sets of trials was enabled. Then, the 'views' were utilised to interrogate the findings of the effectiveness review strand, this determined the suitability of existing intervention and additionally the cross-synthesis discovered what sorts of interventions would be favourable to patients but are missing and perhaps a missed opportunity. Study two was novel in its focus on seeking the views of Pakistani women and purposively sampling for first and second generation differences.

Perhaps just as important as the question this thesis has answered is the array of important questions that it poses.

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## Appendix 3.1

### Search terms

#### Type 2 diabetes & BME & (health literacy or self-management)

Unless stated otherwise all the search terms are free text terms; MeSH stands for exploded Medical Search Term (Medline medical index search term); the dollar sign (\$) stands for any character(s); the question mark (?) = to substitute one or no characters; adj = adjacency; tw = text word.

#### Diabetes mellitus, type 2

1. diabetes mellitus, non insulin dependent [MeSH]
2. obesity in diabetes [MeSH]
3. (obes\$ adj diabetes\$) [tw]
4. insulin resistance [MeSH]
5. impaired glucose toleran\$ [tw]
6. impaired fasting glucose [tw]
7. glucose intoleran\$ [tw]
8. insulin\$ resistan\$ [tw]
9. MODY [tw]
10. dm2 [tw]
11. T2DM [tw]
12. NIDDM [tw]
13. non insulin depend\$ [tw]
14. noninsulin depend\$ [tw]
15. noninsulin?depend\$ [tw]
16. non insulin?depend\$ [tw]
17. type 2 diab\$ [tw]
18. type II diab& [tw]
19. keto\$ adj resist\$ adj diabet\$ [tw]
20. adult onset diabet\$ [tw]
21. late onset diabet\$ [tw]
22. matur\$ onset diabet\$ [tw]
23. slow onset diabet\$ [tw]
24. stabl\$ onset diabet\$ [tw]
25. metabolic\$ syndrome\$ [tw]
26. pluri?metabolic\$ syndrome\$ [tw]
27. (insulin\$ defic\$ adj relative\$) [tw]
28. or/1-27

BME

1. Minority Groups [MeSH]
2. Ethnic Groups [MeSH]
3. ethnic minorit\$ [tw]
4. Multilingualism [MeSH]
5. Refugees [MeSH]
6. Population Groups [MeSH]
7. Asian Continental Ancestry Group [MeSH]
8. South?Asian\$ [tw]
9. Asian\$ [tw]
10. Cultural Characteristics [MeSH]
11. Cross cultural comparison [MeSH]
12. Cultural competency [MeSH]
13. Cultural diversity [MeSH]
14. ((underserv\$ or disadvantag\$ or deprive\$ or inequality) adj6 (group\$ or population\$ or communit\$ or woman or mother\$ or elderly\$)) (tw) is second part necessary since such a list would not be exhaustive.
15. race [tw]
16. raci\$ [tw]
17. ethnic\$ [tw]
18. ethnic\$ adj minorit\$ [tw] NB. If have 17 do I need 18?
19. multi?ethnic\$ [tw]
20. multi?racial\$ [tw]
21. BME [tw]
22. (migrant\$ or immigrant\$) [tw]
23. refugee\$ [tw]
24. asylum seeker\$ [tw]
25. cultural diversit\$ [tw]
26. multi?lingual [tw]
27. multi?cultural [tw]
28. cross?cultural [tw]
29. trans?cultural [tw]
30. Islam [MeSH]
31. Hinduism [MeSH]
32. Buddhism [MeSH]
33. (islam\$ or muslim\$ or Moslem\$ or hindu\$ or sikh£ or buddhis\$) [tw]
34. Pakistan\$ [tw]
35. India\$ [tw]
36. Bangladesh\$ [tw]
37. Bengal\$ [tw]
38. Sri Lank\$ [tw]
39. Nepal\$ [tw]
40. or/1-37

Health Literacy

1. Health?literacy [tw]
2. Health adj litera\$ [tw]
3. Health adj informati\$ [tw]
4. Health adj knowledge [tw]
5. Health adj belie\$ [tw]
6. Health education [MeSH]
7. Health Promotion [MeSH]
8. health\$ educa\$ [tw]
9. health\$ promot\$ [tw]
10. (health adj5 (behavio?r or education\$ or promotion\$)) [tw]
11. Educated choice [tw]
12. Informed choice [tw]
13. Decision making [MeSH]
14. Informed decision making [tw]
15. Information seeking behaviour [tw]
16. Empowerment [tw]
17. Self-expression [tw]
18. Salutogenesis [tw]
19. Obtain\$ [tw]
20. Access\$ [tw]
21. Read\$ [tw]
22. Numera\$ [tw]
23. Litera\$ [tw]
24. Writ\$ [tw]
25. Speak\$ [tw]
26. Basic [tw]
27. Find [tw]
28. Seek [tw]
29. Discuss\$ [tw]
30. Comprehend\$ [tw]
31. Expos\$ [tw]
32. Understand\$ [tw]
33. Compliance [tw]
34. Adherence [tw]
35. Concordance [tw]
36. Interpre\$ [tw]
37. Competen\$ [tw]
38. Process [tw]
39. Skill [tw]
40. Communicati\$ [tw]
41. Comprehens\$ [tw]
42. Act\$ [tw]
43. Use\$ [tw]
44. Usability [tw]
45. Evaluate [t[tw]w]
46. Control [tw]

47. Responsibil\$ [tw]
48. Evaluat\$ [tw]
49. Apprais\$ [tw]
50. Analys\$ [tw]
51. Knowledg& [tw]
52. Navigat\$ [tw]
53. Pamphlets [MeSH]
54. 19 or 20 or 21 or 22 or 23 or 24 or 25 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53
55. education\$ adj 54[tw]
56. knowledg\$ adj 54[tw]
57. information adj 54 [tw]
58. advice adj 54 [tw]

### Self Management

1. disease management [MeSH]
2. blood glucose [MeSH]
3. blood glucos\$ [tw]
4. self-monitoring [tw]
5. Blood Glucose Self-Monitoring [MeSH]
6. ((blood sugar\$ or blood gluco\$) adj self-monitoring) [tw]
7. self-testing [tw]
8. Patient Care Planning [MeSH]

*(Specific synonyms reflecting lifestyle Interventions)*

9. exercise [MeSH]
10. motor activity [MeSH]
11. physical education and training [MeSH]
12. physical fitness [MeSH]
13. exercis\$ [tw]
14. exertion\$ [tw]
15. sport\$ [tw]
16. Walking [MeSH]
17. Jogging [MeSH]
18. Swimming [MeSH]
19. walking [tw]
20. jogging [tw]
21. swimming [tw]
22. physical educat\$ [tw]
23. physical fitness [tw]
24. physic\$ activ\$ [tw]
25. Life style [MeSH]
26. Health behavior [MeSH]
27. Sports [MeSH]
28. Exertion [MeSH]



29. Exercise-therapy [MeSH]
30. Nutrition therapy [MeSH]
31. nutrition\$ [tw]
32. diet therapy [MeSH]
33. behaviour therapy [MeSH]
34. behavio?r therap\$ [tw]
35. problem solving [MeSH]
36. feeding-behaviour [MeSH]
37. food [MeSH]
38. life?style [tw]
39. health\$ behav\$ [tw]
40. bicyc\$ [tw]
41. cycling [tw]
42. weight lift\$ [tw]
43. Weight lifting [MeSH]
44. gymnastic\$ [tw]
45. danc\$ [tw]
46. diabetic diet [MeSH]
47. diet [tw]
48. diet therapy [MeSH]

*(Specific synonyms reflecting lifestyle and prevention interventions: )*

49. Preventive Medicine [MeSH]
50. Preventive Health Services [MeSH]
51. (prevent\$ or prophyla\$ or avoid\$) [tw]
52. 3 or 5 or 8 or 9-59

*(General synonyms reflecting self-management: )*

53. teach\$ [tw]
54. attitud\$ [tw]
55. practice\$ [tw]
56. communicat\$ [tw]
57. education [MeSH]
58. education [tw]
59. self care [MeSH]
60. self?care [tw]
61. self?help [tw]
62. patient education [MeSH]
63. patient adj educati\$ [tw]
64. patient compliance [MeSH]
65. self efficacy [MeSH]
66. self?efficacy [tw]
67. self?efficac\$ [tw]
68. program\$ [tw]
69. evaluation [tw]
70. self?monitoring [tw]
71. self adj efficacy [tw]
72. self adj manage\$ [tw]
73. self adj monitor\$ [tw]
74. skill\$ [tw]

75. stages adj change [tw]
76. peer support [tw]
77. social support [MeSH]
78. ((Patient\$ or consumer\$ or client\$ or peer\$) adj train\$) [tw]
79. ((Patient\$ or consumer\$ or client\$ or peer\$) adj teach\$) [tw]
80. ((Patient\$ or consumer\$ or client\$ or peer\$) adj instruct\$) [tw]
81. ((Patient\$ or consumer\$ or client\$ or peer\$) adj skill\$) [tw]
82. (Lay adj (Led or Run or Expert\$ or Worker\$ or advisor\$ or consultant\$ or leader\$ or educator\$ or tutor\$ or instructor\$)) [tw]
83. (Layperson\$ or Lay adj Person\$) [tw]
84. Expert adj patient [tw]
85. peer\$ [tw]
86. peer adj group [tw]
87. peer?group [tw]
88. peer group [MeSH]
89. (volunteer\$ near train\$ or aide\$) [tw]
90. (volunteer adj worker\$) [tw]
91. (voluntary adj worker\$) [tw]
92. (user adj led) [tw]
93. EPP
94. X-pert

## **Appendix 3.2**

**Critical appraisal tool (Intervention strand)**

**Critical appraisal tool ('Views' strand)**

**CRITICAL APPRAISAL FORM (INTERVENTIONS)**

	ID of paper	
DE	Bibliographic details	Author, title, source, year, funding body
DE	Review date	
DE	Include paper?	Y/N
	COMMENTS	

*Purpose*

DE	What are the aims of this paper?	
DE	If the paper is part of a wider study what are its aims?	
QA	Have the aims been clearly stated?	Y/N/U
DE	What is the study rationale?	
QA	Is the rationale explicitly articulated?	Y/N/U
	COMMENTS	

*Setting*

DE	Within what geographical and care setting is the study carried out?	
QA	Is the setting appropriate and/or sufficiently specific for examination of the research question?	Y/N/U
	COMMENTS	

*Theoretical Framework*

DE	Is there a theoretical framework?	Y/N/U/N-A
DE	What theoretical framework guides/informs the study?	
	COMMENTS	

DE	What type of self-management behaviour is explored?	Drugs, exercise, diet, health service use, blood monitoring, other
DE	Is there a stated measure of self-management?	Y/N/U/N-A
DE	What is it?	
QA	Is there a clear description of the self-management behaviour?	Y/N/U
	COMMENTS	

*Methods*

DE	What is the study design?	Randomised controlled trial (RCT), cluster RCT, Controlled clinical trial (CCT) Controlled before and after study (CBA), Interrupted time series (ITS), cross sectional, prospective, quasi-experimental, cohort, case-study.
DE	Over what time period is the data collected? (Start of recruitment to follow-up.)	
	COMMENTS	

*Sample*

DE	What was the recruitment procedure (E.g. events, persons, times and settings- procedure question)?	
DE	What was the sampling procedure?	Theoretically informed, purposive, convenience, chosen to explore contrasts, random, consecutive-design question.
DE	What were the inclusion criteria?	
DE	What were the exclusion criteria?	
DE	Over what period were participants recruited?	
DE	What were the participation rates?	

DE	What was the size of the study sample, and of any separate groups?	
QA	Was a sample size calculation done?	Y/N/U/N-A
QA	Was the target sample achieved?	Y/N/U
DE	What are the key demographic variables?	Age/gender/education level/ethnicity etc.
QA	Is the sampling procedure appropriate to the study aims?	Y/N/U
DE	Is recruitment data provided?	Y/N/U
QA	Is attrition data provided?	Y/N/U/N-A
QA	Was follow-up 80%+?	Y/N/U/N-A
	COMMENTS	

*Intervention*

DE	Was there a control/comparison group?	Y/N/U/N-A
QA	Were participants randomly allocated to groups?	Y/N/U/N-A
QA	Was there concealment of allocation to groups?	Y/N/U/N-A
	COMMENTS	

DE	What was the intervention?	Diet, physical activity, medication adherence, service use, other.
DE	How long was the duration of the intervention?	
DE	How was the intervention delivered?	
DE	By whom was the intervention delivered?	
DE	To whom was the intervention aimed?	
DE	What was the comparison intervention?	(N-A if 'control' or 'usual care')
DE	How long was the duration of the comparison intervention?	
DE	How was the comparison intervention delivered?	
DE	By whom was the comparison intervention delivered?	
DE	To whom was the comparison intervention aimed?	
QA	Is there sufficient detail given of the nature of the intervention and the comparison intervention?	Y/N/U
	COMMENTS	

*Data collection (quantitative)*

DE	What data collection methods are used to obtain and record information on appropriateness/effectiveness of interventions? (For	Questionnaire, interview, focus group, etc, other.
----	--	--



	example, provide insight into data collected, appropriateness and availability for independent analysis)	
DE	Detail on data collection methods	
QA	Is the process of data collection adequately described?	Y/N/U
QA	Are data collected blind?	Y/N/U/N-A
	COMMENTS	

DE	DE	DE	DE		DE	
Outcome measures used to identify effectiveness/ appropriateness of interventions	How measured	When measured	Valid measure	Comment	Reliable measure	Comment
			Y/N/U		Y/N/U	
			Y/N/U		Y/N/U	
			Y/N/U		Y/N/U	

*Data collection (qualitative)*

DE	What data collection methods are used to obtain and record patient's views?	Questionnaire, interview, focus group, etc, other.
DE	Detail on data collection methods	
QA	Is the information collected with sufficient detail and depth to provide insight?	Y/N/U
QA	Is the process of fieldwork adequately described?	Y/N/U/N-A
	COMMENTS	

*Data Analysis (quantitative)*

DE	How were the data analysed?	
DE	Unit of allocation/randomisation (i.e. who or what was allocated to study groups)	Patient/Provider/Practice/Institution/Community/Firm/Clinic day/Other (specify)/Unclear
DE	Unit of analysis (i.e. results analysed as events per practice. Can be more than one)	Patient/Provider/Practice/Institution/Community/Firm/Clinic day/Other (specify)/Unclear
QA	Was there an adequate description of data analysis methods?	Y/N/U
QA	Is there justification for the data analysis methods reported?	Y/N/U

QA	If there is multiple testing/many outcome measures, are these accounted for in the analysis/commentary? (Type 1 error.)	Y/N/U/N-A
QA	Was there an intention to treat analysis? (Included participants in analysis despite whether they dropped out. Common in RCT type designs.)	Y/N/U/N-A
QA	If more than one group was analysed, were the groups comparable before the intervention?	Y/N/U/N-A
QA	In what respects were they comparable and in what were they not?	
QA	Does the analysis adjust for confounding variables?	Y/N/U/N-A
DE	How were important confounding variables controlled (e.g. matching, randomisation, in the analysis stage)?	
QA	Was this adjustment adequate to justify the author's conclusions?	Y/N/U/N-A
	COMMENTS	

*Data Analysis (qualitative)*

DE	How were the data analysed?	
QA	Was there an adequate description of data analysis methods?	Y/N/U/N-A

QA	Was the reliability and validity of data analysis methods reported? (E.g. includes original data extracts; evidence of iterative analysis; efforts to establish validity - searching for negative evidence, use of multiple sources, data triangulation; reliability/consistency over researchers, check interpretations with informants.)	Y/N/U/N-A
QA	Is there evidence of reflexivity, that is, providing insight into the relationship between the researcher, setting, data production and analysis?	Y/N/U/N-A
	COMMENTS	

*Findings*

DE	What are the key findings?	
DE	Is there a stated measure of health literacy?	Y/N/U/N-A
DE	What is it?	
DE	Is the level of health literacy defined?	Y/N/U/N-A
DE	More detail on defining health literacy	
DE	Is health literacy mapped onto levels?	Y/N/U/N-A
DE	What level of health literacy do the interventions map?	

	COMMENTS	
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EFFECTIVENESS

QA	Are findings reported for all outcomes?	Y/N/U/N-A
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	COMMENTS			
DE	Outcome	Before	After	Comments

APPROPRIATENESS

DE	Examples of what worked well	
DE	Why was this successful?	
DE	For whom was this successful?	
DE	Examples of what did not work	
DE	Why did these hinder success?	

DE	For whom did these hinder success?	
DE	Was this intervention acceptable to patients?	Y/N/U/N-A
	COMMENTS	

*Implications*

QA	Are the findings interpreted within the context of other studies and theory?	Y/N/U
DE	What are the implications for policy/ service practice?	
QA	Was there any consumer involvement?	Y/N/U
QA	Are the strengths and limitations of the study identified?	Y/N/U
QA	Is the conclusion justified given the conduct of the study? (For example, sampling procedure; measure of outcome used and results achieved.)	Y/N/U
	COMMENTS	

	OVERALL COMMENTS	
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**CRITICAL APPRAISAL FORM (VIEWS)**

Qualitative	X
Mixed methods	

	ID of paper	
DE	Bibliographic details	
DE	Review date	
DE	Include paper?	Y
	COMMENTS	

*Purpose*

DE	What are the aims of this paper?	
DE	If the paper is part of a wider study what are its aims?	
QA	Have the aims been clearly stated?	Y/N/U
DE	What is the study rationale?	

QA	Is the rationale explicitly articulated?	Y/N/U
	COMMENTS	

*Setting*

DE	Within what geographical and care setting is the study carried out?	
QA	Is the setting appropriate and/or sufficiently specific for examination of the research question?	Y/N/U
	COMMENTS	

*Theoretical Framework*

DE	Is there a theoretical framework?	Y/N/U/N-A
DE	What theoretical framework guides/informs the study?	N-A
	COMMENTS	

DE	What type of self-management behaviour is explored?	Drugs, exercise, diet, health service use, blood monitoring, other
DE	Describe other	



DE	Is there a stated measure of self-management?	Y/N/U/N-A
DE	What is it?	
QA	Is there a clear description of the self-management behaviour?	Y/N/U
	COMMENTS	

*Sample*

DE	What was the recruitment procedure (E.g. events, persons, times and settings- procedure question)?	
DE	What was the sampling procedure?	Theoretical informed, purposive, convenience, chosen to explore contrasts, random, consecutive-design question.
DE	What were the inclusion criteria?	
DE	What were the exclusion criteria?	
DE	What were the participation rates?	
DE	What was the size of the study sample, and of any separate groups?	
QA	Was the target sample achieved?	Y/N/U
DE	What are the key demographic variables?	

QA	Is the sampling procedure appropriate to the study aims?	Y/N/U
QA	Is recruitment data provided?	Y/N/U
QA	Is drop-out data provided?	Y/N/U
	COMMENTS	

*Data collection (qualitative)*

DE	What is the study design?	Longitudinal, cross sectional.
DE	What data collection methods are used to obtain and record patient's views?	Questionnaire, interview, focus group, observation, other.
DE	Detail on data collection methods	
QA	Is the information collected with sufficient detail and depth to provide insight into the meaning and perceptions of informants?	Y/N/U
QA	Is the process of fieldwork adequately described? (E.g. account of how data was elicited; type and range of questions; interview guide; length and timing of observation work; note taking)	Y/N/U
	COMMENTS	

*Data Analysis (qualitative)*

DE	How were the data analysed?	
QA	Was there an adequate description of data analysis methods?	Y/N/U
QA	Was the reliability and validity of data analysis methods reported? (E.g. includes raw/original data extracts; evidence of iterative analysis; representative evidence presented; efforts to establish validity such as searching for negative evidence, use of multiple sources, data triangulation; reliability/consistency over researchers, time and settings; check interpretations with informants.)	Y/N/U
QA	Is there evidence of reflexivity, that is, providing insight into the relationship between the researcher, setting, data production and analysis?	Y/N/U
	COMMENTS	

*Findings*

DE	What are the key findings?	
DE	Is 'health literacy' explicitly stated?	Y/N

DE	Are there any identified barriers to good self-management?	Y/N/U/N-A
DE	What are they?	
DE	Are there any identified facilitators of good self-management?	Y/N/U/N-A
DE	What are they?	
	COMMENTS	

*Implications*

QA	Are the findings interpreted within the context of other studies and theory?	Y/N/U
DE	What are the implications for policy/ service practice?	
QA	Was there any consumer involvement?	Y/N/U
QA	Are the strengths and limitations of the study identified?	Y/N/U
QA	Is the conclusion justified given the conduct of the study?	Y/N/U
	COMMENTS	

	OVERALL COMMENTS	
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## **Appendix 4.1**

### **Characteristics of interventions**

1 Agurs-Collins et al, 1997	
Stated aim	To evaluate a weight loss and exercise program designed to improve diabetes management in older African-Americans.
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Hospital</p> <p><u>Frequency and duration of intervention:</u> First 3 months, counselling was provided at 12 weekly group sessions with 8-10 participants (60 min of nutrition education followed by 30 min exercise). One individual diet counselling session during this period. Six biweekly group sessions were offered during the subsequent three months. All group sessions were 90 minutes long. Biweekly sessions were less didactic and more sharing and problem solving than the initial weekly sessions.</p> <p><u>How intervention delivered:</u> Weight loss and exercise programme. Each participant received an individualised weight reduction diet. Nutrition classes were based on prior quail research materials reflecting language, social values and situations relevant to older Americans of African-Americans and covered: relationship of food and physical activity to body weight, insulin activity and blood glucose; carbohydrate and fat in meal planning; food shopping; label reading; recipe modification; food selection in restaurants and creative cooking characteristic to African-American communities. Exercise component of the classes consisted of a 5-minute warm up, 20 minute of low impact aerobic activity and 5 minute of cool down exercises. Participants were encouraged to exercise 2 additional days on their own and to increase physical activity in daily routines.</p> <p>Each session focused on a limited number of concepts to prevent information overload. Each participant received a program outline of topics, in large print and easy to read, to be covered and handouts in class.</p> <p>Group setting provided social interaction and peer support, participants encouraged to bring significant others to class. To</p>

	<p>foster group identity, participants developed a name for themselves POSSE, t-shirts with this were distributed to all.</p> <p><u>Intervention delivered by whom:</u> African-American registered dietician and exercise physiologist.</p> <p><u>Control:</u> Usual care. Attended one class within three weeks of enrolment related to glycaemic control and received two mailings of nutritional information at three and six months.</p>
Participants	<p>Older African-American participants (100%).</p> <p><u>How recruited:</u> Through clinics and community outreach.</p> <p><u>Inclusion criteria:</u> &gt;55 yrs, diagnosis NIDDM, &gt;120% of metropolitan weight standards, had HbA1c levels &gt;8%, were ambulatory and had no medical contraindications to program participation.</p> <p><u>Exclusion criteria:</u> None stated</p> <p><u>Number of participants:</u> 64</p> <p><u>Participation rates:</u> 64 of 198</p> <p><u>Sample size calculated:</u> Y</p> <p><u>Target sample achieved:</u> N</p>
Outcomes	<p><u>Primary outcomes:</u> Weight, blood pressure, lipids, HbA1c.</p> <p><u>Secondary outcomes:</u> Physical activity, nutrition knowledge and dietary components.</p>

<b>2 Anderson et al, 2005</b>	
Stated aim	To evaluate the impact of a problem-based empowerment patient education program specifically tailored for urban African Americans with type 2 diabetes.
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Community</p> <p><u>Frequency and duration of intervention:</u> A program consisting of six weekly two-hour group sessions. Followed by monthly support groups employing same process as weekly sessions.</p>

	<p>Patients could select phone follow-up instead. Where they received individual monthly phone calls.</p> <p><u>How intervention delivered:</u> The interventions include the development and evaluation of: 1) Effective methods and materials for use in diabetes education; 2) Culturally specific educational materials and community-based programs for urban African-Americans with diabetes and 3) the empowerment approach to facilitating self-directed behaviour change for persons with diabetes.</p> <p>At session 1, patient's were given their HbA1c, lipids, BP and weight evaluations in writing with handouts {HL} that provided basic information about normal values and five to eight behaviours that effect these. Patients were given a few minutes to review own data and then educators spent the next two hours answering patients questions about the meaning of their values and their risk for short-term and long-term complications. Patient identified problems became the focus of guided problem-solving discussions based on empowerment approach to facilitate self-directed behaviour change. Educators provided short answers (not lectures) which facilitated a lively iterative process.</p> <p>Sessions 2-6 began with a group discussion of self-management experiments tried by the participants during the preceding week. After a discussion, new questions were addressed. Kept careful records to ensure all diabetes-related topics required by the national diabetes education standards were covered in the six-week program.</p> <p><u>Intervention delivered by whom:</u> Nurse and a dietician</p> <p><u>Control:</u> Wait listed control group</p>
<p>Participants</p>	<p>Urban African-Americans (96%)</p> <p><u>How recruited:</u> Community outreach. Interested participants invited to group enrolment. Then patients decide if they want to join.</p> <p><u>Inclusion criteria:</u> Information not given.</p> <p><u>Exclusion criteria:</u> Information not given.</p>



	<p><u>Number of participants:</u> 239</p> <p><u>Participation rates:</u> Information not given.</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
Outcomes	<p><u>Primary outcomes:</u> Clinical measures, D2 (type 2 diabetes) empowerment scale, seriousness of D2 scale</p> <p><u>Secondary outcomes:</u> None stated</p>

**3 Anderson-Loftin et al, 2005**

Stated aim	To test effects of a culturally competent, dietary self-management intervention on physiological outcomes and dietary behaviours for African Americans with type 2 diabetes
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Primary physician</p> <p><u>Frequency and duration of intervention:</u> Four weekly, 1½-hour classes emphasized planning, purchasing, and preparing healthy low-fat meals and making healthy choices when eating away from home. Four monthly 1-hour peer-professional discussion groups provided professional group education with peer discussion. Weekly telephone follow-up by the nurse case manager was used for additional educational support, early identification of complications, problem solving, and help in making informed choices.</p> <p><u>How intervention delivered:</u> Culturally competent educational classes in low-fat dietary strategies, peer-professional group discussions, and follow-up by a nurse case manager. Participants were taught to make healthy, low-fat food choices using ethnic food models. Because of low literacy levels in the target population, focusing on 1 major dietary concept improved chances for success by simplifying the intervention and behavioural change required. In black cultural traditions, meals are social events with friends and family. Therefore, a traditional African American meal prepared with low-fat techniques and</p>

	<p>ingredients was served to participants and family members following most classes.</p> <p><u>Intervention delivered by whom:</u> Educational classes were taught by a local registered dietician with experience in nutrition therapy for rural black southerners with diabetes.</p> <p><u>Control:</u> Usual care</p>
Participants	<p>African-Americans (100%)</p> <p><u>How recruited:</u> Referred by physician.</p> <p><u>Inclusion criteria:</u> (1) African American, (2) medical diagnosis of type 2 diabetes, (3) aged 18 or older, (4) no mental or physical limitations that would preclude participation in group activities and discussion, and (5) at least one indicator of diabetes complications defined as high risk and modifiable by diet</p> <p><u>Exclusion criteria:</u> Not stated</p> <p><u>Number of participants:</u> 97</p> <p><u>Participation rates:</u> 97 of 242</p> <p><u>Sample size calculated:</u> Y</p> <p><u>Target sample achieved:</u> Y</p>
Outcomes	<p><u>Primary outcomes:</u> Physiological (HbA1c, lipids, BMI) and dietary behaviours</p> <p><u>Secondary outcomes:</u> Medication history, diabetes education and exercise.</p>

<b>4 Baradaran et al, 2006</b>	
Stated aim	To develop a culturally appropriate educational intervention programme for South Asians with D2. Then investigated whether this intervention could produce an improvement.
Interventions	<p><u>Country:</u> Scotland</p> <p><u>Setting:</u> Day care centres and three general practices.</p> <p><u>Frequency and duration of intervention:</u> The educational intervention consisted of three sessions, one dietician-led</p>

	<p>sessions of about one hour's duration, and one podiatrist-led session of about one and a half hours' duration. They were carried out and completed within three months.</p> <p><u>How intervention delivered:</u> The format of the educational programme was based on group education; the size of each group being between 6 and 12. Learning process in the groups was a combination of didactic elements (lecture) and interactive group discussion. During classes patients were asked to discuss some of their experiences and problems. Then the educator explained issues relevant to diabetes.</p> <p>The educators also used some simple support material including visual aids, food examples. Additionally some booklets and leaflets about diabetes, diet and foot care, translated into Urdu, Punjabi and Hindi, provided by Diabetes UK, were given to each patient after each session. Furthermore the educational team used an information video (25 minutes) in the second session which was recorded in their language.</p> <p><u>Intervention delivered by whom:</u> Educators able to speak Punjabi, the preferred language that most patients speak at home.</p> <p><u>Control:</u> Routine care</p>
<p>Participants</p>	<p>South Asian (100%)</p> <p><u>How recruited:</u> South Asian people were identified from day care centres catering for significant numbers of ethnic minorities, and three general practices which had more than 70% of their patients from different ethnic minority groups. Letters were sent to all individuals via their general practitioner and/or day care staff inviting them to participate in this study. If there was no response, patients were telephoned by the relevant care staff.</p> <p><u>Inclusion criteria:</u> South Asian people (defined as anyone of Indian subcontinent origin, whether from Pakistan, India, Bangladesh or Sri Lanka) with Type 2 diabetes over the age of 30 years.</p> <p><u>Exclusion criteria:</u> None stated</p> <p><u>Number of participants:</u> 118</p>

	<p><u>Participation rates:</u> 118 of 299</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
Outcomes	<p><u>Primary outcomes:</u> Knowledge</p> <p><u>Secondary outcomes:</u> Attitude toward seriousness and complications, Practice. (All outcomes measured using one questionnaire)</p>

<b>5 Borges et al, 2008</b>	
Stated aim	To determine whether a 15-minute intervention which was culturally and linguistically appropriate would improve foot self-care knowledge and behaviours in adult patients with D2.
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Emergency departments</p> <p><u>Frequency and duration of intervention:</u> a-15-min b-5-min</p> <p><u>How intervention delivered:</u> a- Brief foot self-care intervention. that used educational and behavioral strategies, designed to increase self-efficacy for foot self-care and ultimately change foot self-care behaviors. b- Foot risk assessment using a monofilament, designed to encourage patients' involvement in assessing their feet.</p> <p><u>Intervention delivered by whom:</u></p> <p><u>Control:</u> Control group- no other details provided.</p>
Participants	<p>Hispanic (70%+)</p> <p><u>How recruited:</u> Emergency department patients who met the inclusion criteria were offered the opportunity to participate in the study.</p> <p><u>Inclusion criteria:</u> 40 years of age or older, resided within the county, had a diagnosis of type 2 diabetes, were triaged as nonemergent, and agreed to a home visit.</p> <p><u>Exclusion criteria:</u> Those triaged as emergent, those with active foot ulceration or other foot pathology, or those who were unable</p>

	<p>to communicate verbally.</p> <p><u>Number of participants:</u> 167</p> <p><u>Participation rates:</u> 167 of 226</p> <p><u>Sample size calculated:</u> Y</p> <p><u>Target sample achieved:</u> Y</p>
Outcomes	<p><u>Primary outcomes:</u> Self-efficacy scale; summary of self-care activities; self care observation guide; acculturation; foot self-care knowledge</p> <p><u>Secondary outcomes:</u> None stated</p>
Other notes	3 arm intervention

<b>6 Brown et al, 2002</b>	
Stated aim	To determine the effects of a culturally competent diabetes self-management intervention in Mexican Americans with type 2 diabetes.
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Community</p> <p><u>Frequency and duration of intervention:</u> 52 contact hours over 12 months.</p> <p><u>How intervention delivered:</u> 3 months of weekly 2-h instructional sessions on nutrition, self-monitoring of blood glucose, exercise, and other self-care topics and 6 months of biweekly plus 3 months of monthly 2-h support group sessions to promote behaviour changes through problem-solving and food preparation demonstrations. The intensive instructional and support group intervention was provided in the preferred language.</p> <p><u>Intervention delivered by whom:</u> Bilingual Mexican American nurses, dietitians, and community workers from Starr County.</p> <p><u>Control:</u> 1 year waitlist control with usual care.</p>
Participants	Low income Mexican-Americans (100%)

	<p><u>How recruited:</u> Rosters of ongoing studies.</p> <p><u>Inclusion criteria:</u> 35 to 70 years of age and (2) diagnosed with type 2 diabetes. Each subject identified a family member (preferably a spouse), first-degree relative, or close friend to participate as a support person.</p> <p><u>Exclusion criteria:</u> Pregnancy or medical conditions for which changes in diet and walking were contraindicated (eg, renal failure).</p> <p><u>Number of participants:</u> 256</p> <p><u>Participation rates:</u> Information not provided.</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
Outcomes	<p><u>Primary outcomes:</u> D2 related knowledge, health beliefs, HbA1c, FBG, lipids, BMI.</p> <p><u>Secondary outcomes:</u> None stated.</p>

<b>7 Brown et al, 2005</b>	
Stated aim	To compare two culturally competent diabetes self-management interventions designed for Mexican Americans: "extended" (24 h of education, 28 h of support groups) and "compressed" (16 h of education, 6 h of support groups).
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Community</p> <p><u>Frequency and duration of intervention:</u> Compressed 22hr intervention: 8 weekly sessions &amp; 3 support group sessions</p> <p><u>How intervention delivered:</u> (1) weekly instructional sessions on nutrition, home glucose monitoring, exercise, and other self-care topics and (2) support group sessions to promote behavioural changes through problem solving, goal setting, and food preparation demonstrations. The compressed intervention was strengthened over the original extended intervention by increasing nutritional content and adding Spanish-language</p>

	<p>videotapes and other educational materials.</p> <p><u>Intervention delivered by whom:</u> Offered in Spanish by local bilingual Mexican American nurses, dieticians, and community workers.</p> <p><u>Control:</u> Extended 52hr intervention: 12 weekly sessions and 14 biweekly support group sessions.</p>
Participants	<p>Low income Mexican-Americans (100%)</p> <p><u>How recruited:</u> Rosters of ongoing studies.</p> <p><u>Inclusion criteria:</u> 35 to 70 years of age and (2) diagnosed with type 2 diabetes. Each subject identified a family member (preferably a spouse), first-degree relative, or close friend to participate as a support person.</p> <p><u>Exclusion criteria:</u> Pregnancy or medical conditions for which changes in diet and walking were contraindicated (e.g., renal failure).</p> <p><u>Number of participants:</u> 216</p> <p><u>Participation rates:</u> Information not given</p> <p><u>Sample size calculated:</u> Y</p> <p><u>Target sample achieved:</u> Y</p>
Outcomes	<p><u>Primary outcomes:</u> HbA1c, FBG, D2 knowledge</p> <p><u>Secondary outcomes:</u> None stated</p>

<b>8 Brown et al, 2007</b>	
Stated aim	To compare two culturally competent diabetes self-management interventions designed for Mexican Americans: "extended" (24 h of education, 28 h of support groups) and "compressed" (16 h of education, 6 h of support groups).
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Community</p> <p><u>Frequency and duration of intervention:</u> Compressed 22hr</p>

	<p>intervention: 8 weekly sessions &amp; 3 support group sessions</p> <p><u>How intervention delivered:</u> (1) weekly instructional sessions on nutrition, home glucose monitoring, exercise, and other self-care topics and (2) support group sessions to promote behavioural changes through problem solving, goal setting, and food preparation demonstrations. The compressed intervention was strengthened over the original extended intervention by increasing nutritional content and adding Spanish-language videotapes and other educational materials.</p> <p><u>Intervention delivered by whom:</u> Offered in Spanish by local bilingual Mexican American nurses, dieticians, and community workers.</p> <p><u>Control:</u> Extended 52hr intervention: 12 weekly sessions and 14 biweekly support group sessions.</p>
Participants	<p>Low income Mexican-Americans (100%)</p> <p><u>How recruited:</u> Rosters of ongoing studies.</p> <p><u>Inclusion criteria:</u> 35 to 70 years of age and (2) diagnosed with type 2 diabetes. Each subject identified a family member (preferably a spouse), first-degree relative, or close friend to participate as a support person.</p> <p><u>Exclusion criteria:</u> Pregnancy or medical conditions for which changes in diet and walking were contraindicated (e.g., renal failure).</p> <p><u>Number of participants:</u> 216</p> <p><u>Participation rates:</u> Information not given</p> <p><u>Sample size calculated:</u> Y</p> <p><u>Target sample achieved:</u> Y</p>
Outcomes	<p><u>Primary outcomes:</u> Health beliefs</p> <p><u>Secondary outcomes:</u> HbA1c</p>

<p><b>9 Clancy et al, 2007</b></p>	
Stated aim	To evaluate patients' perceptions of specific primary care



	<p>domains such as ongoing care, coordination of services, comprehensiveness of care, cultural competency of care delivered, community orientation, and diabetes-specific loci of control.</p>
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Primary care centre</p> <p><u>Frequency and duration of intervention:</u> After provider training and baseline data collection, patients randomized to group visits were divided into 6 groups that met monthly for 12 months, each consisting of 14 to 17 patients. Group visits, meant to be the patients' main source of primary medical care.</p> <p><u>How intervention delivered:</u> Participating physicians and nurses received on-site training by a senior internist who previously conducted group visit training.</p> <p>Group visit scheduling allowed for 2 hours: 10 to 15 minutes for warmup and socialization, 30 to 45 minutes for an interactive discussion of a health-related topic, and 60 minutes for one-on-one consultations with the physician.</p> <p>Group visit content was guided by the patients and directed by the physicians to cover educational topics included in the core curriculum such as nutrition, exercise, foot care, medication, complications and the emotional aspects of diabetes.</p> <p><u>Intervention delivered by whom:</u> Co-led by 1 of 6 primary care internal medicine physicians and 1 of 3 registered nurses in the clinic.</p> <p><u>Control:</u> Usual care</p>
Participants	<p>African-American (83%)</p> <p><u>How recruited:</u> A pool of more than 2000 patients were identified through a query of the APCC electronic medical record. Identified patients were invited to participate through telephone or on-site solicitation.</p> <p><u>Inclusion criteria:</u> Aged <math>\geq</math>18 years with a diagnosis of type 2 diabetes and an HbA1c level <math>\geq</math>8.0%.</p>

	<p><u>Exclusion criteria:</u> Primary diagnosis of substance abuse or dependence, current pregnancy, dementia, inability to hear, inability to speak English, or lack of transportation to the clinic.</p> <p><u>Number of participants:</u> 186</p> <p><u>Participation rates:</u> 186 of 506</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
Outcomes	<p><u>Primary outcomes:</u> Patient satisfaction in underserved communities; survey evaluating patient's sense of control; scale evaluating patients perceptions of physicians dependability.</p> <p><u>Secondary outcomes:</u> None stated</p>

<b>10 Clancy et al, 2006</b>	
Stated aim	To evaluate the effect of group visits on clinical outcomes, concordance with 10 American Diabetes Association (ADA) guidelines
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Primary care centre</p> <p><u>Frequency and duration of intervention:</u> Monthly for 1 yr. Each group visit scheduled for 2 hours: 10-15 minutes for warm-up &amp; socialisation, 30-45min for interactive discussion of health related topics such as foot care or healthy eating strategies &amp; 60 min for one-on-one physician consultation</p> <p><u>How intervention delivered:</u> Patients randomised to group visits were divided into 6 cohorts, 14-17 pts ea. Cohorts met on a different floor in the same evening as clinic. One-on-one visits available for care needed between scheduled group visits or for medical needs not amenable to group visits. Group visit content, although patient-guided, was physician-directed to cover educational topics included in the core curriculum such as nutrition, exercise, foot care, medications, complications of diabetes, and the emotional aspect of diabetes.</p> <p><u>Intervention delivered by whom:</u> 1 of 6 primary care physician</p>

	<p>and 1 of 3 nurses. All trained in intervention.</p> <p><u>Control:</u> Usual care</p>
Participants	<p>Disadvantaged population (80+% Black).</p> <p><u>How recruited:</u> Identified eligible participants from hospital records. Interviewer invited them to participate through telephone or on-site using script.</p> <p><u>Inclusion criteria:</u> &gt;18 yrs with poorly controlled diabetes mellitus (HbA1c&gt;8%)</p> <p><u>Exclusion criteria:</u> Diagnosis of substance use, pregnant, dementia, inability to hear, speak English or obtain transportation to clinic.</p> <p><u>Number of participants:</u> 186</p> <p><u>Participation rates:</u> Information not given</p> <p><u>Sample size calculated:</u> Y</p> <p><u>Target sample achieved:</u> Y</p>
Outcomes	<p><u>Primary outcomes:</u> HbA1c, lipids and blood pressure.</p> <p><u>Secondary outcomes:</u> None stated.</p>

<b>11 Gary et al, 2003</b>	
Stated aim	To determine whether multifaceted, culturally sensitive, primary care-based behavioural interventions implemented by a nurse case manager and/or a community health worker could improve indicators of diabetic control In a sample of African-Americans.
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Medical centre</p> <p><u>Frequency and duration of intervention:</u> Until 2-year assessment.</p> <p><u>How intervention delivered:</u></p> <p><i>Nurse case manager intervention</i> 45-min face-to-face clinic visits and/or telephone contacts. Coordinated care according to the American Diabetes Association (ADA) Clinical Practice</p>

	<p>Recommendations. She provided direct patient care, management, education, counselling, follow-up, referrals, and physician feedback and prompting, which included advising regimen changes and implementing changes under physician's orders. Approximately three visits three times per year, plus additional contacts as needed.</p> <p><i>Community health worker intervention</i> 45-60-min face-to-face home visits and/or telephone contacts. Unlike the NCM, the CHW did not directly implement therapeutic strategies (e.g., recommend change in medication doses). CHW facilitated preventive care by offering to schedule appointments and visits, along with providing education. Main responsibilities were to monitor participant and family behaviour, reinforce adherence to treatment recommendations, mobilize social support, and provide physician feedback, which included reporting on identifiable problems such as high blood pressure readings or dietary habits. Approximately three visits three times per year, plus additional contacts as needed.</p> <p><i>Combined NCM/CHW intervention</i> Combined the individual activities. Additionally, the two interventionists conducted biweekly conferences to coordinate interventions and promote synergy.</p> <p><u>Intervention delivered by whom:</u></p> <p><i>Nurse case manager intervention</i> Registered nurse.</p> <p><i>Community health worker intervention</i> Local high school graduate who was enrolled in college part time and had no previous formal health care training.</p> <p><i>Combined NCM/CHW intervention</i> NCM and CHW.</p> <p><u>Control:</u> Usual medical care only.</p>
<p>Participants</p>	<p>Urban African-Americans (100%)</p> <p><u>How recruited:</u> Reviewed medical charts for eligible participants and invited them to participate in the study.</p> <p><u>Inclusion criteria:</u> Age (35-75), African American ancestry, presence of D2 and residence in East Baltimore. Received</p>

	<p>primary care within the previous year.</p> <p><u>Exclusion criteria:</u> Co-morbid conditions (e.g., cancer, AIDS) or indication of end-stage complications of diabetes (kidney dialysis, blindness or amputation).</p> <p><u>Number of participants:</u> 186</p> <p><u>Participation rates:</u> 186 of 822</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
Outcomes	<p><u>Primary outcomes:</u> HbA1c</p> <p><u>Secondary outcomes:</u> Lipid profile, blood pressure. Dietary practices and physical activity levels assessed through questionnaire.</p>

<b>12 Gregg et al, 2007</b>	
Stated aim	<p>To apply an acceptance approach to coping with diabetes. Acceptance and commitment therapy attempts to teach individuals to experience their thoughts and feelings rather than attempting to alter or stop them. Individuals are asked to work toward those goals and values they hold while experiencing their thoughts and feelings.</p>
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Community health centre</p> <p><u>Frequency and duration of intervention:</u> A workshop based on an ACT manual covered each of the above educational topics in an abbreviated form (approx 4 hr), plus mindfulness and acceptance training.</p> <p><u>How intervention delivered:</u> Mindfulness and acceptance training was regarding difficult thoughts and feelings about diabetes, exploration of personal values related to diabetes, and a focus on the ability to act in a valued direction while contacting difficult experiences.</p> <p><u>Intervention delivered by whom:</u> The workshop was led by the</p>

	<p>author of the manual.</p> <p><u>Control:</u> A 7 hour workshop that followed a patient education manual</p>
Participants	<p>Low income DII patients. 10% African-American; 28% Hispanic; Asian pacific-Islander 30%; Arabic 4%, Other 4% (Caucasian 24%; Native-American 1%)</p> <p><u>How recruited:</u> English-speaking participants with Type 2 diabetes receiving medical care at a low-income community health center and referred to diabetes education by their primary care provider</p> <p><u>Inclusion criteria:</u> English-speaking participants with Type 2 diabetes receiving medical care at a low-income community health center. (HL issue)</p> <p><u>Exclusion criteria:</u> no exclusion criteria based on psychiatric, medical, or substance use disorders</p> <p><u>Number of participants:</u> 81</p> <p><u>Participation rates:</u> 81 of 106</p> <p><u>Sample size calculated:</u> Y</p> <p><u>Target sample achieved:</u> Y</p>
Outcomes	<p><u>Primary outcomes:</u> HbA1c</p> <p><u>Secondary outcomes:</u> Self-management score, understanding of D2 and satisfaction with treatment all based on scales.</p>

<b>13 Gucciardi et al, 2007</b>	
Stated aim	To determine the impact of two culturally competent education methods (individual counselling only and individual counselling in conjunction with group education) on nutrition adherence and glycaemic control in Portuguese Canadian adults with D2 and to compare and explain differences in outcomes between the two groups using the Theory of Planned Behaviour.
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Hospital Diabetes Education Centre</p>

	<p><u>Frequency and duration of intervention:</u> 15 hrs over three consecutive days.</p> <p><u>How intervention delivered:</u> Group classes included approximately five to eight patients. Various teaching methods included didactic methods, mutual goal setting, situational problem solving, cognitive reframing and role-playing. One key component of group education is nutrition therapy (six hours) which is predominantly interactive and sensory-stimulating. Throughout the nutrition classes, the dietician emphasized four key messages: (1) limited and consistent intake of carbohydrates at each meal; (2) adequate daily intake of fruits and vegetables; (3) lower intake of saturated fats (4) reduced fat in cooking.</p> <p><u>Intervention delivered by whom:</u> A multidisciplinary health care team</p> <p><u>Control:</u> Individual Counselling Intervention delivered by Portuguese-speaking educators. The frequency and duration of each follow-up visit depended upon the patient's progress and achievement of their metabolic targets and educational objectives in accordance with Canada's standards for diabetes education. At each visit, reassessed patients' status and identified patient priorities. With each patient, mutually agreed upon management goals and nutritional care plans were established with the educator during counselling. Also, throughout counselling, nutrition therapy is based on an assessment of individuals' metabolic profile (i.e. blood glucose, lipid and blood pressure) and on existing co-morbidities. The key nutritional messages from the group classes were also emphasized in one-on-one counselling.</p>
Participants	<p>Canadian Portuguese (100%)</p> <p><u>How recruited:</u> Identified all newly referred Portuguese-speaking patients from diabetes education centre. Called patients prior to their first scheduled appointment to inform them of the study. Patients who agreed to participate were asked to arrive at the centre a half-hour before their appointment.</p> <p><u>Inclusion criteria:</u> The inclusion criteria included diagnoses of type 2 diabetes, speaking Portuguese, willingness to participate</p>

	<p>in the Portuguese education programming and to be randomized into the intervention or control group.</p> <p><u>Exclusion criteria:</u> Exclusion criteria included being on renal dialysis, prior attendance at a similar educational program or the diagnosis of a mental illness.</p> <p><u>Number of participants:</u> 87</p> <p><u>Participation rates:</u> 87 of 115</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
Outcomes	<p><u>Primary outcomes:</u> Attitudes, subjective norms, perceived behavioural control, intentions towards nutritional adherence, self-reported nutritional adherence and glycaemic control.</p> <p><u>Secondary outcomes:</u> None stated</p>

<p><b>14 Hawthorne et al, 1997</b></p>	
Stated aim	<p>To develop a set of culturally appropriate pictorial flashcards for the education of Manchester Pakistanis with diabetes, and to evaluate the effectiveness of the cards when combined with an individual tuition package.</p>
Interventions	<p><u>Country:</u> England</p> <p><u>Setting:</u> Manchester Diabetes Centre and ten neighbouring general practices</p> <p><u>Frequency and duration of intervention:</u> 6 months.</p> <p><u>How intervention delivered:</u> Four topics for D2 education chosen following focus group discussions were appropriate diet, value of glucose monitoring, D2 complications and services at D2 clinic. Each topic had teaching objectives, interview questions and pictorial flashcards. The intervention group underwent structured education and discussed flashcards to understand points. were shown the flashcards by the linkworker, together with the structured education package. They were taught to check their urine for sugar, if they did not already do it.</p>



	<p><u>Intervention delivered by whom:</u> Link worker fluent in Urdu/Punjabi, having received intensive in house training from a multidisciplinary health professional team.</p> <p><u>Control:</u> No information provided.</p>
Participants	<p>British Pakistani (100%)</p> <p><u>How recruited:</u> Entered into the study if attending Manchester Diabetes Centre or ten neighbouring general practices.</p> <p><u>Inclusion criteria:</u> Pakistani patients with type 2 diabetes attending the Manchester Diabetes Centre and ten neighbouring general practices</p> <p><u>Exclusion criteria:</u> If enrolled in any other study, if they or a spouse had received formal diabetes education in the preceding six months, if they were planning to go abroad during the study period, or if they were thought by the clinic doctor to be too ill to take part.</p> <p><u>Number of participants:</u> 201</p> <p><u>Participation rates:</u> Information not provided.</p> <p><u>Sample size calculated:</u> Y</p> <p><u>Target sample achieved:</u> Y</p>
Outcomes	<p><u>Primary outcomes:</u> Knowledge, self-caring skills, attitudes to D2, HbA1c.</p> <p><u>Secondary outcomes:</u> None stated</p>

**15 Hendricks et al, 2000**

Stated aim	To determine whether objective clinical, patient performance, quality-of-life and subjective outcomes are significantly different among African-American men with D2 who received follow-up at either one-month or three-month intervals after participating in a structured D2 self-management education program.
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Community</p> <p><u>Frequency and duration of intervention:</u> 2 hours per week for</p>

	<p>four weeks.</p> <p><u>How intervention delivered:</u> All participants attended D2 self-management group education classes (2-4 participants) regardless of follow-up condition as recommended by ADA. Teaching strategies included audiovisual presentations, lectures and Socratic method of instruction, which is the use of questions in an exchange with patients to provide information that empowers them.</p> <p><u>Intervention delivered by whom:</u> Clinical social worker and nurse practitioner (both certified diabetes educators).</p> <p><u>Control:</u> The comparison intervention was the same. The only difference between the two groups is that one group had a monthly follow-up and one had a three monthly follow-up.</p>
Participants	<p>African-American men (100%)</p> <p><u>How recruited:</u> Through the local African-American churches and public service announcements in the print and broadcast media.</p> <p><u>Inclusion criteria:</u> African-American men with diabetes.</p> <p><u>Exclusion criteria:</u> None stated.</p> <p><u>Number of participants:</u> 30</p> <p><u>Participation rates:</u> Information not provided</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
Outcomes	<p><u>Primary outcomes:</u> HbA1c, perception of general care, D2 knowledge. Daily foot care, dietary, exercise and medication compliance (only measured post program).</p> <p><u>Secondary outcomes:</u> None stated</p>

<b>16 Jaber et al, 1996</b>	
Stated aim	To assess the effectiveness of a pharmaceutical care model on the management of D2 in urban African-American patients.

<p>Interventions</p>	<p><u>Country:</u> US</p> <p><u>Setting:</u> Medicine out patient clinic</p> <p><u>Frequency and duration of intervention:</u> Intervention follow-up on two-weekly basis until glycaemic control reached. Thereafter patients came to the clinic every 2-4 weeks for the duration of study (4 months).</p> <p><u>How intervention delivered:</u> Condition-specific model of pharmaceutical care included: (1) diabetes-specific pharmacotherapeutic evaluation and dosage adjustments (2) comprehensive and individualised patient education regarding diabetes and its complications (3) training on the recognition and treatment of hypoglycaemia and hyperglycaemia. (4) medication counselling (5) specific instructions on dietary regulation and an exercise plan (6) individual training for self-monitoring of blood glucose with detailed written instructions for specific testing times relative to meal consumption were provided <i>{HIL issue}</i>. Patients were further instructed to record date and time of any hypoglycaemic events as well as symptoms they experienced during these events. Evaluation of current hypoglycaemic therapies were performed during each clinic visit based on the self-tested glucose responses performed 4x/day for 2days/wk. Hypoglycaemic regimens adjusted in light of this.</p> <p><u>Intervention delivered by whom:</u> Pharmacist</p> <p><u>Control:</u> Usual care</p>
<p>Participants</p>	<p>Urban African-Americans (100%)</p> <p><u>How recruited:</u> Subjects at clinic who met the study criteria were contacted by a letter which was followed up by a telephone call.</p> <p><u>Inclusion criteria:</u> Urban African-American patients with NIDDM currently attending a general internal medicine outpatient clinic.</p> <p><u>Exclusion criteria:</u> IDDM, renal dysfunction, hepatic disorder, significant cardiac complications within the last 6 months, mental incompetence, or a history of non-compliance with</p>

	<p>regular clinic visits within the last two years.</p> <p><u>Number of participants:</u> 39</p> <p><u>Participation rates:</u> 45 of 156</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
Outcomes	<p><u>Primary outcomes:</u> Fasting plasma glucose, HbA1c</p> <p><u>Secondary outcomes:</u> BP, creatinine, total cholesterol, triglycerides, lipo-protein concentrations.</p>

<b>17 Keyserling et al, 2002</b>	
Stated aim	To determine whether a culturally appropriate clinic- and community-based intervention for African-American women with D2 will increase moderate-intensity physical activity.
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Primary care practice</p> <p><u>Frequency and duration of intervention:</u> During the first 6 months, groups A and B received the clinic based component, which included individual counselling visits with a nutritionist at months 1, 2, 3, and 4. In addition, group A also received the community-based component, which consisted of two group sessions and monthly telephone calls from a peer counsellor. During the second 6 months, group A participants continued to receive monthly phone calls from a peer counsellor and attended one group session.</p> <p><u>How intervention delivered:</u> Group A-clinic and community based intervention. Group B- clinic intervention only.</p> <p>The intervention combined traditional clinic-based nutritional counselling with a coordinated community component using peer counsellors and included 1) PA component developed to increase moderate-intensity to 30 min a day, 2) dietary component designed to decrease fat intake and improve control and distribution of carbohydrate intake, and 3) diabetes care</p>

	<p>component addressing various aspects of diabetes self-care</p> <p><u>Intervention delivered by whom:</u> Nutritionist and peer counsellor</p> <p><u>Control:</u> Group C- Minimal intervention involving mailed pamphlets.</p>
Participants	<p>African-American women (100%)</p> <p><u>How recruited:</u> List of patients meeting entry criteria computerised for two sites, physician then identified appropriate visits. At five sites without computerised records, clinician invited patients to participate during routine visits.</p> <p><u>Inclusion criteria:</u> African-American women aged &gt;40 years with type 2 diabetes, defined as diagnosis of diabetes at &gt;20 years with no history of ketoacidosis.</p> <p><u>Exclusion criteria:</u> None stated.</p> <p><u>Number of participants:</u> 200</p> <p><u>Participation rates:</u> Information not provided.</p> <p><u>Sample size calculated:</u> Y</p> <p><u>Target sample achieved:</u> N</p>
Outcomes	<p><u>Primary outcomes:</u> PA levels measured by accelerometer worn while awake.</p> <p><u>Secondary outcomes:</u> Dietary intake; HbA1c, cholesterol; weight; D2 knowledge scale; D2 health status, mental and social well-being scale.</p>
Other comments	3 treatment conditions.

**18 Lujan et al, 2007**

Stated aim	To determine the effectiveness of an intervention led by <i>promotoras</i> (community lay workers) on the glycemic control, diabetes knowledge, and diabetes health beliefs of Mexican Americans with D2 living in a major city on the Texas-Mexico border.
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<p>Interventions</p>	<p><u>Country:</u> US</p> <p><u>Setting:</u> Community</p> <p><u>Frequency and duration of intervention:</u> 6 months</p> <p><u>How intervention delivered:</u> A team of 2 promotoras delivered 8 weekly, 2-hour, participative group classes and telephone followup to the intervention participants. The classes (1) were available in English and Spanish, (2) were developed by a certified health educator in conjunction with the promotoras who delivered the intervention, (3) adhered to American Diabetes Association (ADA) curriculum guidelines, (4) were interactive and involved small groups, (5) had hands-on demonstrations and handouts, and (6) included diabetes self-management goal-setting and attainment progress reports (7) culturally specific. Promotoras also contacted class participants by telephone biweekly to answer any questions or concerns, reinforce education and promote behaviour change. After classes ended inspirational faith-based health behaviour change postcards, were mailed biweekly for 16 weeks to participants.</p> <p><u>Intervention delivered by whom:</u> Promotoras (community lay workers) who had had 60 hours of training on D2 self-management.</p> <p><u>Control:</u> Usual care.</p>
<p>Participants</p>	<p>Mexican-Americans (100%)</p> <p><u>How recruited:</u> Through clinic posters and mailed invitations.</p> <p><u>Inclusion criteria:</u> (1) 40 years of age or older, (2) self-reported Mexican American ethnicity, (3) diagnosed with type 2 diabetes for at least 1 year, (4) taking or having taken hypoglycemic agents within the past 6 months, (5) willing to participate, (6) noncompletion of a formal diabetes education program at the clinic, and (7) ability to speak English or Spanish.</p> <p><u>Exclusion criteria:</u> Patients who have type 1 diabetes, were younger than 40 years, had been diagnosed with diabetes for less than 1 year, and were being treated for complications that would interfere with their ability to participate in the classes. Only 1</p>

	<p>participant per household was eligible to participate in the trial.</p> <p><u>Number of participants:</u> 149</p> <p><u>Participation rates:</u> 67%</p> <p><u>Sample size calculated:</u> Y</p> <p><u>Target sample achieved:</u> Y</p>
Outcomes	<p><u>Primary outcomes:</u> HbA1c, bilingual D2 knowledge measure, bilingual D2 health belief measure.</p> <p><u>Secondary outcomes:</u> None stated</p>

<b>19 Mayer-Davis et al, 2004</b>	
Stated aim	Evaluated lifestyle interventions for diabetic persons who live rurally.
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Primary health centres</p> <p><u>Frequency and duration of intervention:</u> <i>Intensive-lifestyle</i> participants met weekly for first 4 months of core curriculum (intensive), every other week for next 2 months (transition) and once a month for last 6 months (maintenance).</p> <p><i>Reimbursable-lifestyle intervention</i> was four 1-hour sessions over the 12-month study and included 3 group sessions and 1 individual session. The total time allotted for delivery of this intervention was determined by the approximate number of hours reimbursed annually by Medicare.</p> <p><u>How intervention delivered:</u> <i>Intensive lifestyle intervention</i> focused on nutritional and the physical activity components. Encouraged moderate weight loss with a goal of reducing 25% of calories from dietary fat and a minimum of 150 minutes of physical activity per week, similar in intensity to brisk walking for individuals who had very sedentary lifestyles. Energy intake goals were added as necessary. Regular use of group sessions with simplified written materials and inclusion of additional culturally appropriate examples such as modifications of regularly consumed foods and suggestions for physical activity.</p>

	<p>Self-monitoring tools for diet and physical activity were retained in a very simple format. Information regarding selected aspects of diabetes care (e.g., encouragement to monitor blood glucose at home) was incorporated, although the intervention retained a clear focus on diet and physical activity.</p> <p><i>Reimbursable-lifestyle intervention</i> was a condensed version of the intensive lifestyle intervention where key elements were delivered.</p> <p><u>Intervention delivered by whom:</u> Nutritionist</p> <p><u>Control:</u> Usual care was delivered in one individual session by a single nutritionist at the beginning of the twelve month period including information related to diet and physical activity derived from materials developed by ADA.</p>
Participants	<p>Medically underserved rural communities (circa 80% Black)</p> <p><u>How recruited:</u> Potentially eligible participants identified through D2 registries at health centres. Introductory letter sent, followed up with a recruitment and eligibility-screening phone call. Those eligible and interested in participating completed two screening visits to further establish eligibility and interest in the study. Eligible participants completed a 3-day "run-in" program designed to confirm both interest in participation and the minimal ability to self-monitor diet and physical activity. At third visit collected baseline measurements.</p> <p><u>Inclusion criteria:</u> 45 years+, clinical diagnosis of diabetes, (BMI) of 25 +.</p> <p><u>Exclusion criteria:</u> Any limitation that would prohibit full participation e.g. cancer, multiple/recent myocardial infarction or stroke, dialysis for end-stage renal disease, severe psychiatric disease/dementia, inability to walk.</p> <p><u>Number of participants:</u> 187</p> <p><u>Participation rates:</u> 143 of 664 contacted from medical registers. 46 of 53 attended screening based on local publication efforts.</p> <p><u>Sample size calculated:</u> Y</p>



	<u>Target sample achieved:</u> N
Outcomes	<u>Primary outcomes:</u> Weight loss <u>Secondary outcomes:</u> HbA1c, lipid profile and blood pressure
Other comments	Participants were randomized into 1 of 3 interventions: intensive lifestyle intervention, reimbursable-lifestyle intervention, or usual care.

<b>20 Middelkoop et al, 2004</b>	
Stated aim	To determine whether diabetes nutrition education that is more attuned to their own culture improves metabolic control in Surinam South Asian patients.
Interventions	<p><u>Country:</u> The Hague (the Netherlands)</p> <p><u>Setting:</u> Three general practices and a diabetes out-patient clinic</p> <p><u>Frequency and duration of intervention:</u> Intensive guidance for a period of approximately three months, after which the patients continued to receive guidance from the care-providers, but with longer intervals.</p> <p><u>How intervention delivered:</u> The intervention consisted of the referral of South Asian diabetes patients by their attending physician to a specialist diabetes nurse and a dietician. These care-providers received specific training to improve their knowledge of the South Asian cultural and culinary traditions. They made use of newly developed education materials, consisting of an audio-cassette containing general diabetes information recorded in the Surinam-Hindi language and two booklets: one with general information on nutrition, and one containing a carbohydrate variation list, both based on South Asian cooking. Expected that, because the education materials were more recognizable, there would be an improvement in the interaction between patients and care-providers. As a result, compliance with the therapy would improve, with regard to nutrition, as well as physical activity and medication.</p> <p><u>Intervention delivered by whom:</u> Nurses and the dieticians</p>

	<p><u>Control:</u> Waiting list control (included in the second half of intervention, controlled before-and-after study so not included in SR)</p>
Participants	<p>Surinam South Asian origin (100%)</p> <p><u>How recruited:</u> Included in the study were all patients who were known by the GPs or in the out-patient clinic to have type 2 diabetes mellitus, were of Surinam South Asian origin and who visited a surgery or the out-patient clinic during the first six months of 1998 in connection with their regular diabetes control.</p> <p><u>Inclusion criteria:</u> Have D2 and of Surinam South Asian origin</p> <p><u>Exclusion criteria:</u> Comorbidity that would make it impossible to interpret changes in metabolic control (e.g. recent myocardial infarction, dementia)</p> <p><u>Number of participants:</u> 113</p> <p><u>Participation rates:</u> Info not given</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
Outcomes	<p><u>Primary outcomes:</u> HbA1c, lipid profile</p> <p><u>Secondary outcomes:</u> None stated</p>

<b>21 Noel et al, 1998</b>	
Stated aim	To examine the effects of patient choice between two education curriculums that emphasized either the standard or nutritional management of type 2 diabetes on class attendance and other outcomes among a mostly Hispanic patient population
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Out-patient, ambulatory care centre</p> <p><u>Frequency and duration of intervention:</u> 5 weekly 2-hour sessions</p> <p><u>How intervention delivered:</u> The experimental nutritional program modified the ADA's recommended curriculum to</p>

	<p>devote 60% of its content to nutritional management practices and 40% of its content to non-nutritional management. The nutritional program did not provide a specific meal plan, but instead recommended that patients use the food pyramid as a guideline and promoted gradual, continuous changes in eating habits. In addition, educators assigned to the standard program took measures of blood glucose, blood pressure, and weight when patients arrived for class as a usual care practice.</p> <p><u>Intervention delivered by whom:</u> The 2 curriculums were taught by 2 separate groups of diabetes educators</p> <p><u>Control:</u> Standard program was 'usual care' diabetes education program based on DA recommendations for D2, 40% of content focuses on nutritional management and 60% focuses on non-nutritional management practices. Patients given meal plan and advised to make many changes at once. <i>Clearly not 'usual care' in a comparable sense, still receiving education.</i></p>
<p>Participants</p>	<p>Mostly Hispanic (85%)</p> <p><u>How recruited:</u> Physician or self-referred.</p> <p><u>Inclusion criteria:</u> Adults 18 years of age or older who had not attended or completed diabetes education classes within the previous 12 months and who received the majority of their health care at the health care system where the study took place</p> <p><u>Exclusion criteria:</u> Not stated</p> <p><u>Number of participants:</u> 596 participants.</p> <p><u>Participation rates:</u> Information not provided.</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
<p>Outcomes</p>	<p><u>Primary outcomes:</u> Attendance and follow-up participation.</p> <p><u>Secondary outcomes:</u> Class satisfaction; D2 knowledge; self-care behaviours; functional status; importance of D2 care (all through questionnaires.) Hba1c; fasting serum cholesterol and BMI.</p>

22 Nothwehr et al, 2001	
Stated aim	To compare the effects of two programs that present diet and exercise components in a different sequence.
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> YMCA</p> <p><u>Frequency and duration of intervention:</u> Healthy eating component (10 weeks) followed by a physical activity component (6 weeks) and vice versa. Each week session was 90 minutes.</p> <p><u>How intervention delivered:</u> Facilitator initiated topics during the nutrition education component leading to interactive discussions focused on problem solving. Activity sessions involved providing related handouts and keeping a food record for the first two weeks used to increase awareness and stimulate discussion. Most sessions also included food tasting or actual cooking of healthy alternatives sometimes taken from specialist cook books with low-fat alternatives to African-American dishes. Similarly, the physical activity component had interactive discussion and group problem solving surrounding key topics. Handouts were provided with key messages and participants were given a one-year membership of YMCA facilities. Following group sessions, participants engaged in a moderate level of physical activity. For the first three sessions participants followed a low-impact audiotape that involved simple movements to music. They were provided with copies of this to take and use at home. During the remaining three weeks the facilitator introduced participants to the exercise equipment at the YMCA. Participants were encouraged to engage in a minimum of 150 minutes of physical activity each week and to record their activity on a provided form. This also gave space to record problems which served for discussion in subsequent sessions.</p> <p><u>Intervention delivered by whom:</u> An African-American employee of the YMCA who had served as the wellness coordinator at that location for several years.</p>

	<u>Control:</u> Two intervention conditions, where nutrition and physical activity training were sequenced differently.
Participants	<p>African-American women (100%).</p> <p><u>How recruited:</u> Through posters advertising a healthy lifestyle program for African-American women with adult-onset diabetes.</p> <p><u>Inclusion criteria:</u> African-American women with D2 for at least 1 year, aged 30-65, BMI 27 or greater, walk independently and able to provide consent.</p> <p><u>Exclusion criteria:</u> Pregnant, history of heart disease or any other major illness.</p> <p><u>Number of participants:</u> 23</p> <p><u>Participation rates:</u> Not applicable</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
Outcomes	<p><u>Primary outcomes:</u> Attendance. Adherence to behaviours recommended in the program: percent of calories consumed from fat, fruit and vegetable intake and minutes of exercise per week.</p> <p><u>Secondary outcomes:</u> Resting heart rate, BMI and blood pressure.</p>

<b>23 Rosal et al, 2005</b>	
Stated aim	To determine the feasibility of conducting a randomized clinical trial of an innovative self-management intervention to improve metabolic control in low-income Spanish-speaking individuals with D2 and second to obtain preliminary data of possible intervention effects.
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Community setting</p> <p><u>Frequency and duration of intervention:</u> Initial 1-hour individual session, followed by 10 weekly 2.5-3 hour group sessions and two-15 minute individual sessions during the 10-week period</p>

	<p>immediately prior to the group session.</p> <p><u>How intervention delivered:</u> Through culturally familiar experiences. A drama was developed to convey important messages to be discussed at each session. In the context of a love story, the characters of the drama communicate key diabetes-related messages, present common self-management challenges and model successful coping strategies. Work indicated that watching soap operas for several hours every day is a common activity among men and women in this population. This drama was read to participants during the session, with pauses to highlight and discuss important messages. <i>{IIL issue.}</i></p> <p>The intervention also utilised the concept of a traffic light for simplifying educational messages. Accordingly, large visuals were prepared using this concept to convey info about dietary guidelines and normal, borderline and abnormal glucose values. With input from the participants, visuals were developed to categorise the foods that they consumed most frequently. Foods that can be eaten in larger amounts were represented in green, foods that should be eaten cautiously were represented in yellow, and foods to avoid were represented in red. Self-monitoring daily logs, also using the traffic light concept and pictures, were designed for diet, physical activity and SMBG.</p> <p><u>Intervention delivered by whom:</u> Diabetes nurse, nutritionist and assistant in community room well known to residents.</p> <p><u>Control:</u> Usual care and given a simple, commonly used booklet describing the importance of lifestyle factors in D2 management and making recommendations.</p>
Participants	<p>Low income Spanish-speaking patients (100%).</p> <p><u>How recruited:</u> A list was randomly generated by each recruitment site where every fifth individual being approached.</p> <p><u>Inclusion criteria:</u> Have a health care provider; have a diagnosis of DII; 18yrs+; have home phone; have doctors approval to participate in the PA component of the intervention; able to provide informed consent in English or Spanish.</p> <p><u>Exclusion criteria:</u> History of diabetes ketoacidosis; gestational</p>

	<p>diabetes; planning to move out of the area within study period; using steroids for short periods during the previous year; cardiovascular event in previous 6 months.</p> <p><u>Number of participants:</u> 25</p> <p><u>Participation rates:</u> 23 of 54</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
Outcomes	<p><u>Primary outcomes:</u> Feasibility assessed through recruitment, completion and attendance rates. Physiological assessments (HbA1c, lipids, body mass); behavioural assessments (24 hour dietary recall, physical assessment questionnaire, 24 hour SMBG recall); Psychosocial assessments (D2 knowledge; QoL scale; self-efficacy scale; depression scale)</p> <p><u>Secondary outcomes:</u> None stated</p>

<b>24 Rothman et al, 2005</b>	
Stated aim	To assess the impact of a pharmacist-led disease management program on cardiovascular risk factors and HbA1c levels among a vulnerable population.
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Medical centre</p> <p><u>Frequency and duration of intervention:</u> 12 mths</p> <p><u>How intervention delivered:</u> All patients attended a one-hour diabetes education session. After which participants were randomly allocated to the intervention or control arm.</p> <p>Intervention arm received intensive D2 management for a year. This included intensive educational sessions and counselling. Applied evidence based algorithms to reduce cardiovascular risk factors and improve glycaemic control. Clinical pharmacist was in contact with patient in person or telephone every 2-4wks, with the provision of diabetes counselling as well as medication management. Also access to diabetes care coordinator who was trained to address issues related to health behaviour and health</p>

	<p>education. Coordinator called patients regularly to remind them of appointments and address barriers to care.</p> <p><u>Intervention delivered by whom:</u> Clinical pharmacists and diabetes care coordinators.</p> <p><u>Control:</u> All patients attended a one-hour diabetes education session. After which control participants received usual care.</p>
Participants	<p>Minority and low-income populations (60+% African-American)</p> <p><u>How recruited:</u> Info not given</p> <p><u>Inclusion criteria:</u> Patients with D2 receiving outpatient care at a single academic medical centre</p> <p><u>Exclusion criteria:</u> None stated</p> <p><u>Number of participants:</u> 217</p> <p><u>Participation rates:</u> Information not provided.</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
Outcomes	<p><u>Primary outcomes:</u> HbA1c, aspirin use, lipid levels.</p> <p><u>Secondary outcomes:</u> D2 knowledge, treatment satisfaction.</p>

**25 Skelly et al, 2005**

Stated aim	<p>(a) evaluate the effects of a culturally sensitive symptom focused intervention on symptom distress, diabetes knowledge, perceptions of quality of life, HbA1c levels, and self-care practices of older rural African American women with type 2 diabetes and (b) determine participant satisfaction with the intervention.</p>
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> One health department, two community practices, and one community health centre providing primary care.</p> <p><u>Frequency and duration of intervention:</u> Biweekly visits of no longer than 1 hour. Total 6 hours.</p> <p><u>How intervention delivered:</u> Participants in each group received</p>



	<p>two pre-intervention visits in their homes, each lasting no longer than 1 hour during which the study instruments were administered and demographic data were collected and a final evaluation visit.</p> <p>In addition, the treatment group received the four Diabetes Symptom-Focused Management Intervention modules. This was delivered in the homes of the participants at biweekly visits of no longer than 1 hour. To tailor the intervention to an individual and incorporate personal and cultural beliefs and preferences, an in-depth semistructured interview was planned for the second preintervention visit. The purpose of this interview was to provide each woman with an opportunity to discuss the meaning of diabetes for her and share thoughts and feelings about her experiences with diabetes, successful and unsuccessful coping strategies, and preferences for support.</p> <p><u>Intervention delivered by whom:</u> Nurse-investigator.</p> <p><u>Control:</u> Participants in each group received two pre-intervention visits in their homes, each lasting no longer than 1 hour during which the study instruments were administered and demographic data were collected and a final evaluation visit.</p>
Participants	<p>Older rural African American women</p> <p><u>How recruited:</u> Potential participants were identified by staff members at the clinic sites and informed briefly about the nature of the study and requirements for participation. Interested subjects were contacted by telephone by the principal investigator, who further reviewed the purposes of the study, requirements for participation, and the voluntary nature of the study and answered any question. For those women indicating an interest in participating, an appointment was made to visit the subjects at their home.</p> <p><u>Inclusion criteria:</u> Aged between 50 and 85 years, had a history of type 2 diabetes, and had no known cognitive, affective, or functional limitation that would preclude participation in the intervention.</p> <p><u>Exclusion criteria:</u> Severe depression, severe intellectual</p>

	<p>impairment.</p> <p><u>Number of participants:</u> 47</p> <p><u>Participation rates:</u> 47 of 52</p> <p><u>Sample size calculated:</u> Y</p> <p><u>Target sample achieved:</u> Y</p>
Outcomes	<p><u>Primary outcomes:</u> Symptom distress, D2 knowledge, Quality of life, HbA1c, D2 self-care practices, satisfaction with intervention.</p> <p><u>Secondary outcomes:</u> None stated</p>

<b>26 Vazquez et al, 1998</b>	
Stated aim	To describe the methods used to develop a culturally specific preventive nutrition intervention for adult Caribbean Latinos.
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Clinical</p> <p><u>Frequency and duration of intervention:</u> 7 month programme. 12-week program of intensive group sessions that focused on the development of skills that promote dietary behaviour change. Culturally sensitive program incorporated language, literacy, customs, attitudes, perceptions and behaviours of the participants. {NB, HL issue} Followed by 8 bimonthly problem-solving sessions to reinforce self-management skills. Group sessions incorporate interactive discussion to impart and clarify new information, acquisition of practical behaviour skills and a demonstration segment that includes healthy food preparation methods, shopping, eating practices and stress reduction techniques.</p> <p><u>How intervention delivered:</u> Specialists helped participants evaluate antecedents and consequences of personal food behaviours. Environmental situations that might result in over-consumption of foods especially fat, subsequent weight gain discussed. Problem solving and identification of alternative behaviours also explored. Through role play and other</p>

	<p>interactive activities, participants learned techniques for self-monitoring including: identification of problem food behaviours; managing high risk situations; techniques of relapse prevention and methods for sustaining new dietary behaviours. Demonstration segment allowed subjects to observe and participate in food prep and portion control activities that emphasised low-fat cooking methods and modifies traditional recipes. New food items introduced and new recipes prepared so that participants could taste test and discuss products that met program nutrient guidelines.</p> <p><u>Intervention delivered by whom:</u> Multidisciplinary bilingual, bicultural team of researchers, practitioners and Latino community-based partners with expertise in medicine (nutritionist and psychologist).</p> <p><u>Control:</u> No information provided other than reference to 'control group.'</p>
Participants	<p>Caribbean-Latino (100%)</p> <p><u>How recruited:</u> Community outreach. Snowballing. Hospital clinics, health centres.</p> <p><u>Inclusion criteria:</u> Both parents of Caribbean Latino origin, diagnosed D2, BMI between 27 and 40, ability to understand and provide informed consent.</p> <p><u>Exclusion criteria:</u> Known underlying conditions that affect weight (pregnancy, malignancy, HIV disease, chronic congestive heart failure, renal failure, cirrhosis or treatment with corticosteroids and thyroid or metabolic disorder), substance abuse problems, emotional difficulties during interview with psychologist and unwillingness or inability to participate in complete protocol.</p> <p><u>Number of participants:</u> 38</p> <p><u>Participation rates:</u> Information not given</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>

Outcomes	<p><u>Primary outcomes:</u> Dietary behaviours: energy intake; fat; carbohydrate and fibre.</p> <p><u>Secondary outcomes:</u> None stated.</p>
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<b>27 Vincent et al, 2007</b>	
Stated aim	To test the feasibility and examine the effects of a culturally tailored intervention for Mexican Americans with D2.
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> Community health clinic</p> <p><u>Frequency and duration of intervention:</u> 8 weeks, 2 hour sessions</p> <p><u>How intervention delivered:</u> Group sessions. Included didactic content, cooking demonstrations, and group support. Considered essential by the ADA and included pathophysiology of diabetes, complications, treatment modalities, diet, exercise, and self-management strategies. Self-monitoring of blood glucose and how to interpret results were also included. Content on stress and stress management, heredity, and culture (including traditional Mexican American ideas of causes of diabetes) was included as well.</p> <p><u>Intervention delivered by whom:</u> Promotora. Unclear if health professionals too.</p> <p><u>Control:</u> Usual care</p>
Participants	<p>Mexican-Americans (100%)</p> <p><u>How recruited:</u> Participants were recruited in a number of ways: flyers describing the study in Spanish were posted in high-traffic areas of the clinic, providers and staff were informed of the study and asked to refer prospective participants, and an experienced bilingual <i>promotora</i> contacted potential participants using the clinic's diabetes roster and informed them of the study.</p> <p><u>Inclusion criteria:</u> Self-identification as Mexican American, age between 18 and 75 years, diagnosis of type 2 diabetes, fluency in Spanish, and ability to walk without assistance.</p>

	<p><u>Exclusion criteria:</u> Pregnant; had a medical condition, such as heart failure, in which dietary changes and exercise were contraindicated; were cognitively impaired; or had participated in a diabetes self-management program within the previous 12 months.</p> <p><u>Number of participants:</u> 20</p> <p><u>Participation rates:</u> 20 of 60</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
Outcomes	<p><u>Primary outcomes:</u> Self-efficacy measure, D2 knowledge measure, self-care measures and biological outcomes of weight, BMI, HbA1c, blood glucose.</p> <p><u>Secondary outcomes:</u> None stated.</p>

<p><b>28 Ziemer et al, 2003</b></p>	
Stated aim	<p>Whether a simpler meal plan that emphasizes “healthy food choices” (without emphasis on weight loss per se) would be as effective as a traditional exchange-based meal plan (emphasizing weight loss).</p>
Interventions	<p><u>Country:</u> US</p> <p><u>Setting:</u> D2 clinic</p> <p><u>Frequency and duration of intervention:</u> Patient’s initial visit included extensive evaluation and education focused on self-care. Patients scheduled for return visits at 1, 2, and 4 weeks and then at 2, 4, and 6 months. Approximately 1 h was spent on nutritional counselling at the initial visit and 30 min at each of three subsequent clinic visits.</p> <p><u>How intervention delivered:</u> All patients are routinely scheduled to see a dietician at the initial visit and at 1, 2, and 4 weeks where patients receive individualized instruction in separate sessions. All patients are managed with a stepped care protocol that emphasizes non-pharmacologic therapy during the first 2 months. During this period, anti-diabetic pharmacologic agents</p>

	<p>are either discontinued or reduced in dose for patients who are not ketosis prone and do not have symptomatic hyperglycaemia. If glycaemic goals are not reached after 2 months, pharmacotherapy is reinstated or intensified. At each visit, individualized patient instruction was based on 24-h recalls to direct dietary reinforcement.</p> <p><u>Intervention delivered by whom:</u> Team that includes nurses, dietitians, podiatrists and endocrinologists.</p> <p><u>Control:</u> Traditional exchange based meal plan. Same duration as intervention group. Low literacy educational material {<i>HIL</i>} consisted of “Eating Healthy Foods” (American Dietetic Association, 1988). Patients were instructed in both food exchanges and portion sizes. Patients classified as obese (&gt;120% of ideal body weight) were assigned meal plans that were 500 kcal below their estimated daily energy.</p>
<p>Participants</p>	<p>90% African-American.</p> <p><u>How recruited:</u> Recruited at initial clinic visit and randomized according to day of visit.</p> <p><u>Inclusion criteria:</u> Had D2, able to understand spoken English, no major complicating medical illnesses and were judged to be capable of performing basic self-management skills.</p> <p><u>Exclusion criteria:</u> None stated.</p> <p><u>Number of participants:</u> 648</p> <p><u>Participation rates:</u> Not applicable</p> <p><u>Sample size calculated:</u> N</p> <p><u>Target sample achieved:</u> U</p>
<p>Outcomes</p>	<p><u>Primary outcomes:</u> Comparing changes in HbA1c as the primary outcome</p> <p><u>Secondary outcomes:</u> Changes in weight, serum lipids, and blood pressure as secondary outcomes</p>

## **Appendix 4.2**

### **Line-by-line coding**

The following 21 categories were developed from the line-by-line coding stage of thematic synthesis. Detail is provided overleaf for one of these categories.

- 1- Stigma**
- 2- Desire to maintain roles**
- 3- Influence of gender norms**
- 4- Emotional responses to diagnosis (and s-m)**
- 5- Self confidence**
- 6- Familial support and understanding**
- 7- Perception of HP**
- 8- HP's inappropriate exchange**
- 9- Approach to education**
- 10- Novel suggestions for education**
- 11- Educational requirements**
- 12- Resource implications on service use**
- 13- Learning through others experiences**
- 14- Lacked biomedical knowledge**
- 15- Have biomedical knowledge**
- 16- Traditional beliefs**
- 17- Difficulty of self-management**
- 18- Identified causal relationships**
- 19- Strategies**
- 20- Spirituality and fatalism**
- 21- Ascribed aetiology**

Category	Line-by-line Code
<p>4-</p> <p><b>Emotional responses to diagnosis (and self-management)</b></p>	<ul style="list-style-type: none"> <li>- <u>Guilt</u>: due to problems of being honest with health professionals when failing to follow the advice (46)</li> <li>- <u>Self-recrimination</u>: at not meeting diet demands (34)</li> <li>- <u>Denial</u>: (35, 44, 31, 36, 63, 49, 35, 67, 52)</li> <li>- <u>Anger</u>: not enough time with health professionals to raise issues of concern (46); not being understood (34); type 2 diabetes regimen (52, 83,36)</li> <li>- <u>Frustration</u>: with difficulty of diabetes regimen (83, 52, 66, 70)</li> <li>- <u>Anxiety</u>: with diabetes experience (62, 65, 76, 80)</li> <li>- <u>Depression</u>: (36, 51, 52, 38, 83)</li> <li>- <u>Fear</u>: of diabetes adds to differences associated with good self-management (67); and chronic complications (51, 60, 80, 84, 36, 37, 74, 65)</li> <li>- <u>Stress</u>: with managing diabetes (67)</li> <li>- <u>Helpless and pessimistic health views</u> (66, 84) negative outlook on future without cure (30, 29, 44, 36, 42) and inevitably poor outcomes (29, 30, 42, 52, 65)</li> <li>- <u>Resignation</u>: largely due to high incidence in these high risk groups (30, 38, 66, 67, 80, 74, 82, 44).</li> </ul>



**Appendix 7.1**  
**Interview Schedule**

### WARM UP QUESTIONS

Firstly, I'd like to ask you about the early experiences you had when you learnt that you had D2.

- When did you find out you had diabetes?
- How did you feel at that time?

### SECTION 1: EXPLORING PERSONAL EXPERIENCE AND IDENTITY

I'd like to move on and ask you to think about how things are now.

- How do you feel *now* about your diabetes?
- In terms of managing your diabetes how do you think your feelings of **xxx** affects this?

*Prompt – Do these feelings help? Or do these feelings make it more difficult?*

Follow-up - Why do you think that is?

### SECTION 2: EXPLORING ROLES AND IDENTITY

We have talked about some of your experiences with D2. I now want to move on to ask you some questions about diabetes and your different roles in everyday life.

So, we know that women have different roles in their day-to-day lives. And for some women - their family, social or work roles can be an issue which affects their D2 self-management. For other women - this is not an issue.

I am really interested to hear about your opinions and experiences of this. And will ask you about your roles individually.

- What do you feel is the case for you in terms of your family life where you may be mothers, daughters and wives? Do these roles affect your D2 management? In what way?
- Has having D2 affected what you are able to do in these roles in comparison to what was normal before? In what way?

*Prompt- This is to say, for example, that being a mother may impact on your D2 self-management*

*Prompt- This is to say, for example, that your D2 self-management may affect your motherhood.*

- What is the case for you in terms of your diabetes and your social life, your role as friends or associates? Do these social roles have an affect on your D2 management? In what way?

- Does having D2 affect what you are able to do in your social life in comparison to what was normal before? In what way?
- Do you have a job?
- What is the case for you in terms of your diabetes and your work life, your role as employees or colleagues? Do these work roles have an effect on your D2 self-management? In what way?

*Prompt -? Does having D2 affect what you are able to do in your work roles in comparison to what was normal before?*

It seems from what you say that you feel the qualities you provide to others {have/have not} changed over your life, particularly before and after your illness.

Do you think this is the same case for men as it is for women?

*Ask about family/social/work roles separately.*

Do you think this is the same case for women of different ages as it for younger/older women?

*Ask about family/social/work roles separately.*

- We have talked about whether the qualities you provide to others have been affected by D2.

Do you feel the qualities you seek from family/friends/{colleagues} have changed over your life course, particularly before and after your illness?

*Prompt-What are these differences? (E.g. practical support like considering diabetic diet restrictions when throwing dinner parties, or providing emotional support in managing illness)*

Follow-up-(Explore each change that has been mentioned.)

Why do you think this has happened?

How do you feel about these changes?

Follow-up - Do you think this is the same case for men?

Follow-up - Do you think this is the same case for women of different ages?

- We have focused on the drawbacks of having diabetes. Have there been any benefits? Are there any good things that have come about because of your diabetes?

*Prompt-E.g. healthy eating/physical activity has improved general quality of life.*

### SECTION 3: EXPLORING HEALTH LITERACY AND SELF MANAGEMENT

I'd now like to move on to the final section where I will ask you about the practicalities of managing diabetes in your day-to-day life.

- To start with, can you tell me in detail, how you manage your diabetes in the context of a typical day (from when you wake up to when you go to bed)?

Follow-up - Are there any times when you are unable to follow this routine?

Why is that?

Follow-up - So would you say you {do/don't} tend to follow medical advice in managing your diabetes? (If tend not to...follow-up and ask for details.)

**(Functional health literacy - compliance to enable daily functioning)**

- Can you think of any occasions when you sought out extra information about your diabetes?

*Prompt -From friends, family, health professionals, library, or internet. If there was something you didn't understand and wanted to know more about?*

Why did you seek more information?

What did you want to know?

**(interactive health literacy - Patient uses their initiative to solicit additional information)**

- Can you think of any occasions when you experienced a new situation because of your illness? **(critical health literacy – acquired ability to discriminate from handling novel situations)**

*Prompt -e.g. first hypo episode*

Follow-up - How did you deal with that first time?

Follow-up - How do you deal with that type of situation now?

Follow-up - Why has your response changed?

We are nearing the end of the interview now.

- Finally, I would like to ask you if there is anything that we have not already covered which you feel influences your ability to self-manage your diabetes and you wish to talk about?

*Prompt- ? Ability to read write and speak English?*

Thank you very much for speaking with me about this. That is the end of the interview. I'm sure all the information you have provided today will prove very useful to my study.

**Appendix 7.2**  
**Information sheet**



## Participant Information Sheet

### Perspectives of British-Pakistani females with Type 2 diabetes on self-management

We would like you to take part in the above named study but before you decide, please read the following information.

#### What is the purpose of this study?

- We are doing this research to find out what factors influence self-management of Type 2 diabetes in British Pakistani women.
- There could be many reasons why some women find it hard to self-manage, which may affect their health.
- By understanding these factors, it is hoped that we will be able to better support women to self-manage their diabetes.

#### Who is doing the study?

The study is being conducted by the University of Leeds as part of my PhD qualification. My PhD is being supervised by Dr Cath Jackson, Professor Francine Cheater and Dr Peter Knapp.

#### Who is being asked to participate?

Women of Pakistani origin, who are aged over 18 years and have been diagnosed with Type 2 diabetes, are being asked to help with the study.

#### What will be involved if I take part in this study?

- If you take part, you will be interviewed by a female researcher of Pakistani origin, about your experiences of managing your diabetes. Example questions include 'What diabetes care activities do you carry out?' and 'What do you do when you have a problem caused by the diabetes?'
- The interview will last about 1 hour and will take place at a time and place you choose.
- The interview can be done in Urdu or English.

- If you are interested in taking part please contact Rabiya Majeed- her details are provided overleaf.
- You can call her just to ask questions about the study and then decide if you want to or do not want to take part.

### **What are the advantages and disadvantages of taking part?**

There will be some demands on your time as described above. We don't think any of the questions we want to ask you are embarrassing or upsetting. But if any question is asked that you do not wish to answer that is absolutely fine.

There are few risks of taking part in this study, although you may find the interview tiring or boring. If you do, you will be free to leave at any time. You may not get any personal medical benefits from agreeing to take part. However, if you take part you will be helping us understand the issues that help and hinder women to manage their type 2 diabetes. Your answers could help other women in the future. If you do take part you will be rewarded with a £10 gift voucher to thank you for the time you have given. We will also cover any travel expenses.

### **Can I withdraw from the study at any time?**

You do not have to take part in the study, no-one will mind if you say no. You can also say yes and then change your mind. You are free to withdraw from the study at any time and do not have to give a reason why. No information you have provided during the study will be used without your permission.

### **Will the information I give be kept confidential?**

To keep an accurate record of what is discussed, the interviews will be tape recorded. The tapes will be copied out and examined to find important topics raised by you. But no records of names will be made. All information you offer during the interview will be kept private and confidential. The tapes will be destroyed within three years of the project completion date. Transcripts will be stored for seven years in a locked filing cabinet in a secure office. It will not be possible to identify you in any way from the reports, spoken or written. Our procedures for processing, storing and destroying your data comply with the Data Protection Act 1998.

**What will happen to the results of the study?**

The results of the study will be written as a document and sent for publication in a medical journal. It will also make up part of Rabiya Majeed's PhD. If you take part then you will be given the option to receive a summary of the results once they are produced. No one will be named in any written or spoken document.

**Who has reviewed this study?**

Ethical approval for this study has been sought and obtained from the School of Healthcare Research Ethics Committee at the University of Leeds.

**If you agree to take part, would like more information or have any questions or concerns about the study please contact:**

**Miss Rabiya Majeed, PhD student  
School of Healthcare, University of Leeds, LS2 9UT  
TELEPHONE: 01642 898087  
MOBILE: 07929148573  
E-MAIL: [hcrm@leeds.ac.uk](mailto:hcrm@leeds.ac.uk)**

**Thank you for taking the time to read this information sheet.**



**Appendix 7.3**

**Consent form**



**Participant Consent Form**

Perspectives of British-Pakistani females with Type 2 diabetes on self-management

**The participant should complete the whole of this sheet herself**

	<b>Please confirm the statements by putting your initials in the box below</b>
I have read and understood the participant information sheet	
I have had the opportunity to ask questions and discuss this study	
I have received satisfactory answers to all of my questions	
I have received enough information about the study	
I understand that I am free to withdraw from the study: 1 At any time 2 Without having to give a reason for withdrawing	
I understand that recording equipment will be used during the interview, but the tapes will be destroyed in three years and no records of names will be kept	
I understand that any information I provide, including personal details, will be confidential, stored securely and only accessed by those carrying out the study	
I understand that any information I give may be included in published documents but my identity will be protected	

I agree to take part in this study	
Participant Signature .....	Date.....
Name of Participant	
Researcher Signature .....	Date.....
Name of Researcher	

Thank you for agreeing to take part in this study.

## **Appendix 7.4**

### **Initial and final version of coding framework**

**Preliminary coding framework (initial version)**

<b>Code</b>	<b>Sub-code</b>
1) Feelings around diabetes	a) Early b) Current c) Benefits
2) Experiences of diabetes	a) Early b) Current c) Benefits
3) Understanding of diabetes	a) Biomedical b) Traditional c) Lacking d) Health professional
4) Feelings towards body	-
5) Diabetes and family life	a) Role of mother b) Role of wife c) How family help d) How family hinder
6) Diabetes and social life	a) Managing social situations b) Talks about eating times
7) Diabetes and work life	a) Made concessions b) Refused diabetes to influence
8) How others deal with their diabetes	a) Men b) Women of different ages c) Friends and family with diabetes
9) Self-management per se	a) Daily routine b) Detrimental effect c) General reference

	<ul style="list-style-type: none"> <li>d) Changes over time</li> <li>e) Symptoms</li> </ul>
10) Health Literacy (descriptors)	<ul style="list-style-type: none"> <li>a) Compliance to advice</li> <li>b) Seek extra information</li> <li>c) New diabetes experience</li> <li>d) Other</li> </ul>

**Coding framework (final version)**

Code	Sub-code
1) Feelings around diabetes	<ul style="list-style-type: none"> <li>a) Compare to 'normal'</li> <li>b) Compare to 'old self'</li> <li>c) Compare to 'worse off'</li> <li>d) Early feelings</li> <li>e) Current feelings</li> <li>f) Humour</li> <li>g) Religious or fatalistic notions</li> <li>h) Towards body (feelings)</li> </ul>
2) Experiences of diabetes	<ul style="list-style-type: none"> <li>a) Early experiences</li> <li>b) Daily routine</li> </ul>
3) Understanding of diabetes	<ul style="list-style-type: none"> <li>a) Alternative remedies</li> <li>b) Benefits</li> <li>c) Biomedical understanding</li> <li>d) Blood sugar</li> <li>e) Co-morbidity</li> <li>f) Diet</li> <li>g) Emotions</li> <li>h) Focus on medication</li> <li>i) Health professionals</li> </ul>

	<ul style="list-style-type: none"><li>j) Insulin</li><li>k) Physical Activity</li><li>l) Self management changes with time</li><li>m) Symptoms</li><li>n) Traditional understanding</li></ul>
4) Diabetes and family life	<ul style="list-style-type: none"><li>a) Role of mother</li><li>b) Role of wife</li><li>c) Role of daughter sister other</li><li>d) How family help</li><li>e) How family hinder</li></ul>
5) Diabetes and social life	<ul style="list-style-type: none"><li>a) Food and social life</li><li>b) How friends help</li><li>c) How friends hinder</li><li>d) Managing social situations</li></ul>
6) Diabetes and work life	<ul style="list-style-type: none"><li>a) Refuse diabetes to influence work</li><li>b) Support at work</li><li>c) Work concessions result from diabetes</li><li>d) Work influences management</li></ul>
7) How others deal with their diabetes	<ul style="list-style-type: none"><li>a) Men</li><li>b) Women of different ages</li><li>c) Friends and family</li><li>d) Gender roles</li></ul>
8) Health Literacy (descriptors)	<ul style="list-style-type: none"><li>a) Compliance to advice</li><li>b) Seek extra information</li><li>c) New diabetes experience</li><li>d) Empowered perspective</li><li>e) Other</li></ul>